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ABSTRACT

This appendix to the second part of the hearings on the kind of services children receive through charity; how charities obtain funds from the public; and how much they spend on fundraising, general management, and program services, consists of the complete text of the formal statement of the Epilepsy Foundation of America submitted at the April 5 hearing. Appended are several communications and a "National Directory of Chapter Program Services." (JM)

CHILDREN'S CHARITIES, 1974

HEARINGS

BEFORE THE

SUBCOMMITTEE ON CHILDREN AND YOUTH

OF THE

COMMITTEE ON LABOR AND PUBLIC WELFARE UNITED STATES SENATE

NINETY THIRD CONGRESS

SECOND SESSION

ON

EXAMINATION OF THE KIND OF SERVICES CHILDREN RECEIVE THROUGH CHARITY, HOW CHARITIES OBTAIN FUNDS FROM THE PUBLIC, AND HOW MUCH THEY SPEND ON FUND-RAISING, GENERAL MANAGEMENT, AND PROGRAM SERVICES

PART 3

EPILEPSY FOUNDATION

APPENDIX

Printed for the use of the Committee on Labor and Public Welfare

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MEMORANDUM

Due to an oversight, the complete text of the formal statement of the Epilepsy Foundation of America submitted at the April 5 hearing was not included in Volume 2 of the hearings on children's charities. Volume 2 does include the transcript of the oral testimony. In this document the Subcommittee provides the text of the EFA statement as submitted and supplementary material.

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Epilepsy
FOUNDATION OF AMERICA

Suite 406 • 1828 L Street N.W. • Washington D.C. 20036 • (202) 293-2930
MEMBER NATIONAL HEALTH COUNCIL

STATEMENT

SUBMITTED TO

THE SUBCOMMITTEE ON CHILDREN AND YOUTH

OF

THE U.S. SENATE COMMITTEE ON LABOR AND PUBLIC WELFARE

APRIL 5, 1974

BY

PAUL E. FUNK
EXECUTIVE VICE PRESIDENT

DAVID D. DALY, M.D.
CHAIRMAN BOARD PROGRAM/LONG RANGE PLANNING COMMITTEE

THOMAS M. ENNIS
EXECUTIVE DIRECTOR

AND

H. LEROY SMITH, JR.
CONTROLLER

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CONTENTS IN BRIEF

Epilepsy—The more you know about it, the more you want to help.

1. INTRODUCTION

Mr. Chairman and members of the Committee:

My name is Paul E. Funk and I reside at 1659 32nd Street, N.W., Georgetown, Washington, D.C. I am currently the full-time, paid Executive Vice President of the Epilepsy Foundation of America responsible for paid staff and the implementation of directives of the all-volunteer national Board of Directors, all of whom serve without compensation. My predecessor in this post was Mr. John W. West, who for many years, was Treasurer of the District of Columbia.

At the request of our president, Mr. Paul D. Holland and our Chairman, Dr. A. B. Baker, both of whom devote endless hours to this cause, and by designation of the Board, I act as chief executive officer and spokesman for the Foundation.

I am particularly pleased to appear before this Committee in the latter role, Mr. Chairman, not only because EFA is always happy to have an opportunity to illuminate the many and complex problems involved in the medical and social management of the epilepsies (as our letterhead states: "The more you know about it, the more you want to help") but also because so many of the distinguished members of the Committee on Labor and Public Welfare have always been extremely helpful to us in many ways over the years as we go about the task of interpreting the person with epilepsy -- and his needs -- to the society in which he lives.

Appearing with me today are Thomas M. Ennis, Executive Director, and H. Leroy Smith, Jr., Controller, of the Foundation staff. Statements from both are incorporated in this document. Mr. Smith is a Certified Public Accountant and Mr. Ennis is a Juris Doctor. We are also honored to have with us David D. Daly who is a medical doctor and president of the International League Against Epilepsy, the world-wide organization of professionals in this field.

I am a businessman. On December 1, 1970, I assumed my present responsibilities at the unanimous request of the Board which was anxious to accelerate the fine work already done by the two-year old organization, to tighten certain budgetary and administrative controls (the Foundation operated at a $396,000 deficit in 1969) and to bring to the voluntary health field the most effective communications and organizational techniques of American business.

Among many business posts I have held are: Vice President of McCann-Erickson, Inc.; President and Chairman of McCann/ITSM, Inc., a company which I helped found; Chairman of the Board of what is now Tinker-Dodge-Delano, Inc., and a Vice President of the Interpublic Group of Companies, Inc., the world's largest advertising, public relations and marketing organization. I have frequently served as faculty for seminars conducted by the American Management Association.

My interest in epilepsy and its problems goes back some 12 years. Like Peter Falk who testified on February 19, I was originally recruited to the national board of a predecessor epilepsy organization as a volunteer to participate in public information and education activities and was told this would take "about eight hours a year." Later, I also joined the Board of the former Epilepsy Association of America in order to encourage merger between the two organizations.

Since then, I have served in other volunteer positions as Chairman of the Public Relations Committee, Chairman of the Unity (merger) Committee, a First Vice President, Chairman of the Program and -- more recently -- as President (at which point the "eight hours a year" expanded to as many as 30 hours a week!) for two terms.

I believe that I am reasonably familiar with the history, objectives and needs of the epilepsy movement ... much of which was outlined more than ten years ago here in this city at a public meeting at which both I and the distinguished ranking minority member of this Committee, Senator (then Representative) Robert A. Taft, Jr. and I spoke.

Background Information

Because the Foundation is a quasi-public organization, much information in regard to the nature and cost of services provided, methods of raising funds, management and delivering services is already a matter of public record. Not only here in Washington, but also in the several states. Also, much information has been provided the Subcommittee staff over the past several weeks. Staff members have had free and unrestricted access to EFA financial records and files. And you have already expressed appreciation in regard to the cooperation extended. So, it is somewhat difficult to decide what still further additional information would be most valuable to the Subcommittee. But there are indeed some things that EFA would like to put on the record.

Focus of the Hearings and of this Statement

If I interpreted correctly the opening statement of the Chairman on February 4, the purpose of these hearings is:

> To explore "whether existing legislation is adequate to protect the interest of the beneficiaries of and contributors to" the organizations being invited to testify "and trying to determine if new legislation is needed."

The Foundation will address itself to all three of these points in this statement, as well as the specific matters outlined in an April 1 letter from the Chairman.

EFA Has Been Following the Hearings With Interest

The testimony already on record has served as "thought starters" for our key volunteer officers and directors which has resulted in a two-page article in the March issue of EFA's monthly newspaper, NATIONAL SPOKESMAN, entitled "Looking at Voluntaries: What They Are, What They Do, and What Their Futures May Be, with Special Emphasis on EFA." It addresses itself to several basic considerations involved in evaluating the place of voluntary health agencies in our society -- some of which will be developed at greater length in this statement -- and warrants your careful review. I would request that it be included in the permanent records of these hearings.

"<u>You Have to Look at the Cause Itself</u>"

This comment by Mrs. Ellen R. Grass, Senior Vice President of EFA and President for the International Bureau for Epilepsy, emphasizes an important point.

So, too, does the comment by Dr. David D. Daly, Chairman-elect of EFA's National Professional Advisory Board, who is here with us today, that "<u>Program must be relevant to the disorder.</u>" So, too, does the comment by Gene Pulliam, EFA Director and Chairman of the Fund Raising Committee, that "the harder it is to raise money, the more it costs ... you've got to realize the influence that stigma has on fund raising. People avoid our cause as they seek to avoid those who have the condition."

It was these -- and other -- considerations, we believe that Arthur Jack Grimes, Director for Membership of the National Health Council -- of which EFA is a member -- had in mind when he testified "If it were possible to prescribe a <u>single basis</u> for comparison, or method of calculating a fund raising cost ratio that would be applicable uniformly, such effort would be most useful. Facts do not appear, however, to justify expectation that this can be done..."

In short, the history and experiences of the Foundation can be utilized by the Subcommittee for translation into meaningful legislation beneficial to our society. But first, it is perhaps necessary that we discuss: the epilepsies.

2. WHY THE EPILEPSIES ARE A MAJOR NATIONAL HEALTH PROBLEM

(Statement of David D. Daly, M.D., chairman of
the program and long range planning committee)

My name is David D. Daly. I am Professor of Neurology at the University of Texas, Southwestern Medical School in Dallas. I received the Doctor of Medicine and Doctor of Philosophy degrees at the University of Minnesota. Over the years my major professional interest has been in the problems of epilepsy, which I have pursued both as a practicing physician at the Mayo Clinic, as well as in the academic environment of a medical school. I have been and am a scientific consultant to the National Institute of Neurological Diseases and Stroke and was a member of the Secretary of Health, Education and Welfare's National Advisory Committee on the Epilepsies. Currently I am Chairman-Elect of the Professional Advisory Board of the Epilepsy Foundation of America and President of the International League Against Epilepsy, a world-wide federation of professional societies concerned with this problem. My testimony before this committee considers the reasons why epilepsy is, and should be, regarded as a national health problem.

I believe an excellent summary of the problem was that presented to the Senate on November 19, 1973, when the distinguished Senator from Colorado -- whom we are honored to count among the Honorary Directors of the Foundation -- introduced Senate Joint Resolution 173 calling for a National Commission for the Control of Epilepsy and its Consequences. That measure is presently in the Committee on Labor and Public Welfare.

Senator Dominick pointed out then that:

> "Epilepsy strikes all age groups, but particularly the young. For example, more than 670,000 elementary school children and more than 300,000 secondary pupils, are afflicted with epilepsy. If left untreated, it creates severe learning barriers, deters social development, and prevents its victims from achieving self-sufficiency. With proper treatment, epilepsy can usually be controlled and its victims can live productive lives -- providing they are amoung the lucky ones with access to adequate treatment and the resources to pay for it.
>
> "One of the most difficult barriers to adequate treatment of epilepsy victims -- and one of the most challanging problems facing the new National Commission for the Control of Epilepsy and its Consequences -- is publir ignorance about this widely misunderstood disorder."

He urged that the nation "begin to focus more national attention and resources on the problem" and called for a National Plan to be developed.

May I begin by amplifying on some of the numbers which Senator Dominick referred to.

The Professional Advisory Board of the Epilepsy Foundation of America has good reasons to believe that about four million people in the United States (about two percent of the population) have epilepsy in some form, with the majority of cases beginning in the first two decades of life. That comes to a larger patient population at any one time than those suffering from cancer, tuberculosis, cerebral palsy, muscular dystrophy and multiple sclerosis combined.

I indicated that this is what the Board believes to be a reasonable estimate. No national survey on the incidence and prevalence of this widespread disorder has ever been done, and there is wide disagreement among professional biostatisticians on what would be a proper methodology to undertake one.

A major obstacle is the difficulty of counting heads when the disorder in question can be hidden from view and carries one of the most virulent stigmas of any health condition. Many people with epilepsy can "pass" -- and they do. Furthermore, epilepsy is not required to be reported by a physician to his health department in most states. In states where such a provision exists, we have some indications that physicians tend to shy away from a diagnosis which will label their patients and place restrictions upon them.

The Professional Advisory Board's view has recently been at least partially supported by the National Institute of Neurological Diseases and Stroke, which estimates "from two to four million" as the number of Americans with epilepsy.

What, then, is the nature of the condition which affects so sizable a patient population?

Epilepsy is a disabling, virtually lifelong condition that, except in cases where total seizure control is achieved (perhaps 50 percent of the total), has a dominant effect on the whole life experience of the individual who has it and those who are closest to him.

It becomes a significant -- the significant -- fact of his life. It negatively affects his ability to support himself by his own efforts; an active or only partially controlled seizure disorder prevents him from ever experiencing the dignity and feeling of self-worth that comes from gainful employment.

It keeps him from driving a car, and if that seems like a relatively minor matter, consider that in most parts of this country a man without a car or access to a car is a man who is isolated from recreation, from entertainment, from sources of income, from the wider community.

Epilepsy, with the stigma that so stubbornly clings to it, further isolates the individual who has it from close interpersonal relationships. From the time the children first laugh at school, through the teenage years when dating and group activities are often closed to him, the person with epilepsy learns that he will have few friends, that he may never marry, that his disability will forever color his relationships with others. In many cases, he encounters subtle rejection even among his family -- parents, grandparents, brothers and sisters.

The combined result of the medical effects of this disorder, their long-term nature, and the equally long-term effect of the social rejection is a chronically ill patient population with needs of long-term psychological and social supportive services. And this adds up to a major national expense, and a tragic national problem in terms of numbers and of human isolation.

Cost to the Nation

Although we recognizethe moral fallacy of attempting to estimate a human problem in terms of dollars and cents, this is a form of measurement which can give a graspable dimension to the problem.

In a recently published study, the research staff at the Epilepsy Foundation of America calculated epilepsy's annual cost to the nation (including unemployment) at more than four billion dollars. These included identifiable cost factors assisted by extrapolation, and based on a four million patient population. The cost factors included physician fees, anticonvulsant medications, the cost of institutionalization, special education, vocational rehabilitation, various public assistance programs, medical and social research, unemployment wages and hour loss and veterans' benefits.

THE COST OF THE EPILEPSIES TO THE NATION

(As Estimated by the Epilepsy Foundation of America

Program	Annual Cost for Epilepsy
Aid to the Permanently and Totally Disabled	$ 70,266,690.00
Aid to the Blind	420,423.20
Aid to Families with Dependent Children	53,172,876.00
Vocational Rehabilitation	9,648,134.00
Social Security Disability Benefits	65,038,880.00
Crippled Children's Program	4,700,000.00
Medicaid	31,300,000.00
Medicare	125,300,000.00
Veterans Administration	89,430,210.00
Special Education	85,610,270.00
Institutionalization	231,649,000.00
Unemployment Wage and Hour Loss	1,720,224,000.00
Private Medical Costs	1,879,945,000.00
Research	5,895,252.00
TOTAL	$ 4,372.600,735.20

As I have already alluded to briefly, epilepsy is a complex mix of medical and social factors. I should like to present a quick summary of precisely what is involved in the medical, physiological, neurological side of epilepsy.

Epilepsy has been observed as far back as history records. References appear in the Bible and the writings of Hippocrates. The term "epilepsy" comes from the Greek word meaning "to be seized." In ancient times people with epilepsy were believed to be seized by demons. Famous people thought to have had epilepsy include Alexander the Great, Julius Caesar, St. Paul, Buddha, Napoleon, Handel, Dante, Socrates, Tchaikovsky and Alfred Nobel. Dostoevsky is known to have had the disorder and incorporated the symptoms of his illness into his novels.

As a medical entity epilepsy is symptomatic of a disorder of the central nervous system, characterized by sudden seizures due to abnormal electrical discharges of brain cells. Because these symptoms are varied and complex, they are more correctly termed "the epilepsies."

Epilepsy may be defined as a "disruption of the normal rhythm of the brain, an occasional, periodic, excessive and disorderly discharge of nerve cells in the brain."

Seizures may consist only of lapses of consciousness or only minor twitching movements, depending on the severity of the electrical discharge, the region where the disturbance originates and the nature of the stimulation to the brain. Isolated convulsions are not necessarily epileptic -- the term is generally applied only to seizures which occur repeatedly.

KINDS AND CAUSES

The International Classification of Seizure Types* includes

I. PARTIAL OR FOCAL SEIZURES (seizure beginning locally)

  A. Partial seizures with elementary symptomatology (generally without impairment of consciousness)

    1. With motor symptoms (includes Jacksonian seizures)

    2. With special sensory of somatosensory symptoms

    3. With autonomic symptoms

    4. Compound forms

  B. Partial seizures with complex symptomatology (generally with impairment of consciousness)

    (temporal lobe or psychomotor seizures)

    1. With impairment of consciousness only

---

* Gastaut, H. "Clinical and electroencephalographical classification of epileptic seizures," Epilepsia 11:102-113, 1970.

2. With cognitive symptomatology
3. With affective symptomatology
4. With "psychosensory" symptomatology
5. With "psychomotor" symptomatology (automatisms)
6. Compound forms

C. Partial seizures secondarily generalized

II. GENERALIZED SEIZURES (bilaterally symmetrical and without local onset)

1. Absences (petit mal)
2. Bilateral massive epileptic myoclonus
3. Infantile spasms
4. Clonic seizures
5. Tonic seizures
6. Tonic-clonic seizures (grand mal)
7. Atonic seizures
8. Akinetic seizures

III. UNILATERAL SEIZURES (or predominantly)

IV. UNCLASSIFIED EPILEPTIC SEIZURES
(due to incomplete data)

Causes

Epilepsy is termed "idiopathic" when no cause has been found for the seizures. Heredity appears to be a factor in some types. "Symptomatic" epilepsy, where a cause can be traced, may be triggered by many chemical or physiological conditions. Some of these are injuries incurred at birth or from severe injury after birth, for example, head injury caused by an auto accident; infectious diseases, such as meningitis or encephalitis; metabolic or nutritional disorders; brain tumors and strokes.

Diagnosis

Diagnosis of epilepsy involves a careful recording of the patient's history, complete physical and neurological examination. The electroencephalograph (EEG) helps identify epilepsy by measuring the brain's electrical patterns and recording them on a graph. The EEG may be useful in determining what type of treatment may be effective.

Treatment

DRUG THERAPY is today by far the most prevalent method of dealing with the epilepsies. Through the use of antiepileptic drugs, it is estimated that about 50% of people with epilepsy can achieve sufficient control of their seizures to lead full, active lives, and another 30% will experience fewer seizures. About 15-20% are not helped by available medications.

The ideal drug dosage controls the patient's seizures without side effects which interfere with his general well-being. Some drugs are more effective in controlling certain types of seizures; here the EEG is helpful in graphing seizure patterns. Dosage determination has been greatly facilitated by use of gas-liquid chromatography, a technique which accurately measures the concentration of a drug or drugs in the patient's blood.

Nearly half of all epilepsy patients require two or more drugs for effective seizure control. At the moment diphenylhydantoin and phenobarbital are the most widely used anticonvulsant drugs in the United States.

SURGERY is indicated in a very small number of cases where an identifiable lesion (injured area) can be removed by surgical techniques, and where this removal will not impair brain functions.

EMOTIONAL ADJUSTMENT is an important therapeutic factor; fatigue and emotional stress can increase the patient's tendency toward seizures and negate the beneficial effects of drug therapy. Epilepsy patients are encouraged to be as active and busy in the world as their disorder permits.

It may sound as if science has answered all problems; that is still, unfortunately, far from the truth. Just in the medical area, we still do not know:

What triggers the abnormal electrical discharge which results in an epileptic seizures;

What happens chemically in the brain cells during a seizure;

How a seizure spreads from its origin, as it sometimes does, to involve the whole brain;

How epileptic drugs work, and what effect they have on the brain;

Why some drugs are effective while some chemically similar ones are ineffective in controlling seizures;

Why drugs are ineffective with some patients and effective with others.

There is no question that our understanding is growing. We have methods of treating a goodly number of patients very successfully -- though not as many as we would like -- and there is an excellent chance for normal living in half the patient population. This is a far brighter prognosis than faced by sufferers from many other neurological problems.

But it leaves out an important part of what epilepsy is in our society today, the problem which helps to transform a reasonably treatable medical entity into a tragically frustrating social problem.

It is no exaggeration to say that for many people a diagnosis of "epilepsy" is a social and psychological disaster. I have known colleagues who will not use the word. I have dealt with families who refuse to accept the diagnosis -- totally refuse despite all the evidence.

The reason, of course, is that epilepsy has a powerful stigma, the roots of which we do not fully understand. Psychological explanations tend to fix on the nature of the seizure. Every seizure, it is suggested, reinforces the fear and prejudice of witnesses that such a person cannot be relied upon to participate fully in society, since he is liable at any time to go out of control.

Another suggestion is that when a human sees distortions of himself (in that an epileptic seizure does appear to distort a known person into something unfamiliar), then the viewer sees a threat to himself. He is reminded, the suggestion is, of his own vulnerability and rejects the possibility, and the threatening object. Fear, discomfort, resentment result in rejection -- in stigma.

One must recognize that the epileptic seizure is strange in appearance and frightening to the uninitiated. It has been said that it looks as if punishment of immense proportions is taking place before the onlooker, and fearing some kind of similar retribution may somehow come his way, the onlooker seeks to put the greatest distance he can between himself and the sufferer.

Yet another explanation is that our society places some premium on predictability and regularity. In such a society the loss of control over the physical functioninc become psychologically painful especially in a society such as ours in which self-control and individual responsibility for actions is accorded moral virtue.

I have labored this point perhaps, but, it is without question central to the national social problems that epilepsy presents.

Now, let me detail for you some of the non-medical areas in which having epilepsy carries a particular impact:

1. Restrictive or discriminatory legislation: Nine states still authorize sterilization of epilepsy patients under certain conditions. Most states require proof of a specified seizure-free period before issuing drivers' licenses. We do not quarrel with the licensing requirements; only that they not be arbitrary, and that they allow those who can drive safely to be allowed to. We do maintain that there be strict confidentiality of medical records submitted to licensing, education and other bureaus.

2. People with epilepsy are barred from military service and are usually discharged should epilepsy develop while in the service.

3. Education: Most children whose epilepsy is under reasonable control can attend and benefit from regular classes in public or private schools. The psychological trauma of having seizures in front of other children can be very great; however, an informed and sympathetic teacher can ameliorate the problem to some degree. According to a recent Foundation survey of educators around the country, there are few facilities for children of normal intelligence whose epilepsy is severe and uncontrolled; most such schools serve children primarily with mental retardation. Placement of one or two normal IQ children in classes with all mentally retarded further damages their already shaky self-image.

4. Employment: The Epilepsy Foundation of America estimates that up to one-fourth of medically controlled epilepsy patients of normal intelligence are chronically unemployed. This results from a combination of (a) personal apprehension on the part of employers; (b) resistance of other employees; (c) discriminatory workmen's compensation laws; and (d) lack of proper training, counseling and placement of employable people with epilepsy.

In 1972 in a ringing address to EFA Chapter Workshop delegates, Senator Harrison A. Williams, Jr., Chairman of the Labor and Public Welfare Committee appealed for help in "getting the job done" to improve opportunities for the handicapped. Senator Williams, father of the Subcommittee on the Handicapped, and a chief proponent of the now established Special Office of the Handicapped in HEW, urged delegates to keep up the pressure on public officials. Calling the exclusion of adults with epilepsy from most employment "shameful," he added "I am confident that, with your help, the changes that have been delayed for too long with at last be made."

5. Insurance: Automobile, health and life insurance premiums for those with epilepsy are often much higher than the standard rates, if they are obtainable at all. The largest group policies (Blue Cross/Blue Shield) generally exclude those with epilepsy, regardless of the degree to which they are handicapped or how long they had seizure control.

6. Recreation: Recreational facilities and programs often refuse to accommodate someone with epilepsy who has physical or emotional problems.

7. Public attitudes: Expressed public attitudes towards epilepsy appear to have improved, but a significant number of people still have damaging misconceptions about the disorder. Nor does the continuing employment discrimination bear out the apparently accepting attitude reflected by the Gallup Polls (see Table A).

Nine years ago a study was made on "Rejection" listing prejudices of two different types of employers -- personnel directors and school administrators -- in hiring persons with various disabilities.

Table B illustrates that the employers ranked people with epilepsy among the least desirable employees (persons with disabilities are ranked from most desirable employee to least desirable). The Table is adapted from the book *Physical Disability and Human Behavior* by James W. McDaniel, Ph.D.

TABLE A

Public attitudes toward epilepsy	1949	1969
Percentage of people objecting to their children associating with person with epilepsy	24%	9%
Percentage of people who believe epilepsy is a form of insanity	13%	4%
Percentage of people who believe persons with epilepsy should be employed	45%	76%

Based on 1949 and 1969 Geo. Gallup Surveys

TABLE B

Preference of Business Hiring Accountants	
1	non-disabled
2	tuberculosis
3	wheelchair
4	deaf
5	psychiatric
6	ex-prisoner
7	epileptic
Preference of Schools Hiring Accountants	
1	non-disabled
2	tuberculosis
3	wheelchair
4	deaf
5	psychiatric
6	epileptic
7	ex-prisoner
Preference of Schools Hiring Teachers	
1	non-disabled
2	tuberculosis
3	wheelchair
4	psychiatric
5	ex-prisoner
6	deaf
7	epileptic

Other clues on public attitudes come from the increasing number of articles appearing in newspapers and magazines, many of which have been entered in EFA's annual Journalism Award competition:

> "EPILEPSY PREYS ON SELF-ESTEEM--I mention my personal history not to condemn any person or institution but to illustrate the fact that while an epileptic loses confidence in himself, others tend to do even more."

Gastonia, North Carolina
GAZETTE

"FRIEND'S SEIZURES ARE FRIGHTENING--I have a friend who has epileptic seizures which just started in the last two years, and she is in her 60s...frankly the seizures scare me to death, too."

Chardon, Ohio
GEAUGA TIMES LEADER
(Cleveland Metro. Area)

"EDUCATION IS KEY IN DEALING WITH EPILEPSY--But much more needs to be done to erase the stigma and prejudice that there is 'something so different' about the epileptic."

DesMoines, Iowa
TRIBUNE

"EDUCATION PROCESS: TRUTH ABOUT EPILEPSY--Epilepsy, he notes, can happen to any one of us. For those to whom its happened, says a volunteer with the society for 10 years, 'the stigma becomes a greater handicap than the epilepsy itself.'"

Santa Barbara, California
NEWS PRESS

<u>What It's Like to Have Epilepsy</u>

It is unlikely that anyone other than a person with this disorder can fully understand its terrors and uncertainties, its effect upon personality, and the widespread stigma and discrimination. But the letters received by the Foundation from parents and patients provide some measure of the problem and I would like to share just a few with you. From the regular column "Foundation Mailbag" appearing in EFA's monthly newspaper come these actual quotations:

> "...all of my friends stopped hanging around us. That hurt me so badly because I wanted so much to be like them -- normal. This girl and I had become real close friends, and her mother told her not to hang around me because I'm an epileptic -- as if I had committed some kind of crime."
>
> "My parents were very concerned when I told them that I was going to college in another state. They had been brainwashed to think that I could not handle college...."
>
> "When I first found out I had epilepsy I wanted to die and actually tried to kill myself. I have heard people talk about epileptics, they still think these people are devil possessed or crazy. Am I?"
>
> "When my daughter is old enough to understand what happens when I have a seizure, will she hate me for bringing her into the world with a mother like me?"

> "Regardless if the good doctors call the disorder fits, fainting spells, black outs, grand mal, petit mal, etc. it still spells epilepsy! There is not any brand name product on the market today nor will there be in the future that will "whitewash" the name epilepsy to make the public like and/or understand the problem of the epileptic."

For further information see the document entitled "What It's Like to Have Epilepsy."

What you have just heard, of course, is subjective. One could argue that personality element, and other variables account for the "everyone hates me" tone. Last summer the Foundation conducted a survey of a relatively small sample of epilepsy patients and parents of children who have epilepsy to find out what elements of the disorder they believed had significant effects on their lives: The tables appear below.

Parents:

What do you feel is the greatest problem your child faces?

Social acceptance, attitudes and public opinion, stigma	36.0%
Seizures, brain damage, other medical, mental retardation	14.2
Self-acceptance, self-adjustment, emotional	13.8
Driving, employment, insurance	13.5

As you now view your child's career, do you believe that epilepsy will be a problem in his future career?

Yes	52.3
No	37.2

Adult Patients:

Do you have, or have you had problems attributable to epilepsy in:

Getting a job	42.1%
Holding a job	33.8
Obtaining life insurance	33.8
Obtaining health and accident insurance	30.1
Obtaining a driver's license	35.2

Clearly, the problems related to stigma, interpersonal relationships and the dominant problems of employment were central to this group.

Again in 1974 in response to still another survey of 168 adults with epilepsy and 203 parents with children with the disorder -- with responses from 49 states -- the following answers were given to the question:

> If the Epilepsy Foundation of America were to undertake a major national campaign - which single issue do you believe we should tackle first:

Public Information and Education	23.7
Employment Discrimination	18.4
Diagnoisis/Treatment	16.5
Program for Low-Cost Medication	11.7
Research Findings	10.3
Prevention	8.9
Insurance Prejudices	6.7
Rehabilitation	3.6

As a matter of fact, these are very close to the program priorities currently being undertaken by the Foundation.

To understand the work of the Epilepsy Foundation, it is necessary to have some understanding of the health care, social welfare, education, and rehabilitation "establishments" of the United States. The following will give some idea of the groups involved:

Installations of Interest

Rehabilitation facilities	3,000
Sheltered workshops	1,200
Special education facilities	600
Voluntaries	235
Veterans Administration hospitals	168
Medical Schools (85 affiliated with VA hospitals)	115
Clinics	400
Hospitals	7,100

Medical Professionals

Physicians		345,000
Board certified	38%	
Treat patients	90%	
Office-based	69%	
Hospital-based	31%	
General practitioners	19%	

Neurologists	3,300	
(2,600 inpatient care)		
Neurosurgeons	2,700	
Psychiatrists	21,000	
Nurses		723,000
(36,000 school nurses)		
EEG technicians		3,300

Social Professionals

Social workers	137,000
(24,000 in health field)	
Vocational rehabilitation counselors	11,000
Psychologists	26,000
Special education teachers	120,000
Teachers	2,100,000
(1,122,000 elementary)	

Note: The Library of Congress Congressional Research Service has done a report on what the federal government is doing in the area of epilepsy.

This research service report does not include one promising program of NINDS, namely the Comprehensive Care Epilepsy Centers Program.

This program seeks to develop ways in which a given geographic population of epileptic patients can receive top quality care through utilization of existing resources and the development of a coordinating center. The care would emphasize the utilization, rehabilitative and social services, together with the most recent medical advances, such as new drugs and measurements of serum levels of anti-epileptic drugs. The program emphasizes continuing education, association with a medical school and investigators in basic and clinical research. The first feasibility grants for this program will soon be awarded.

Scope of the Problem

Finally, just a word on epilepsy as part of the whole area of neurological dysfunction. Twenty million Americans have some kind of disorder of the nervous system. These neurological dysfunctions constitute a huge national burden in terms of both economics and human suffering.

The scope of the problem is not limited to its medical aspects. It requires a costly network of special educational facilities, vocational training centers, public information programs and enlightened legislation. It demands an increasing number of teachers, counselors and therapists as well as medical personnel.

Neurological diseases account for 20% of hospitalizations each year, and 12% of deaths.

The cost is staggering to the government (for welfare and Social Security disability payments, Medicaid and Medicare, special education and vocational rehabilitation) to the family and to the individual (for hospitalization, drugs, special education and therapy).

Disability	Estimated Cases	Estimated Annual Cost*
Mental Retardation	6,000,000	$3.5 billion
Epilepsy	4,000,000	$4.37 billion**
Parkinson's Disease	1,000,000	$400,000,000
Cerebral Palsy	750,000	$1.6 billion
Multiple Sclerosis and related diseases	500,000	$1 billion
Muscular Dystrophy	250,000	$400,000,000
Huntington's Disease	50,000	$ 25,000,000
Myasthenia Gravis	30,000	$ 94,000,000

* Taken from Neurological and Sensory Disabilities: Estimated Numbers and Cost, prepared by the Information Office, National Institute of Neurological Diseases and Stroke, National Institutes of Health, Bethesda, Maryland, revised 1973.

** "The Cost of the Epilepsies to Individuals, Families and To The Nation," data assembled by the Epilepsy Foundation of America, Washington, D. C., 1974.

Federal support for health issues is generally channelled through the National Institutes of Health (NIH). The institute responsible for the major work on epilepsy within NIH is the National Institute of Neurological Disease and Stroke (NINDS). The Institute spends approximately $4 million on epilepsy research; 20% of these funds goes towards operating costs and "on-campus" research within the Institute, and 80% supports outside research grants. The Budget Office of NINDS informed us that epilepsy obligations for Fiscal Year 1973 were $4,035,000.

The National Institute of Child Health and Human Development (NICHHD) has funded grants relating to epilepsy from the mental retardation aspect. According to the Research Grants Index, published by the Division of Research Grants of NIH, NICHHD supported three grants in FY 1972. These expenditures seem small judged either in terms of the previously described needs, or in the population of patients who continue to suffer from epilepsy.

3. WHAT EFA IS, WHAT IT DOES AND HOW IT CAME TO BE

The Epilepsy Foundation of America is a nonprofit, voluntary health organization with national headquarters at 1828 L Street, N.W., Washington, D.C. It was formed in 1968 by a group of citizen volunteers, many of whom were persons with epilepsy or parents of children with epilepsy. All were active in two predecessor organizations (Epilepsy Association of America and The Epilepsy Foundation) anxious to create one strong, unified national organization devoted to solving a major national health problem affecting at least 4,000,000 Americans.

While it is not the only epilepsy related organization still to claim national scope (the Chicago-based National Epilepsy League offers a national low cost drug program and information services) it is by far the largest, and in recent years has come to occupy what most observers would describe as the spokesman role for people with epilepsy in this country. The publication entitled "Programs for the Handicapped" published by the Office of the Assistant Secretary for Human Development of the U.S. Department of Health, Education and Welfare states: "The only major 'national' nonprofit agency in the field of epilepsy is the Epilepsy Foundation of America, founded in 1967."

EFA Purposes

The organization's goal is to improve the lot of the person with epilepsy by:

-- Promoting, conducting and supporting research into the causes and treatment of epilepsy;

-- Making known the available treatments for epilepsy;

-- Improving educational and vocational opportunities for persons with epilepsy;

-- Educating and providing information to the general public with a view toward eradicating misconceptions about epilepsy;

-- Promoting and supporting clinics, schools and other facilities or means of treating, educating, training, obtaining employment for, caring for, or otherwise helping persons with epilepsy;

-- And providing financial support to individuals and other organizations engaged in activities that further any of the purposes of the Foundation.

Leadership

The Foundation's activities, under its latest by-laws adopted November 30, 1973, are charted and guided by a 43 member Board of Directors. The Board consists of 10 directors elected by 156 local chapters throughout the United States; 10 directors elected by a Professional Advisory Board made up of 50 distinguished physicians and specialists; 19 representing the general public; and 4 who are directors by virtue of their positions in the organization. Other material in this statement describes these bodies in greater detail.

All members of these boards serve without compensation, save for reimbursement of travel expenses where requested.

About 30 percent of the board either have a family member with epilepsy or suffer from the disorder themselves.

Legal Information

Incorporated under the laws of the State of Delaware, the Epilepsy Foundation of America is a 501(c)(3) tax exempt corporation and contributions to it are deductible for federal income tax purposes under the Internal Revenue Code of 1954.

Finances

Dues from local chapters and contributions from 1,037,000 individual private citizens -- averaging $3.13 each -- numerous firms, and 230 charitable foundations support the work of EFA headquarters in research, fellowships, training programs, counseling, vocational rehabilitation, and public information and education.

The Foundation has no contract or agreement between persons making soliciations and persons on whose behalf the solicitation is made which in any manner (a) bases the amount of receipts received by the person on whose behalf the solicitation is made on the amount or number of contributions received from the solicitation; or (b) bases the fee or other charge of the person making the solicitation on the amount or number of contributions received.

Program and Operating Expenditures

The total income and total expenditures of the Foundation vary from year-to-year but the most recent financial statement audited by Price Waterhouse & Co., and as published in the Annual Report released in May, 1973, shows the following as categorized by the standards of the National Health Council, of which EFA is a member.

Revenues (Including all chapters)	$4,147,162
Costs of solicitations, administrative, managerial and certain fixed costs of doing business and running programs	1,976,904
Net Available Income	2,170,258

Program Expenditures

	Total	Percent Revenues Allocated
Research	176,004	8.1%
Professional Education & Training	188,019	8.7%
Public Health Education	364,161	16.8%
Community Services	1,059,536	48.8%
Patient Services	318,029	14.6%
Transferred to Reserves & Capital Fund	64,509	3.0%
TOTAL EXPENDITURES	$2,170,258	100.0%

Like many other voluntary health organizations, the majority of EFA's service functions are rendered through the local chapters, with the headquarters office operating as a chapter service unit and as a national spokesman through which the views of the organization may be presented and the needs of the person with epilepsy may be voiced.

Further information in regard to all of the foregoing is developed in detail elsewhere in this statement.

How the Epilepsy Foundation of America was Formed

For the complete story see the brochure entitled "History of the Epilepsy Movement in the United States" which you may want to make a part of the printed record of these hearings.

The birth of a strong, national movement to combat the effects of epilepsy came late to this country. Efforts to create such an organization were begun as long ago as 1898, when a group of doctors gathered in the New York Medical Library and founded the National Association for the Study of Epilepsy and for the Care and Treatment of the Epileptic. But this was never much more than a very small group of good people with good intentions. As its initial leaders became discouraged, no others appeared to take up the cause. Epilepsy's stigma in the days when seizures were very prevalent among all patients was even more virulent than it is today.

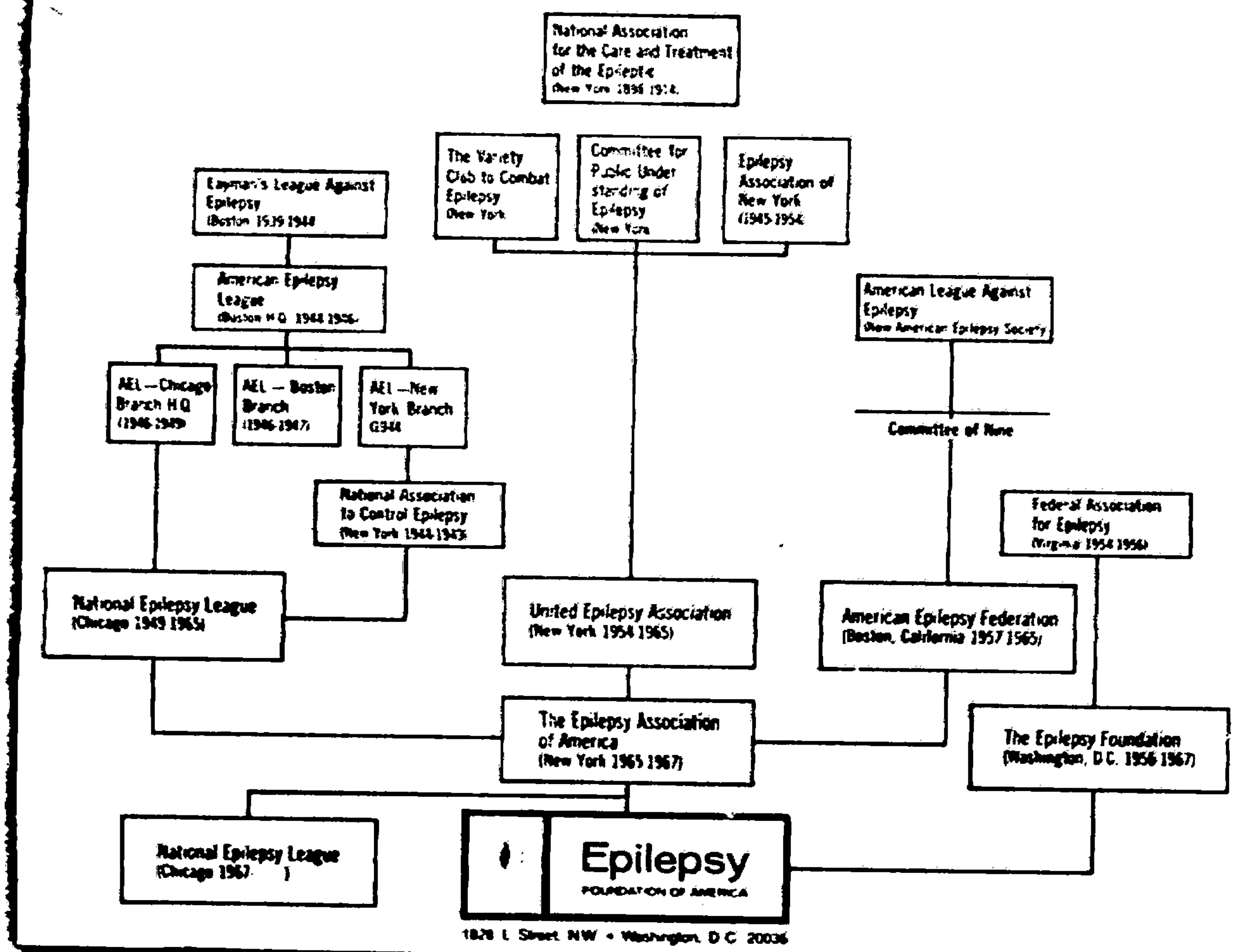
As the other voluntary agencies for TB, heart, crippled children were established and grew stronger, further efforts were made to establish a similar source of help for epilepsy. The distinguished neurologist, Dr. William Lennox, with the support of Mrs. Eleanor Roosevelt, founded the Laymen's League Against Epilepsy in Boston in 1939. Other organizations were established too, but their influence and their numbers were small. Volunteers were difficult to recruit, few people, it seemed, wanted to join a chapter, few people wanted to be associated with epilepsy at all, any way.

It was not until after the Second World War, when seizure control became achievable for numbers of patients through improved treatment methods, that the movement began to gather momentum. By the early fifties, some strong chapters had been established in various parts of the country to provide information, comfort and support to adults, to children with epilepsy and to their parents. However, these chapters were affiliated -- if they were affiliated at all -- with competing national groups (see chart on the following page) not one of which had the strength or resources to make any real national impact ... on a continuing basis.

Accomplishments Along the Way

Clinics were established and/or supported and EEG(electroencephalogram) machines were purchased through local fund raising drives. Support was given the establishment of a national veterans epilepsy center. The demands of several voluntary health groups resulted in the establishment of the National Institute of Neurological Diseases and Blindness (now NINDS) in 1950. Laws were changed including some particularly offensive sections of the Immigration Act. But much, much more needed doing.

History of the Epilepsy Movement



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Governmental and National Health Council Involvement

This state of affairs distressed the Health Council, which recognized that unless there was some national voice speaking for the needs of the individual with epilepsy, those needs would continue to go unmet. At the request of the American Epilepsy Federation, one of the quasi-national groups, the Health Council agreed in the early Sixties to try to bring the separate parties together. A committee was formed, and the importance of the effort to create a national voice for epilepsy was recognized by the Social and Rehabilitation Service (then called the Vocational Rehabilitation Administration) which granted almost $14,000 to the Health Council to defray costs of negotiating meetings.

Months of negotiation followed. There were conflicts in what should be the program priorities of the new national group. The separate organizations were reluctant to give up the services they had developed, and believed to be of value but which were not as favorably regarded by rival groups.

Finally, after years of discussion and intermediate mergers along the way, a compromise was reached, a compromise which merged the boards of the largest organizations, and retained most of the program elements in dispute. Had this not been done, no national group would have emerged. As it was, one of the three negotiating parties, the National Epilepsy League, withdrew almost immediately and has returned to its separate status. In 1971, the Epilepsy Foundation of America qualified for membership in the National Health Council, and set about expanding its chapter network so that the few who informed, comforted, and counseled in the Fifties would become the many.

Commendation

Congratulatory statements poured in from across the country. President Lyndon B. Johnson wrote EFA as follows:

> "The formation of the Epilepsy Foundation of America is, indeed, a milestone in a major health field. And all who have worked to bring it to fruition deserve our admiration and our thanks ...
>
> "A unified approach to volunteer efforts across the nation will hasten the day when all Americans will achieve a new and better understanding of this disorder. Only with such increased public awareness can we hope to continue to stimulate research, encourage education, and unfold unprecedented opportunities for employment for epilepsy sufferers."

This bipartisan support has continued to this day. Under date of October 1, 1973, President Richard M. Nixon wrote as follows:

> "To promote a better understanding of epilepsy and to honor the contributions of the Epilepsy Foundation of America we set aside November as Epilepsy Month.
>
> "Through the works of thousands of volunteers in the Foundation's chapters across our Nation we are discovering more effective and readily available treatment for a disorder that affects four

> million Americans. And we are achieving a more favorable and positive public attitude toward epilepsy victims.
>
> "I congratulate the Epilepsy Foundation of America for giving national attention to this little-understood disorder, and I urge all Americans to support its efforts to help persons with epilepsy take their rightful places as contributing members of our society."

Secretary of Health, Education and Welfare John W. Gardner wrote as follows under date of December 8, 1967:

> "The formation of a single national voluntary agency devoted to Epilepsy further strengthens an effort which has already made significant contributions to both medical and public understanding of this disorder."

Upon merger, messages were received from 36 governors. At least 24 past or present members of this body sent EFA congratulatory messages. It is perhaps appropriate at this time to pay tribute to the full-hearted support which has always been given to the Foundation by the Senate of the United States. In the midst of busy days, I am not certain we have always made clear how much we value this support and how it sustains us in our efforts.

The Years Since Merger

Since 1967 and 1968, the national organization has begun to have the beneficial effect that SRS and the Health Council foresaw. More chapters are providing more services to people with this disorder than ever before; more public information is available and being dispersed, the National Institute of Neurological Diseases and Stroke, at the urging of Congress, now lists epilepsy centers as one of its major priorities, the level of knowledge about this condition is rising, and twenty-three Senators and Representatives now recognize the need for a national approach to the problem -- a national plan -- and have so indicated by co-sponsoring legislative proposals along those lines.

In the years since merger the Epilepsy Foundation of America has, we believe, raised the public's awareness of the disorder, and raised the consciousness of professional people who, in the course of their duties, are likely to be involved with epilepsy.

It has entered into closer relationships with voluntaries serving other developmentally disabled, namely the United Cerebral Palsy Association, Inc., and the National Association for Retarded Citizens. All three groups signed a statement of cooperation last August.

It has developed liaison with federal agencies with epilepsy-related services. Although a joint statement of intent with the Rehabilitation Services Agency signed in 1969 has not yet produced all of the rehabilitation progress initially hoped for, during the past two years a greater understanding has grown, and the Foundation finds vocational rehabilitation officials at federal, state and local levels more cognizant of epilepsy and its problems than ever before. The Foundation believes that this new understanding is at least partly due to its efforts and a recent speech of Texas Vocational Rehabilitation Commissioner Jess Irwin seems to confirm this.

Following the practice of other voluntaries in the field, the Epilepsy Foundation of America has helped its chapters learn how to apply for funds to provide needed services for people with epilepsy. In 1971, the first year in which federal money was available to help people with epilepsy, only 23 chapters filed successful applications for funds. A lack of expertise in very young organizations was the reason; the result was that the intent of Congress, that is, that people disabled by epilepsy should be served, was not generally met. Only about seven percent of funds appropriated to serve three neurological disorders (mental retardation, cerebral palsy and epilepsy) was actually benefiting those with epilepsy. The Foundation, in its role as advocate and spokesman for the rights of those with epilepsy, pointed this out, and set about helping its chapters document the needs, design the programs and prepare the applications in proper form.

The result was that the number of successful grants almost doubled. And, of course, that meant a concurrent increase in the number of people served. This is an example of how a national organization functions to obtain needed services for its population. Furthermore, Division of the Developmental Disabilities has recognized the importance of imparting more information about epilepsy to the State Councils passing on DDSA state plans, and is currently holding a series of teaching institutes on epilepsy in the various regions. EFA provides support, speakers and assistance as requested for these meetings. We believe such cooperative activities wholly appropriate to a national organization, and believe that their existence, and the growth of others like them, to be in the American tradition of what the national headquarters of a voluntary agency does in our society.

Point of View

In 1972 EFA held a Chapters Workshop with 280 citizen-volunteers from every state in the Union meeting here. The full page advertisement which appeared in the April 12, 1972 issue of the WASHINGTON POST had this to say among other things:

> "Today, at the Washington Hilton, a three-day national workshop begins to take a new look at an old -- and tragic -- problem. One that involves grief and anguish for the 4 million afflicted ... and for their families. One with a cost to our society which is colossal.
>
> " ... we and our delegates have a huge -- and complicated -- task ahead of us.
>
> "We come not to petition the President. Nor the Congress. For we believe that they are keenly aware of the problem and of their responsibilities. We believe so because our people are members of Advisory Councils for many governmental agencies ... ranging from the National Institute of Neurological Diseases and Stroke to state and national councils for HEW's Developmental Disabilities Division.
>
> "And, to the extent -- and in the manner -- proscribed by present law, our staff members have long been active in providing governmental officials -- upon request -- with information and statistics relating to the epilepsies.

> "We come rather as <u>volunteers</u> with the firm conviction that <u>the problems of epilepsy -- like most of our nation's problems -- will ultimately be solved by individual actions and attitudes in local communities</u>."

That is still the approach to which this organization is committed.

4. THE MANAGEMENT OF EFA

EFA is, essentially, a confederation.

To one degree or another, millions of persons with epilepsy, millions of their friends and the members of their families, 40,000 members of local EFA chapters (there are currently 164 in the United States), 2,142 officers and directors of local chapters, 575 members of local Professional Advisory Boards, at least 60 agencies of the federal government, at least 130 agencies of state governments, nearly 200 professional societies and voluntary organizations, 50 members of the national Professional Advisory Board, 43 members of the National Board of Directors, 199 paid staff members (138 in the chapters, 61 in the National headquarters) and a number of other entities and/or people are involved in the "management" of the Foundation.

Whether one manages such a universe or is managed by it, is an interesting question. For, to a considerable extent, the situation is not unlike "laying track in front of a train going ninety miles an hour."

EFA, of course, is a voluntary health organization and most of its activities and work are carried on by unpaid volunteers who contribute of their time and talents in a variety of ways.

But there are certain common denominators applicable to national, state and local levels.

EFA Components, Allied Organizations and How They all Work Together

Essentially, the main components of EFA consist of a national Board of Directors, national Professional Advisory Board, a Headquarters Staff, Regional Offices, and a Chapters Network. Across the country EFA is also much involved in a number of professional and voluntary organizations, the most important of which are probably the American Academy of Neurology, the American Neurological Association, American Medical Association, the American Epilepsy Society, United Cerebral Palsy Associations, and the National Association for Retarded Citizens. It is also involved with numerous governmental agencies. All of thoseshare a concern for the person with epilepsy.

They work together with us through liaison, frequent contact and mutual respect.

EFA "Governing," "Advisory" and "Implementing" Bodies

In all instances a volunteer Board of Directors is the governing and policy-making body with ultimate responsiblity for formulating general objectives relating to programs, staffing, financing ... in fact every aspect of Foundation activities by the unit involved.

In all instances a volunteer Professional Advisory Board is the advisory body providing active, authoritative guidance and direction in the design and operation of programs.

In all instances, paid staff is the *implementing* body primarily responsible for carrying out the resolutions and directives of the governing and advisory bodies ... although the bulk of the actual work is done by volunteers.

Management of the National Headquarters Organization

The overall structure outlined above is found in its most developed form here and should perhaps be further described:

One of the first acts of the new organization was to commission the management consultant firm of Booz, Allen & Hamilton to conduct an organizational study and to arrive at recommendations in regard to staffing and methodologies. The study was conducted by Dr. Robert Hamlin who earlier had done a definitive study on similar organizations for the Rockefeller Foundation. His assistant was Maurice Arth, who later served on the EFA Board. The recommendations were subsequently adopted by the Board and have survived -- with relatively minor changes -- into the present, although structure has since been studied and reviewed by many others.

National Board of Directors and its Committees

Present committees of the Board, which meets at least twice a year, include: Fund Raising, Chapter & Field Services, International Relations, Research & Professional Education, Public Information and Education, Government Liaison, Vocational Rehabilitation, Gas Liquid Chromatography, Finance, Legal, Nominating ... and the Executive Committee, which meets at least twice a year (in between Board meetings), and is authorized to act for the full Board.

For further details, see the document entitled "FFA Bylaws and Board Committee Practices." A complete list of names and addresses of current national Board members is attached to this section.

National Professional Advisory Board and its Committees

The full Board meets at least once a year and its Executive Committee meets at least once. In addition to the Executive Committee, committees of the PAB include: Medical-Legal Insurance Committee, Research, Fellowships and Training Grants Committee, Publications Committee, Membership Committee, Government Liaison Committee, Inquiries, Referral and Information Center (Library) Committee, Speaker's Bureau and Seminar Committee, Chapters and Service Development Committee.

For further details, see the document entitled "PAB Bylaws and Guidelines." A complete list of current members of the National Professional Advisory Board -- and their principal affiliations -- is attached to this section.

EFA Headquarters Staff and Headquarters Departments

The headquarters staff presently consists of 61 people. The planning (and delivery) to those with epilepsy of the many kinds of services needed, as well as transmission of many kinds of information to a wide range of "publics", is undertaken by six interrelated departments, each headed by an executive director or deputy director:

ADMINISTRATION AND FINANCE: (21 people in all) which has been headed by Associate Executive Director Brig. Gen. James A. Shannon USAF (Ret.) is responsible for: Budgeting; financial reporting; accounting; personnel management and orientation; office management, work flow, record keeping, contribution processing (8 people), Patient Correspondence (4 people) and other functions.

COMMUNITY SERVICES AND CHAPTER DEVELOPMENT: (12 people) which is headed by Associate Executive Director Don L. Organ, formerly with the National Easter Seal Society, is responsible for: Regional Office management; chapter organization and development; development of guidelines and standards for chapter management and services center; furnishing services for all chapters in all six areas of EFA activity, including counsel on fund raising.

FUND RAISING: (8 people) which is headed by Executive Director Thomas M. Ennis, is responsible for: Campaign planning, direct mail solicitation; approaches to foundations, industry, welfare-oriented organizations and individuals for larger gifts; development of materials for chapters; continuing analysis of fund raising opportunities and directions.

GOVERNMENT LIAISON AND NEW PROGRAM DEVELOPMENT: (6 people) which is headed by Associate Executive Director Dr. Leonard G. Perlman, formerly with the National Institute of Mental Health, is responsible for: Information/action exchange with federal, state and local government agencies; liaison with government in legislation, research programs, social services, and rehabilitation programs; statistical studies; development of EFA "positions papers" on many aspects of epilepsy as a medical and social problem; and management of EFA library and information center.

PUBLIC INFORMATION AND EDUCATION: (7 people) which is headed by Deputy Director James E. Gorman, is responsible for: Development of information/education themes and positions; creation of information and educational materials, literature films exhibits, broadcast announcements, press relations, including news for general and specialized press and broadcast media, and development of articles; news-making special events and activities; speaker's bureau, aid to chapters in all areas.

RESEARCH AND PROFESSIONAL EDUCATION: (3 people) which is headed by Dr. Roger W. Buddington, formerly with the National Institutes of Health, who is responsible for: Fellowships, research and training grants programs; professional and paraprofessional seminars and conferences; liaison with medical profession and related professional societies; guidance to staff on medical/scientific aspects of epilepsy, in cooperation with EFA's Professional Advisory Board.

All departments currently report to the Executive Vice President to whom also report an executive secretary, a special assistant, legal counsel and the organization's auditors.

For further details see the document entitled "EFA Staff" which, although currently out of date, sets forth most long-standing policies and indicates the probable direction of future expansion of HQ staff.

Management of Local Chapters and State Organizations

The management of local chapters and state organizations is in accord with the bylaws of those organizations on file with appropriate bodies in the various states. Relationships with the National Headquarters are in accord with Affiliation Agreements duly executed by local and national officers for their respective organizations. For further details see copies of the three forms which have been turned over to the Subcommittee staff, along with a copy of the "Covenant" sheet provided.

Full Affiliate Chapters are Required to Meet the Following Organizational Criteria

1. A Board of Directors of no less than nine members with an ideal range of from 18 to 30;
2. A Professional Advisory Board of no less than five members with a maximum of 25;
3. An Executive Committee consisting of the chapter president, vice-president, secretary, treasurer and various committee chairmen as appointed (A committee chairman may also serve as any chapter officer except president.);
4. A minimum of the following committees:
   a. Fund Raising Committee
   b. Program Committee
   c. Finance Committee
   d. Nominating/Membership Committee
   e. Information and Education/Public Relations Committee
   f. Government Grants Committee
5. Articles of Incorporation;
6. Bylaws which are compatible with EFA Bylaws;
7. Tax-exempt status as a non-profit, voluntary organization under Section 501(3)(c) of the Internal Revenue Code;
8. Submission to EFA headquarters of any recent changes in local and state regulations concerning fund raising and the operation of a non-profit, voluntary organization. They should be resubmitted if changes have occurred since gaining Provisional status;
9. A chapter bank account with cash flow of no less than $2,000;
10. A fully-equipped, permanent office with listed telephone and a paid or volunteer staff capable of maintaining 9:00 a.m., to 5:00 p.m. hours, Monday through Friday. Sufficient storage space must be available to stock office supplies and a starter supply of all EFA standard literature;
11. A non-profit postal permit from the local post office;

12. Execution of the formal EFA Affiliation Agreement with the following attachments:
    a. List of Board members, officers, and members of the Professional Advisory Board;
    b. List of committees and chairmen;
    c. Copies of chapter's Articles of Incorporation, Bylaws, IRS determination of tax-exempt status, and state and local fund raising/non-profit, voluntary organization regulations (If no regulations exist, a letter to this effect must be included);
    d. Written details in letter form covering bank arrangements and balance, office address and telephone, paid and voluntary staff, storage facilities, and non-profit postage permit;
    e. Annual EFA affiliation payment of 25% of annual income;
13. Provision for a non-voting membership.

Provisional Chapters are Required to Fulfill the Following Organizational Criteria

The local group must have completed initial plans for the following programs:

1. Community Resources Survey
2. A Public Information and Education Program
3. A Patient Information and Referral Program
4. Participation in a School Alert Program
5. Participation in National Epilepsy Month
6. Chapter Speakers' Bureau

Written Working Guides and other information aids are available from EFA Regional Offices to help chapters develop the above programs and others. And, of course, the Regional Manager and specialists from EFA headquarters provide personal assistance when needed.

State Organizations are Concerned Primarily with these Three Vital Functions:

First: Because Federal funds are being distributed more and more through state agencies, the epilepsy movement must be in a position to obtain formula grants such as DDSA. Such Federal funds are allocated to the states, which in turn, use broad discretionary powers in disbursing these funds to local health organizations. To ensure that those persons with epilepsy within a state receive their fair share of Federal funds, it is essential that all EFA chapters in a state cooperate and coordinate their efforts to obtain such funding.

Second: It is important that state legislatures be aware of the needs of those with epilepsy in their states. The state organization has an advantage in handling legislative contacts at the state level, working for and with the chapters to remove or revise inequitable legislation and to supply expertise for new legislation.

Third: As the chapter establishes an active governmental liaison program as well as an effective community education program, the epilepsy movement within a state must be able to speak as one unified voice. State EFA units offer local chapters statewide stature and strength vis-a-vis the state government with its numerous facilities and services for the handicapped. State EFA organizations can also amplify the voice of the local chapter in implementing programs of the national organization.

Other activities of state organizations are by agreement among the chapters in a state. There could well be other functions such as minor administrative activities or statewide publicity campaigns. Because sophistication is needed in working with state governments, professional staff should always be employed -- and office facilities must be obtained.

Volunteer Position Guides and Time Sheets

Written job descriptions and time sheet forms as well as an equivalent salary scale have been developed for key volunteer duties in local chapters.

Chapters Current Classification of Local Organization

Full Affiliates	77
Subchapters	4
Provisions	25
Information Contacts	57
Cooperating Organizations	1
Total Local Organizations	164

Management of Regions

It would, perhaps, be more accurate to speak of liaison, of services to the chapters in a region, of public information and education activities carried on with TV stations, radio stations, newspapers, service clubs, and of the establishment of linkages with medical schools, neurological clinics, sheltered workshops, and a wide variety of agencies of city, county, state and federal governments.

None of the foregoing are adequately described as "management."

But these activities are carried on by five (5) regional offices at the locations indicated, and staff with the following people:

Boston Regional Office (HEW REGIONS I & II)
Joseph Quinn, Regional Manager
Martha Jenkins, Regional Secretary

Atlanta Regional Office (HEW REGIONS III & IV)
M. Duane Ostrom, Regional Manager
Levona Buchner, Regional Secretary

Houston Regional Office (HEW REGIONS VI & VIII)
Sue Sturm, Regional Manager
Frederick J. Ross, Regional Fund Raiser
Sally McCown, Secretary

Chicago Regional Office (HEW REGIONS V & VII)
Arthur G. Petry, Regional Manager
Nancy J. Combic, Regional Secretary

Los Angeles Regional Office (HEW REGIONS IX & X)
Charles C. Stevenson, Regional Manager
Helen Chalker, Regional Secretary

This field staff is presently augmented by five (5) headquarters executives who are in the field to accelerate the accomplishments of current objectives and to update their knowledge of local situations. For further details see March 1974 issue of NATIONAL SPOKESMAN.

Volunteer and Paid Consultants

To augment both staff and law expertise, the Foundation utilizes, from time to time, on an "as needed" basis, a wide variety of specialists -- at both the national and the local levels -- in lieu of adding additional people to staff. Some of these work without compensation but most are paid. The current list of such professionals includes: Director of Program Planning and Evaluation, Harry Sands, Ph.D.; Social Work, Anthony Arangio, Ph.D.; Volunteer and Staff Training - Interpersonal Relationships, Hans Scherner; Bio-Statistics and Epidemiology, Leonard Chiazze, Jr., D.Sc.; Psychology, George Goldin, Ph.D., and Lawrence E. Schlesinger, Ph.D.; Rehabilitation, George Wright, Ph.D.

EFA Priorities and Objectives and How They are Arrived At

The starting point is the person with epilepsy. But over and beyond this, both formal and informal surveys are utilized. Plans are formulated by Board committees and periodically plans are tested against various constituencies. For example, see "What's Your Opinion?" poll last done in 1973.

It is interesting to note how closely the expenditure allocations suggested agree with the results of this opinion poll as indicated in the table on the following page:

GENERAL FUND BUDGET ANALYSIS

Based on Actions Recommended by Board Select Committee, January 25, 1973

NOTE: Analysis is based on Net Available Income (NAI) which is gross general fund income minus Board reserve, fund raising, management and administrative expenses.

Expenditure Classification (National Health Council)	% of NAI as set forth in "What's Your Opinion?" Poll	Results of Opinion Poll
Research	10 %	11 %
Public Health Education	20 %	21 %
Professional Health Education & Training	10 %	10 %
Patient Services	5 %	6 %
Community Services		
NCHC	15 %	14 %
Government Liaison & New Program Development	20 %	20 %
Chapters	20 %	18 %
C/S Subtotal	55 %	52 %
TOTAL	100 %	100 %

The shifts in the above recommended by a select committee of the Board -- and later endorsed by both the Executive Committee and the full Board -- form the basis for the priorities and allocations currently being followed.

Forward Planning

Periodically -- usually every two years -- EFA develops a "Three Year Forward Plan," a detailed three-inch thick compendium of goals and projects and the documentation as to why and how they are being undertaken.

A summary Digest is also prepared (see printed sheet entitled "The Next Three Years" published in late 1973). To-date 92 copies have been requested by other non-profit organizations anxious to improve upon their planning processes.

EFA Budgets -- How Developed and Controlled

Plans begin in various committees on or about August 1 and input on all budgetary requirements are consolidated by the Program and Long Range Planning Committee during late August. Priorities are assigned and meshed with revenues likely to be available.

The Finance Committee of the Board then reviews the resultant plan for fiscal soundness by mid-September and the completed budget and plan for the following year is assembled by October 1 for review and approval by the Executive Committee at its customary late November or early December meeting. Executive Committee recommendations are then approved by the Board of Directors usually in early December.

Budgets are constructed by Health Council classifications, by departments and individual projects. Accounting codes are assigned to all projects. We would concur with Arthur Jack Grimes of the National Health Council, however, that "... Since some of the activities undertaken by many voluntary health and welfare organizations ultimately, necessarily and properly simultaneously serve the program objectives of an agency as well as its management activities and the raising of funds to carry on these other functions, it may not be possible, even with the most meticulous accounting, to completely isolate and precisely report all of an agency's expenditures for any single function, whether it be fund raising, management and general, or a particular program service."

All projects are assigned to headquarters departments for implementation and all budgets are reviewed at least monthly.

All purchasing is by written purchase order, contract or letter of agreement. Expenditures in excess of $500 are normally covered by at least three competitive bids unless the materials or services are unique or there is other good reason for waiving this requirement. All checks in payment of invoices require two signatures.

For further details see printed 1974 Operating Budget.

"Make" or "Buy" Decisions

In all aspects of its operations the Foundation seeks to maximize the effective and efficient use of its resources. Each request for services is analyzed to determine whether it would be more advantageous for the Foundation to provide that service from its "in-house" capability -- when staff time is available -- or whether it can be most economically and efficiently purchased from outside sources.

Departmental and General Staff Meetings

In order to encourage communication between departments, a lot of planning and effort goes into the weekly Monday morning staff meetings. A review of the significant events of the previous week is given by each department head as well as a status report on the various projects within his department. A summary by department is kept on corkboard within the meeting room so as to provide a ready reference to each assignment. Notes are taken during the meeting and follow-up memos are sent to the department head. Currently, each of the staff meetings is attended by one of the Regional Managers, on a rotating basis, thus giving them the opportunity to keep abreast of the developing activities and projects being conducted by headquarters.

Departmental meetings are held from time to time depending upon the need of the department. This is usually weekly. The Chapter's Department has at least two meetings of the Field Staff each year, usually lasting several days. Procedures and policies are reviewed and input by the field is utilized to appraise the effectiveness and appropriateness of headquarters activities from the chapter standpoint.

Reports to Volunteer Leadership

The volunteer leadership of the Foundation is kept apprised of the activities of the various departments by means of Monthly Reports, prepared by the 5th of each month by the heads of each department. The report is both a review of various on-going projects within the department and a preview of activities or problems as seen by the staff person.

Career Staff, Staff Training, Personnel Recruitment, Length of Tenure, and Other Related Matters

The tasks with which the paid staff of the Foundation are confronted are massive ones. The daily mail, phone calls, and the need to respond quickly to problems and opportunities are awesome. Genuine dedication and a desire to help others are required along with increasingly specialized professional knowledge.

We are unable to fully accomplish all we intend. Nor all that is expected of us ... as the daily mail makes clear. Nor will we ever be. That reality is accepted by some, but becomes burdensome to others.

A feeling of relative helplessness in the face of enormous tragedies also presents emotional burdens.

Despite these considerations, the length of tenure of staff members would appear to compare favorably with other organizations. In analyzing all readily available records on headquarters personnel (212 people),we find that the average tenure of all employees ever employed by EFA is 2.7+ years. Average tenure of 61 employees presently on staff is 2.8+ years.

Hire Date	# Still on Payroll
1968 (and prior)	13
1969	1
1970	4
1971	8
1972	6
1973	27
1974	2

National Health Council advises no comparable figures are available in this area. Department of Labor figures (see publication "Employment and Earnings") indicates that overall figures for nondurable U.S. industry to currently be 49 new hires per 100 employees per year.

Staff training is of crucial importance and EFA utilizes a variety of resources -- including staff lectures by nationally known authorities -- whenever time permits.

EFA utilizes employment counselors and personnel recruiters extensively, rather than having people doing such work actually on the EFA staff. Costs are as published by these organizations. As a general rule, the search for high quality people with special credentials takes longer -- and costs more -- than for routine positions. It is EFA's intent to continue to use such resources.

Staff compensation and personnel policies tend to be patterned after those of the government with due regard to National Health Council tables applying to organizations in the "$2,000,000 to $10,000,000" range. For further information see National Health Council tables on staff compensation and the 1974 edition of "Association Executive Compensation Study" published by the

American Society of Association Executives,

Supplier and Prospective Supplier Proposals and Relationships

Like every organization, EFA is besieged by vendors anxious to sell their wares. To the full extent time permits, these vendors receive careful consideration but not all achieve -- or maintain -- our custom. EFA standards for quality and service are high. All work done for EFA and relationships with those suppliers are available for inspection by the Subcommittee.

Management in Summary

The activities of EFA are complex but our philosophy in this area can perhaps best be expressed as: make something happen for persons with epilepsy, make it happen now.

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5. BASIC EFA ACCOUNTING

(Statement of H. Leroy Smith, Controller)

As in a large number of organizations, the accounting function serves three major purposes -- that is (1) to deposit and account for cash, (2) to oversee the disbursement of funds, and (3) to summarize data on the Foundation's financial condition for use by management as well as the public, governments, and other external groups for their varied uses. These objectives are to be accomplished with a minimum of cost since the investor (donor) usually considers those expenditures as a "necessary evil." The result is the development of the "material" criterion which, in essence says that those expenditures on the accounting function are proper to materially perform its major purposes. This is what we are attempting to accomplish.

The deposit is prepared in the processing room, where there are a number of controls to protect the funds. An armored car service is used to collect the mail from the post office and to take the deposit to the bank. There are TV cameras in this processing room with two monitors. Strict rules have been promulgated concerning access to the processing room and on the handling of funds by the processors.

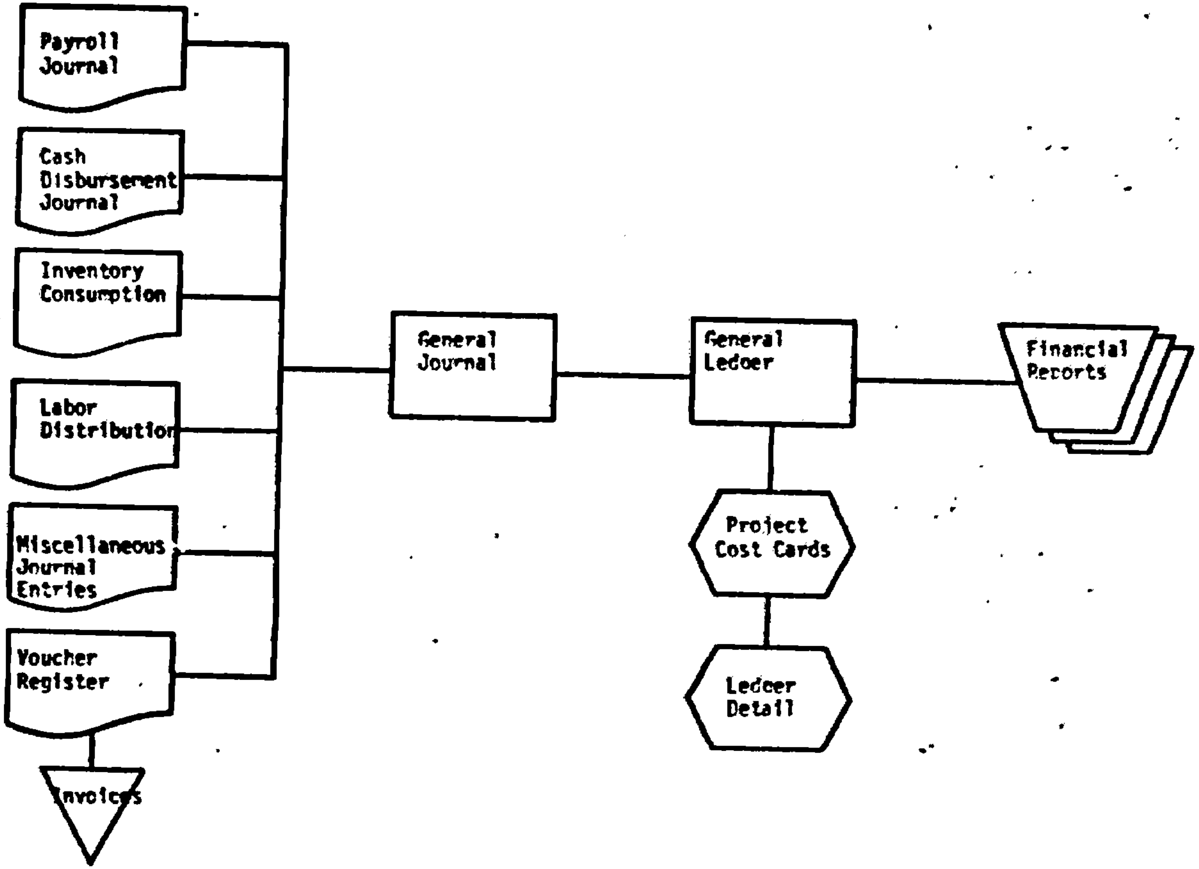
On the disbursement of funds, a number of procedures apply. Most importantly:

1. A purchase order or similar authorization is needed for the expenditure of funds -- with bids if appropriate.
2. Budget authorizations are to be signed by the department head and attested to by the Controller.
3. Invoices are to be approved by the department head responsible for receipt of the material or service before payment.
4. Expense reimbursements are to be approved by the employee's department head and/or supervisor.

The basic accounting system is shown on the attached diagram. The various sources of data are summarized into a transaction journal and then recorded by type (expense, income, asset, liability) in the ledgers. These latter records in the general ledger are, as necessary, supported by detail cards and schedules. Finally, the various financial reports are prepared from the ledger (and supporting schedules).

EPILEPSY FOUNDATION OF AMERICA

ACCOUNTING SYSTEM



6. THE NATURE AND COST OF PROGRAM SERVICES PROVIDED

EFA's Program Overall

"Program," in its broadest sense, means: an activity designed to help people with epilepsy. The Foundation insists that:

> Program = Objectives (based on unmet needs) + a Plan
> (to meet these needs) + Activities (by someone).

Overall Foundation program activities, national and local, encompass 19 categories of services covering (1) medical, (2) social and (3) information areas as follows:

> Medical Assistance, Evaluation, Comprehensive Health Planning, Research, Education and Training (Medical), Treatment (Medical), Diagnosis, Maternal and Child Care, Mental Health, Education and Training (Social), Protective and Socio-legal, Transportation, Treatment (Social, Employment and Vocational Rehabilitation, Financial and Public Assistance, Counseling, Referral Services, Public Education, Information Management.

These are further subdivided into 73 specific program activities, many of which are provided at the chapter level. Currently we are meshing these service areas into the United Way of America Service Identification System (UWASIS) in order that our terminology is a common one. This should facilitate communications, especially as it concerns accountability, program evaluation and future research projects.

EFA "programs," for the most part, deal with services delivered by chapters and other local organizations: local seizure clinics, hospitals, workshops and by local agencies of city, county, state and federal governments.

Implicit in the Foundation's role is the mandate to know what the epilepsy patient needs. This ultimately means "as defined by the patient himself"...as well as by family physicians, neurologists, psychiatrists, legislators, social workers, educators and lay volunteers.

Consumer Input

More people with epilepsy and more parents of children with epilepsy are in contact with the national headquarters of EFA than any other epilepsy installation anywhere in the world. Most of these contacts (52,000 to over 100,000 a year) are by mail and as a staff member once observed "They tell us what they don't tell their doctors...they tell us what they don't tell their social workers...they tell us what they don't tell government officials...they even tell us what they don't tell their wives, husbands or children. The Foundation listens carefully...and yields to no one its trusteeship on behalf of the person with epilepsy."

These contacts provide the information base for all program services.

"Obtaining" Services and "Providing" Services

Various voluntaries have different objectives and policies based to some extent on size of patient population and funding. Some are dedicated to providing specific services in specific locations. The purpose of others is to obtain services. One very effective major voluntary, for example, has long subscribed to the principle of obtaining rather than providing services, as stated in the following official policy:

"While member units may develop and direct service projects for purposes of public education, they will provide such services only on a temporary, contingent, and demonstration basis which includes in its stated objectives the shift of operational responsibility to tax supported agencies or private and independent boards as soon as possible." This organizational principle conforms to the policy of the International League of Societies, of which this voluntary is an active member: "The provision of services must be undertaken by the community as a whole; the problem is too large to be dealt with by voluntary effort...the task of the National Society, therefore, is not to provide services but to influence their development...the local society should not provide services, facilities or finance which ought to be provided by the local authority, but should do all in its power to insure that these are provided."

The history of this voluntary reflects a gradual shift away from the provision of direct services toward increasing activity in the areas of advocacy and social action. Its state and local units have gradually become "spokesmen" in behalf of developmentally disabled persons, and the national component has developed strategies to furnish the needed support and expertise to its units.

This voluntary's patient population, of course, is approximately 6,000,000 people.

Another fine organization emphasizes providing services (although they also endeavor to obtain services) and do an outstanding job in this area. The patient population in this instance is approximately 750,000.

EFA chapters both obtain and provide services but tend to concentrate on the former largely because of financial constraints. EFA's estimated patient population is 4,000,000 people.

With the funding from the Developmental Disabilities legislation and other sources, however, many EFA chapters are finding themselves more actively engaged in providing direct services. Let's therefore next discuss those services.

Services Provided Direct to Patients by Local Chapters

Because they are voluntary organizations, separately incorporated and separately governed by their own local boards of directors -- as well as the fact that needs vary greatly in various local areas -- there is considerable diversity in the services provided directly to patients and to the parents of children with epilepsy by local chapters. This document does not purport to be all inclusive as to services provided throughout the United States.

There are, however, a considerable number of "common denominator" services provided and these are listed in detail and chapter-by-chapter in the pamphlet

"National Directory of Chapter Program Services" which is updated by EFA every year or two.

Thirty-two (32) of these program services -- and suggestions on how to organize and fund them -- are further detailed in "Program Working Guides" developed by National Headquarters to assist and to provide guidance to local chapters.

Costs of these local program services are contained in the 93 financial reports from local chapters on file in the National Headquarters. Such financial reports are required of affiliate and provisional chapters but are not required of information contacts or cooperating organizations.

In 1972 EFA chapters provided one or more services to an estimated 52,000 persons with epilepsy and that number increased to an estimated 72,000 in 1973. The cost to serve each person with epilepsy is somewhat difficult to pin down, since the needs of each client are different and factors such as geographic location also will determine this factor. Since employment is one of the most common difficulties faced by the person with epilepsy, the following estimate was made to approximate the cost of providing services to this type of client. It is estimated for example, that an average 18.5 hours would be needed at an average of $56.00 per service hour, or a total of $1,036 to provide the needed assistance.

Where the local services are funded -- in whole or in part -- by government grants (such as funds available through the Developmental Disabilities legislation) still other cost information is on file in local chapters and with appropriate governmental agencies.

Services Provided by National Headquarters to Local Chapters

In addition to inspiration, encouragement and leadership, the national headquarters currently provides a Chapters Manual, 278 materials and specific services to local chapters. These materials and services are provided (without charge for the most part but priced "at cost") -- through five regional offices -- and are further detailed in a Price List entitled "Materials and Services Available Through Regional Chapter Service Centers" as follows:

Program Materials - 59
Program Services - 7

Public Information & Education Materials - 66
Public Information & Education Services - 5

Professional Education & Training Materials - 58
Professional Education & Training Services - 8

Management & Administration Materials - 9
Management & Administration Services - 8

Fund Raising Materials - 53
Fund Raising Services - 5

Services are provided by five (5) regional managers, headquarters staff members, or consultants employed by the Foundation. Costs of these services -- categorized in accordance with National Health Council standards -- are contained in the Annual Reports of the Foundation. In the most recent calendar year the cost of these services totaled approximately $542,452.

Services Provided Directly to Patients by National Headquarters

Although innumerable activities of the national headquarters staff constitute "service" to patients and to parents, direct services may be categorized essentially as follows:

Information and Referral - year after year thousands of people write the Foundation seeking guidance and answers to their problems. The number has been as high as 100,000 a year (and although the figure is dwindling as more local chapters are established) it still stands at 22,000. Stock letters, stock paragraphs, individualized replies (frequently with current input from members of the National Professional Advisory Board) and a wide variety of consumer pamphlets and other literature are utilized. Three and one-half million pieces of literature were distributed in this manner in the most recent year. Most inquiries -- except where confidentiality is requested -- are also referred to local chapters for personal follow-up.

Personal Counseling - approximately 200 people a year with urgent problems which they have been unable to resolve locally phone the Foundation for personal advice.

Individual Advocacy - in selected instances, particularly where protection of legal, civil or human rights are concerned, the Foundation makes contact with the U.S. Civil Service Commission, administrators of prisons and institutions, and other organizations.

In all of the above instances, the Foundation also endeavors to be of assistance to case workers in Congressional offices.

Cost of the Above Services - as listed in the Foundation's most recent Annual Report -- is currently approximately $71,530 per year.

Financial Support Provided Direct to Child Services Facilities

EFA has for many years provided financial support to the National Children's Rehabilitation Center (NCRC). This is currently the only facility of its kind in the United States, which provides residential care for the child with seizures who has concomitant emotional problems. This multidisciplinary approach combines special education, counseling, medical management of epilepsy and psychotherapy.

Located in Leesburg, Virginia, the NCRC is open to children between the ages of 7 and 17, and the population varies from 50 to 55 residents. Some 700 children have attended this Center since 1958. While most come from the states nearest the Center, children from 38 states and Puerto Rico have attended.

The following states have recognized the Center as an eligible treatment and rehabilitation facility: New Jersey, Maryland, New York, Illinois, Virginia, Washington, D.C. and Ohio. Note that the Center is certified as a private residential school and licensed by the Department of Mental Health and Mental Retardation of Virginia. In Virginia, support for residents also comes from the State Department of Special Education and in some cases the Department of Public Welfare.

Cost of this support will be $170,000 in 1974. It was $220,000 in 1973 and $270,000 in 1972 with the support for the three years providing some 18,642 patient days.

Support in previous years is as indicated in the table below:

1971	$320,000
1970	370,000
1969	418,003
1968	420,000

As indicated in earlier correspondence with the Subcommittee further details on the Center may be obtained from its President, Mr. Harold Babbitt or its Director, Mr. Bernard Haberlein. Other information is also available in NCRC's annual report, in a brochure entitled "National Children's Rehabilitation Center" and other Center literature.

Services Beneficial to All Patients and to All Those Working in Their Behalf

All activities of the Headquarters organization benefit persons with epilepsy in one way or another. Indeed we have no other purpose. But perhaps special mention should be made of at least the following:

Research, Fellowships and Training Grants

In general, it may be stated that research in the epilepsies has application to all children with seizures, while some research may be directed specifically toward the problems of children. Since epilepsy is not solely a disorder of children and youth, the majority of the research supported by EFA is basically investigation into causes, prevention and treatment of seizure disorders.

The EFA Research Brochure provides a listing of research and training projects and programs supported by EFA and its predecessor organizations since 1961 and includes at least 29 projects and programs specifically concerned with children and youth. (See list of specific children problems.) More than $1,014,000 have been spent on research and training grants as of December, 1973.

Research and training programs are under the administration of the EFA Research and Training Institute, a division of the Foundation. All gifts to this Institute are expended solely for its programs with all administrative costs paid by the Foundation. It should be pointed out that EFA has been a prime mover in stating many projects through "seed grants," which when found promising, received major funding from other sources. EFA research funds in the past have served to stimulate new developments in epilepsy as well as to attract more scientists and technologists into the field. Based upon the scientific papers delivered at the annual meeting of the American Epilepsy Society, EFA's track record in backing the right projects is most impressive.

Cost of research grants in 1973 was $176,004 while $188,019 were expended on professional education and training.

Seminars, Professional Education and Training - In 1973 as for many years EFA provided both financial support and staff service to the Western Institute on Epilepsy. This meeting, held in Salt Lake City, Utah, attracted 150 professional and lay workers at an out-of-pocket cost to us of $4,700.

The 1974 - 25th anniversary meeting of the Western Institute was held March 19-20 in Denver, Colorado and while total costs are not yet available, 155 persons were in attendance.

During the past year, EFA was involved as either sponsors and/or faculty in 19 professional educational services and courses, reaching an audience of approximately 4,378. In addition, EFA exhibited at seven national professional society meetings including the American Academy of Neurology, President's Committee on Employment of the Handicapped, and the Association for Children with Learning Disabilities, to mention but a few.

The Research and Training Institute has in 1973 developed two prototype courses for professionals already in the field. One is a five-day course in the medical and social management of the epilepsies for social workers, psychologists, rehabilitation counselors, nurses and allied professionals. The second is a one-day course for physicians in general practice. These courses are designed to upgrade the treatment and services to those with epilepsy, whether children or adults. For further details see brochure entitled "The Medical and Social Management of the Epilepsies."

Fellowship Program and Paramedical Awards

To stimulate interest of physicians and other professional disciplines to pursue careers in the undermanned fields of neurology and epileptology, some fifty-five (55) fellowships have been awarded since 1969 for a total outlay of $48,840. As a result of these funds, studies of the following nature are being initiated:

> "Effects of Anticonvulsant Medication Administration During Pregnancy"
>
> and
>
> "Development of Miniaturized long-term EEG Recording Systems."

These are but a few of the studies.

Awards for training paramedical personnel were resumed in 1973 and ten (10) paraprofessionals thus far have received $600 to attend training sessions for EEG Technologists.

A major program thrust of chapters -- and EFA regions -- is an active education program to acquaint the community with the problem of epilepsy and to gain for the person with epilepsy an understanding and acceptance of him. Such activities reach a pitch during November's epilepsy month.

Because the chapter is representative of the community at large, it often finds itself very successful in obtaining media coverage. Specific programs are directed to professional workers such as teachers, nurses, and rehabilitation counselors. Many chapters have sponsored special workshops and seminars -- with headquarters help -- for professional workers, last year in Utah, Louisiana, Evansville, Michigan and Florida.

National Spokesman

The EFA monthly publication National Spokesman had a total circulation of 25,427 in 1973 and reached an estimated audience of 40,683 including persons with epilepsy, their families and a broad range of professional disciplines from the private and governmental sector. The latest information concerning epilepsy treatment, rehabilitation, new and pending legislation, research and relevant activities are nationally disseminated. Cost was approximately $52,460, plus salaries.

Information Center and Library

The Foundation maintains an Information Center and Library that currently has more than 15,000 articles and 600 texts relevant to persons with seizure disorders. This Center is of course a vital source of information to the lay public, university students and members of the professional community having an interest in epilepsy. Research studies and new publications are constantly being reviewed in order to keep the library abreast of new information. Often letters of inquiry will be referred to our Information Center for research and response. Approximate cost in 1973 was $12,198.

Surveys and Studies

Collecting data and information through the Foundation's research and analysis section serves the function of illuminating and interpreting the needs of our constituency. Findings of our various studies are made public and also serve as catalysts for further action. For example one recent study "The Cost of the Epilepsies to Individuals, Families and to the Nation," indicated the annual cost to be more than four billion dollars. Here the recommended action calls for the need to study the problems of epilepsy in our nation in a coordinated and comprehensive manner.

Still another recent report entitled "A Preliminary Exploration of Awareness of the Epilepsies Among Educators" revealed some interesting results. Of significance was that most State Departments of Education had little or no data regarding children with epilepsy in their school systems. This lack of awareness or desire to investigate the problems of epilepsy in schools further points up the urgent need for information at all levels of the educational system. Other studies completed include: "Emerging Manpower Needs" which projects the number of personnel in various disciplines needed by 1980 to properly diagnose, treat and rehabilitate persons with epilepsy.

"Epilepsy and the Military" reports on the findings and regulations regarding epilepsy and the nation's armed services.

Studies to be completed this year include a survey of sheltered workshops, a "Behind the Stigma" study. Information of this type is needed to compile a directory of workshops for persons with epilepsy needing this kind of work experience. A major "Employment" study including attitudinal surveys of employers will be undertaken as well as methods needed to develop greater employers' understanding of persons with epilepsy. Approximate cost of studies in 1973 was $12,460.

This is but a sampling of the information sought which is keyed to the questions and needs of persons with epilepsy.

Government Liaison

The Foundation's role is to serve as an information resource for Congress and agencies of the government. It is EFA's responsibility to know what developments and trends in government are taking place and to make certain that our chapter network is aware of these developments and prepared to capitalize on them whenever possible by meshing new developments into existing chapter programs. The Foundation responds to various federal regulations in order to maximize the rights of persons with epilepsy. Most recently, EFA has gone on record to support the use of certain brand-name anticonvulsant medications as more effective than generic drugs. This view is, incidentally, backed by evidence from government studies.

Liaison is also maintained with significant federal health agencies and mutually cooperative efforts have been developed with such agencies as the National Institute of Neurological Diseases and Stroke (NINDS), Social and Rehabilitation Service (SRS), and the President's Committee for the Employment of the Handicapped, as examples. In addition, EFA is involved with other voluntary health agencies in order to coordinate efforts as it pertains to the rights and needs of all handicapped. The Foundation, as a member of a consortium of fourteen other voluntaries supported the extension of Developmental Disabilities legislation. Its continuation would, of course, benefit persons with epilepsy as well as others with disabilities originating prior to age eighteen such as mental retardation, cerebral palsy and autism. Approximate 1973 cost was $24,000.

Another concern of this section is model state legislation which could remove age-old discriminatory barriers still on many state statutes. To quote the Honorable Robert A. Taft, Jr. who had written the Foreword to our third survey "The Legal Rights of Persons with Epilepsy," "The Foundation's efforts to bridge the gap between the public's understanding of epilepsy and the realities of the disorder itself continues to bear fruit. Since the Foundation's last survey of state laws in 1965, 27 states have revised their statutes, or enacted new legislation which, in general, helps the epileptic lead a more normal life and make a real contribution to his community." In 1973, approximate cost was $800, plus salaries.

School Alert

"School Alert" now in its tenth year is an annual educational program of the Foundation. Its importance in the epilepsy movement is emphasized by the fact that it is a basic program for every EFA chapter and one of the most important national efforts. In some states such as New York and New

Hampshire, the School Alert program is officially endorsed and conducted in cooperation with state education departments. Since 1972 "School Alert" has been developed in cooperation with the Department of School Nurses and the National Education Association. The "kit" is basically a guide for the classroom teacher, school nurses and other personnel in recognizing epilepsy and managing it properly in the school community. The program incorporates a variety of informational and educational materials including literature, films, posters, lesson plans and other aids which can be adapted to different age levels and classroom situations. Last year approximately 5,000 School Alert kits were disseminated among EFA's regional offices and local affiliates which were provided to local schools, nurses and other professionals. Approximate cost in 1973 was $28,594.

Public Health Education

The most important of these services is undoubtedly the Foundation's Public Health Education activities. The term "public health education" encompasses all the activities of the Information and Education Department of EFA. For it is in public health education that all media are employed, all segments of the public are communicated with, and all knowledge is shared.

The segments of the public with which the Foundation is concerned can be placed in one or more of the following categories:

-- the child or adult who has epilepsy
-- the parents, family or close circle of friends of the person who has epilepsy
-- the general public
-- the social circle of the person who has epilepsy; church or synagogue, fraternal groups, recreational groups
-- children's camp personnel and lifeguards
-- educators and teachers
-- public service employees such as bus drivers, airline personnel, police, firemen
-- social workers such as visiting nurses, psychologists, psychiatrists, public clinics for mental and physical well-being and state employment office personnel
-- medical doctors including those in family practice, general practice, internists, insurance, interns, neurologists, neurosurgeons, brain specialists, gynecologists and pediatricians
-- nurses and other medical personnel in hospitals, doctors' offices, schools, public service and private practice
-- legislators and government personnel at all local, state and federal levels
-- vocational rehabilitation personnel in both public and private sectors
-- employers and unions; personnel directors and training directors

The media which must be employed to reach and teach these segments of the public with facts about epilepsy -- its causes, its symptoms, its control, how it affects the lives of those it touches, its economic burden to the family and the nation and its destructiveness of human potential -- must include every possible means of communication. A beginning list should include television, radio, newspapers, general and specialized magazines, films, slide presentations, videotape, audiotape, group meetings, seminars and institutes, one-to-one counseling, printed literature of all conceivable types and sizes, training programs, new information meetings.

Public health education is considered by many to be the first priority in promoting research, making known available treatment, eradicating misconceptions, encouraging public support by government agencies and legislatures, encouraging voluntary financial support on the part of the general public and removing the prejudice and stigma which plagues the person with epilepsy.

Of the $2,170,258 available for expenditure as published in May, 1973 annual report and audited by Price Waterhouse & Co., $364,161 or 16.8% was directly attributable to public health education (under stringent professional communications management control). This figure does not even begin to calculate the millions of man-hours spent in the course of each year by thousands of volunteers throughout the country who devoted their time and energy to the public health education function.

To cope with the problem of epilepsy at this point in time, a continued, massive, unrelenting public health education program is essential.

Some Further Observations on "Services"

It remains the conviction of the Foundation, that the first - and perhaps ultimately the most important - service a voluntary health movement (which is primarily a lay organization) can render patients is to make certain that their needs are properly interpreted to the society at large and that vigorous advocacy leads to action on the part of the mechanisms of that society to fill those needs in a just and humane manner.

As someone has said, we cannot solve the problem of the nation's four million persons with epilepsy by dividing up our $2.2 million in net resources and sending each of them a half dollar. The cost of drugs alone (usually over $100 a year) is many times that figure.

Neither aspirins, band-aids or a national society in Washington, D.C. will solve all the problems. They are far too immense. They will be solved only by the society at large, the nation as a whole working at solutions in every village and hamlet across the country, alerted and guided by a strong advocate organization -- the Epilepsy Foundation of America.

That will continue to be the No. 1 service to which this organization is committed.

7. HOW PROGRAMS ARE FINANCED METHODS OF RAISING FUNDS

(Statement by Thomas M. Ennis, Executive Director)

At both national and local levels, programs are financed by (a) grants from governmental agencies (b) funds obtained from foundations and/or major donors and (c) contributions from the general public. Some funding is restricted to specific purposes; some is available to the general fund without restriction. In addition, in 42 local areas, funding for chapter programs is obtained from United Way agencies.

EFA believes its fund raising cost to be too high. If the purpose of these hearings is to establish that fact, we stipulate it. Indeed we have stipulated it many times in many places and have invited anyone and everyone to aid us in reducing same.

The facts of the matter are: epilepsy is not a popular cause.

But -- in the face of innumerable difficulties -- very real progress is being made as indicated by the table below:

FUND RAISING COST RATIOS IN RECENT YEARS

	National	Chapter	Consolidated
1969	.53	*	*
1970	.46	*	*
1971	.42	.10	.356
1972	.39	.10	.329
1973	.39	.06	.295 (unaudited)

(Note: * indicated the years in which only National's cost ratio was available)

At one time or another -- in one place or another -- EFA or its predecessor organizations and/or its chapters has conducted virtually every form of fund raising known...both successfully and unsuccessfully. Much depends upon the stature of the people doing the fund raising and the determination, skills and energies they bring to the task.

History of Fund Raising in Epilepsy Movement

Epilepsy Foundation of America has, since its inception, relied heavily upon direct mail solicitation as its main source of Headquarters Income. At various times, EFA and its predecessor organization had received government grants for various rehabilitation projects, but the vast majority of funding has been from public donations. Historically, the various epilepsy organizations (prior to merger) encountered continuing difficulty in establishing fund raising programs. The one successful National fund raising method has been direct mail (used extensively by EFA's predecessor, The Epilepsy Foundation).

Stigma Concerning Disorder may Affect Fund Raising

It is difficult to analyze the reason for the failure of many fund raising programs and the relative success of Direct Mail in the epilepsy movement. It appears that the stigma and misunderstanding often associated with the disorder have made the recruitment of volunteers unusually difficult. Those who have epilepsy in their family are often reluctant to solicit their neighbors or to become involved in local fund raising for fear of being associated with this much misunderstood disorder.

Other Voluntary Agencies Appear to be Less Subject to Stigma Associated With Their Disorders

Although it is difficult to measure objectively, this stigma does not appear to affect volunteer and fund raising efforts for the majority of other National Health Agencies. The fact that donors are able to contribute to EFA in the privacy of their homes has undoubtedly contributed to the success of EFA's direct mail program. In fact much of the mail received is anonymous and frequently requests are made that replies be made in plain, unidentified envelopes.

EFA Now Diversifying Its Methods of Fund Raising

During the last three (3) years EFA has begun to develop other methods of fund raising, so as to make EFA less dependent upon Direct Mail. E.g., Foundation Solicitation, Commerce & Industry, Special Gifts, Deferred Giving, Dances, etc. Thus EFA is presently utilizing many fund raising activities used by other National Health Agencies.

In the Past Limited Chapter Support

The amount of funds contributed by the EFA chapters (in terms of affiliate dues) to EFA National has been limited; only $10,309 in 1971; $79,321 due from 1972 (not all of which has been collected as of this date). EFA is now emphasizing the need to develop chapter funding, so as to eventually reverse this flow of funding. The chapters are receptive to EFA's support of local funding, and are already beginning to make measurable impact in local funding, which will result in greatly increased affiliate income to EFA. Our willingness to make chapter efforts stronger even includes small short-term loans to the chapters. At various times over the past several years financial assistance has been provided to no fewer than 32 chapters. As the chapters become stronger such assistance is no longer required and now involves only two chapters.

1972 Income Figures

In 1972, gross revenues reached $4,147,162, an all-time high and up from $3,424,136 in 1971. Fund raising cost ratios dropped from 35.6% in 1971 to an all-time low of 32.9% in 1972. Combined fund balances at year end (1972) approached the million dollar mark, reaching $811,910.

1973 Income Figures

In 1973 the EFA Headquarters raised $3,639,000, and its chapters raised and received grants totaling $1,400,000 for a combined total of $5,039,000. This represents an increase of nearly $1,000,000, or 25% over 1972. To accomplish this goal the Foundation spent $1,490,000. All of us are greatly concerned about this still too high ratio, but it does represent a decrease from 32.9% in 1972, as indicated. It also represents a decrease for the third consecutive year (1971 - 35.6% of consolidated income).

Direct Mail

In examining EFA's Direct Mail we find that our House list contains the names of more than 250,000 individuals who have donated to EFA four or more times in amounts ranging from one dollar to more than $1,000.

During 1973 our mail efforts directed to EFA's current donors yielded approximately $1,315,000. These mailings cost $248,000 to produce and deliver, or only 18.9% of the amount raised. EFA faces, as to other similar organizations, the high cost of obtaining new names to replace those donors who, for a variety of reasons, leave a House List. In 1973 EFA spent approximately 64 cents of every (prospect list) dollar received to acquire new names. We believe our cost in this area is more efficient than most other organizations who solicit by mail.

Headquarter Plus Chapter Income = Consolidated Income

Thus, our combined mail program, including all computer overhead and including house and new lists, in 1973 raised $3,269,000 and cost EFA approximately $1,380,000, or 42 cents for every dollar raised. This figure, when added to our non-direct mail income, would indicate a cost ratio of approximately 39.8% for all types of headquarters fund raising. The consolidated income figure (Headquarters and Chapters) would be approximately 29.9%. (These figures are subject to the Price Waterhouse final audit, which is now in progress.)

High Cost of Seeking New Names

As mentioned, the high cost of seeking new names (prospect names) is a continuing industry problem, and is now recognized by the New York State Association of Accountants. This organization is in the process of developing a standard for amortizing the costs of mailings for new names over a seven year period. If this accounting system were to be accepted, our Headquarters cost ratio would be considerably lower, perhaps as much as 50% less, for 1973.

Data Concerning Direct Mail - 1971, 1972, 1973

	1971	1972	1973
% Return	6.5	5.8	5.5
Average Gift	$ 2.96	$ 3.04	3.12
Quantity Mailed	13,380,361	16,692,933	18,845,216
Gross Income	$ 2,633,728	$2,940,339	$ 3,266,313
Gross per Thousand Mailed	$ 197.00	$ 176.00	$ 173.00

Criteria for Selecting Lists

In an effort to reduce costs EFA attempts to select lists with the greatest possible rate of return. The criteria for our mailing list is as follows:

A. Donor Lists - A previous cost ratio of .50
B. Commercial Lists - A previous cost ratio of .75

The 1974 budget calls for a total mailing quantity of 16,300,000 pieces.

Through Surveys and Focus Group Interviews, EFA Obtains Donors' Opinions

In an effort to ascertain what the EFA donors wish in terms of programs, we have developed a series of studies and surveys. We feel the input gained from these detailed surveys allows us to be more accurate in terms of actual program needs, thus making a more informed allocation of our relatively limited funds.

Our recent donor surveys clearly indicate the needs in the psycho-social areas in terms of employment, education, insurance, etc.

EFA has developed, and continues to develop, more sophisticated copy tests (some 50 copy tests during the last two years), constantly seeking to improve our rate of return, the reduction of costs and taking into account our donors' interest.

In an effort to make certain EFA's Major Donors receive news about the epilepsy movement and EFA, they regularly receive copies of our National Newsletter, "Spokesman."

Typical Excerpts From a Focus Group Interview

The following is a sample of quotes from a recent Focus Group interview (a free-flowing, in-depth discussion with donors and potential donors) held February 19, 1974, which is one method of ascertaining the donors' and the general public's needs concerning epilepsy:

> Moderator - If you were to give a dollar bill -- how much would you like to see go for administrative purposes and how much would you like to see go for the kinds of things you would like it to go to?
>
> #6 - Well, never having thought about that I think I would like to see...
>
> Moderator - Well, you have obviously thought about it...
>
> #6 - .... Well, o.k., I would like to see at least 50% or more go for research and then the other 50% or less to go to administrative costs. And, of course, salaries are up these days and that might not pay anyone a very good salary.
>
> Moderator - Obviously there has to be administrators -- people that answer the telephone....
>
> #3 - I don't mind my money paying somebody's salary because everybody has to live. But I'm not sure it even goes to that...That's why I mainly give through the church, becuase I know what our church is doing. And I mainly give to charities that give me something in return, like the little tags or the people that make the effort to send you something like the little stickers for the envelopes. Anything that's long and

drawn out I usually give to my daughter or son. Something that is put in bold print and very quickly summarized I will usually tend to read the whole thing. I would read the first page or the big print and skip the fine print.

Penny Letter and Seals

The Penny Letter, still is approximately 18% more efficient than anything else tested in 1973. The addition of seals generally improves the results by some 18%. The National Health Council has, we believe, the following view concerning EFA's use of pennies and seals in the EFA direct mailing program:

A contact report written by General James A Shannon under date of August 24, 1972 following an Ad Hoc Committee meeting at the National Health Council on August 23, 1972, contains the following paragraph:

> "Use of Items of Commercial Value or Unordered Merchandise. This discussion initially involved the same illogical arguments about our penny with all sorts of explanations about how one could define a penny as merchandise. I received strong support from Irving Rimer of the American Cancer Society. And at the conclusion of the discussion the announced consensus, objected to by no one, including Peter Meek, was that our penny should not be considered to be merchandise unless they had a resale value."

Recently EFA has been developing contacts with college, social and fraternal organizations relating to the support of Dance Marathons, raising money for EFA at various college campuses. A number of chapters of the Variety Club International have heavily supported the Epilepsy Movement during the last 10 years; e.g., the Milwaukee Epilepsy Clinic - Variety Club Telethon grossed approximately $92,000 in February, 1974.

New Fund Raising Kits Made Available to Chapters by EFA

Each of the kits indicates in detail the method of developing various local funding. The kits contain suggested art work, publicity items, sale of tickets, organizational structure, etc. A brief description of the Fund Raising Kits follows:

> DANCE MARATHON: primarily supported by the college/university Greek system and lasts for approximately 58 hours (weekend). Funds are raised through voluntary donations, auctions and concession sales. These events are usually conducted during the fraternity/sorority rush periods. Money raised by these events is used for the benefit of the local chapter.
>
> DAWN OF UNDERSTANDING: manned canister day that can involve either adults or adolescents stationed at major thoroughfares or shopping centers seeking voluntary financial support from the public for the benefit of the local chapter.
>
> AMERICAN HOMES SHOWCASE: involves a tour (which can run for several weeks) of a home of historic interest or social prestige in the community and can involve many spin-off activities such as luncheons,

teas, wine tastings, plant sales, art sales, etc. Admission to all functions in the home would be by ticket only with sales benefiting the local chapter.

WALK-A-THON: special event geared to junior high and secondary level students encouraging them to seek sponsors and participating in a mass march of approximately twenty miles for the benefit of epilepsy. The sponsors are asked to pledge whatever they can for each mile a person walks.

CELEBRITY NIGHT: an evening of celebrity entertainment, variety show or play which is mainly sponsored by outside service and social organizations with the receipts from ticket sales and donations benefiting the local chapter.

SPORTSMEN'S NIGHT: recognition of a sports celebrity or team who has public visibility on the local level which can be sponsored by outside service and social organizations with the receipts from ticket sales benefiting the local organization.

CANDLELIGHT BALL: Formal adult gala or teen age/college level dance to which tickets are sold to raise funds which go to the local chapter. Income can also be derived from souvenir program advertisement sales.

CANDLELIGHT MARCH: a neighbor-to-neighbor solicitation recommended to be used during Epilepsy Month. Marchers are recruited by telephone, one-to-one requests. Receipts from the door-to-door donations benefit the local chapter.

Additional Data Gathered from Donors

A series of Focus Group Interviews held in 1974 add additional information concerning the type of program activity of most interest to donors and the general public. In effect, to encourage EFA's donors to actively participate in the epilepsy movement, some 900,000 donors received ballots asking them to vote for the 1974 Poster Child.

New Thrust by EFA to Develop Local Chapter Funding Programs

Perhaps the most significant headquarters effort to increase Chapter Fund Raising was the assignment in late 1973 of key headquarters staff members to work directly from regional offices. The main assignment being to accelerate the accomplishment of several current objectives and to implement Chapter Fund Raising. As indicated, there are already positive signs showing this technique can and will be effective.

1973 Income by Revenue Source

Thus, a quick look at 1973 income by source shows a lessening of dependency upon direct mail as EFA's major source of funding.

REVENUES*	General Fund Budget	General Fund	Restricted Funds	Total
Direct Mail	$ 3,090.0	$ 3,269.2		$ 3,269.2
Foundations		45.5		45.5
Major Donors	220.0	44.4	$ 121.0	165.4
C & I		20.7		20.7
Wills & Bequests	105.0	100.4		100.4
Affiliates	87.0	27.1		27.1
Miscellaneous	45.0	10.7		10.7
Total Revenues	$ 3,547.0	$ 3,518.0	$ 121.0	$ 3,639.0
Less Affiliates	$ 87.0			
	$ 3,460.0			

*Subject to Final Audit

Social & Civic Organizational Support for EFA

For a number of years (since 1967-68) EFA has been involved with various civic and social organizations who have supported EFA Chapter and National Programs. E.g., based on National contacts made by EFA staff in 1968, the Moose organization (nationally) has been active in supporting EFA chapter programs, aiding in fund raising, serving as volunteers, driving patients to clinics, etc. The California Epilepsy Society has received some $5,000 per year from California Moose lodges. Other civic and fraternal and educational organizations supporting EFA or its affiliates are:

Alpha Tau Delta (nursing sorority)
Delta Theta Tau Sorority
V.F.W. - New York
Psi Iota Xi, Washington State

Additional Data Concerning 1974 EFA Direct Mail Program

House Mailing as follows:

(A)	House Mailing I	1-15-74	900M
(B)	" " II	3-12-74	900M
(C)	" " III	5-14-74	850M
(D)	" " IV	8-13-74	850M
(E)	" " V	9-24-74	900M
(F)	" " VI	11-19-74	900M

Other EFA Mailings Scheduled for 1974

Social and Fraternal

Mailing I	Mail Date	5-10-74	400 Letters
Mailing II	" "	9-15-74	400 Letters (Followup)

EFA Headquarters field staff continues to contact various social and fraternal organizations, seeking possible endorsement.

Commerce & Industry

Approach to emphasize corporate public education.

Mail Date 10-15-74 2,000 Letters

Foundations

Mailing I - Approximately 2,000 Foundations (excluding top 100 Foundations, which will be handled by personal contact)

Mail Date 5-30-74
Mailing II Mail Date 10-30-74 (Followup Mailing)

Major Donors

Mailing I Mail Date 6-30-74 ($500 plus donors)
Mailing II " " 9-1-74

Thus for 1974 - 5,300,000 mailing pieces are to be sent to EFA's House List, the remaining letters will be mailed to potential donors.

Deferred Giving

Mailing I (Trust Officers, Major Banks)
Mail Date 7-30-74
Mailing II (1,000 additional Names: 500 law firms, 500 Trust Departments)
Mail Date 11-15-74

Research & Training Institute

Mailing I Mail Date 3-22-74
Mailing II " " 9-30-74

Summary

As outlined, EFA is making every effort to lessen its dependency upon Direct Mail as a primary source of income, and is broadening its base of financial support. It is anticipated that within four (4) years the revenues generated from Chapter Fund Raising Events will (taking the form of Affiliate Dues) begin to provide significant support to EFA's national program.

Samples of Actual Donor Survey Sent in 1971 and 1972

(See Attachment)

Results of 1972 Donor Survey

(See Attachment)

DONOR
PROFILE
STUDY

Epilepsy
FOUNDATION OF AMERICA

Suite 406 • 1828 L Street, N.W • Washington, D.C. 20036 • (202) 293-2930

YOUR
STATE
☐

PLEASE PLACE THE NUMBER OF YOUR ANSWER IN THE BOX TO THE RIGHT
IF NO ANSWER SEEMS CORRECT, PLEASE LEAVE THE BOX BLANK.

A. Are you 1. male 2. female..[ ]

B. How old are you 3. Under 18 4. 18-25 5. 26-35 6. 36-45 7. 46-55 8. Over 55..[ ]

C. Are you 9. Single 10. Married 11. Widow(er) 12. Divorced or Separated...[ ]

D. What is your basic occupation, or if you are a housewife, what is your husband's occupation 13. Professional 14. Managerial 15. Clerical, Secretarial & related 16. Sales 17. Service 18. Skilled or Manual 19. Agriculture 20. Mining 21. Construction 22. Manufacturing 23. Transportation, Communication, Public Utilities 24. Government 25. Wholesale and Retail Trade 26. Finance, Insurance and Real Estate..[ ]

E. What is your income (If both husband and wife are employed, select the answer that reflects your combined income) 27. $5,000-7,500 28. $7,501-10,000 29. $10,001-15,000 30. $15,001-25,000 31. $25,001-40,000 32. Over $40,000..[ ]

F. Do you have a fixed income (i.e. retirement, pension, social security) 33. Yes 34. No..[ ]

G. How many children do you have 35. 0 36. 1 37. 2 38. 3 39. 4 or more....[ ]

H. How many children DO NOT live at home 40. 0 41. 1 42. 2 43. 3 or more...[ ]

I. How many children are in college 44. 0 45. 1 46. 2 47. 3 or more........[ ]

J. Do you 48. Own your home 49. Rent a house 50. Rent an apartment.........[ ]

K. What is the current value of your home 51. Under $15,000 52. $15,000-30,000 53. $31,000-40,000 54. $41,000-60,000 55. Over $60,000............[ ]

L. Are you 56. Catholic 57. Protestant 58. Jewish 59. Other..............[ ]

M. Do you or any member of your immediate family have any form of epilepsy 60. Yes 61. No..[ ]

MEMBER OF THE NATIONAL HEALTH COUNCIL

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Please place the number of your answer in the box to the right.
If no answer seems correct, please leave the box blank.

N. Does any member of your family not considered immediate (aunts, uncles, cousins) have any form of epilepsy 67. Yes 63. No........................[ ]

O. Do you have any friends or acquaintances who have epilepsy 64. Yes 65. No.[ ]

P. Have you witnessed a person having an epileptic seizure 66. Yes 67. No....[ ]

Q. As best you can, tell us why you contributed

You or an immediate member of your family has epilepsy in some form 68. Yes 69. No..[ ]

You realized the need for doing something about the problem 70. Yes 71. No..[ ]

You usually contribute to a number of causes 72. Yes 73. No..............[ ]

You had another reason 74. Yes 75. No....................................[ ]

R. If you knew more about the problem of epilepsy would you have given 76. More 77. Same..[ ]

S. Other than mail appeals, have you seen or heard any message about the Epilepsy Foundation of America or about epilepsy on

78. TV.................[ ]

79. Radio.............[ ]

80. Newspapers.........[ ]

81. Magazines..........[ ]

82. None of these......[ ]

T. Do you buy gifts or other merchandise through the mail 83. Yes 84. No.....[ ]

THANK YOU!

PLEASE RETURN THIS QUESTIONNAIRE IN THE ENCLOSED POSTAGE PAID RETURN ENVELOPE.

DONOR PROFILE STUDY

(505 Responses)

A. Sex:	51%	Male
	48%	Female
B. Age:	3%	18-25 years
	13%	26-35 "
	14%	36-45 "
	25%	46-55 "
	44%	55 years & over
C. Marital Status:	13%	Single
	12%	Widow (er)
	68%	Married
	6%	Separated/Divorced
D. Occupation:	26%	Professional
	9%	Managerial
	8%	Clerical, Secretarial, related
	4%	Sales
	7%	Skilled/Manual
	2%	Agriculture
	3%	Construction
	3%	Transportation/Communications/Public Utilities
	5%	Government
	3%	Retail/Wholesale Trade
	4%	Finance/Insurance/Real Estate
E. Income:	15%	$ 5,000-7,500
	15%	7,501-10,000
	20%	10,001-15,000
	23%	15,001-25,000
	9%	25,001-40,000
	4%	40,001 and over
F. Fixed Income:	41%	yes
	56%	no
G. Number of Children:	28%	none
	17%	one
	23%	two
	16%	three
	15%	four/more
H. Children not living at home:	50%	none
	12%	one
	11%	two
	9%	three/more

I. Children in College: 65% none
10% one
5% two
1% three or more

J. Housing: 72% own home
6% rent house
18% rent apartment

K. Value of Home: 12% under $15,000
32% $15,000-30,000
16% $31,000-40,000
9% $41,000-60,000
6% $61,000 and over

L. Religion: 25% Catholic
58% Protestant
11% Jewish
5% Other

M. Epilepsy in immediate family: 13% yes
87% no

N. Epilepsy in family not considered immediate: 11% yes
83% no

O. Friends/acquaintances with epilepsy: 29% yes
64% no

P. Witness to seizure: 56% yes
40% no

Q. Reason for contribution: 1. Self/immediate family has epilepsy: 12% yes
68% no
2. Realize need: 77% yes
9% no
3. Usual contributor to other causes: 79% yes
8% no
4. Other reason: 9% yes
53% no

R. If knew more about epilepsy would give more: 4% more
82% same amount

S. Excluding mail, where have EFA messages been seen: 58% TV
18% Radio
21% Newspapers
29% Magazines
25% None of these

T. Usually purchase merchandise through mail: 33% yes
61% no

8. THE DELIVERY OF PROGRAM SERVICES

As outlined in Section 6 relating to provision of services, persons with epilepsy are recipients of Foundation programs:

Through its chapter network of 164 local organizations

Through headquarters

Through the regional offices.

And program, as earlier discussed, can mean either the "obtaining" of services or the "providing" of services.

The number of chapters and local organizations associated with the Foundation has risen dramatically in the past four years.

	1970	1971	1972	1973
No. of Local Organizations	77	102	142	164

Because of this growth, the number of services and the number of persons served is increasing. As I mentioned, we believe the chapter system in 1973 served 72,000 persons based on the estimates made by our regional offices. In 1972 the chapters reported that 52,000 persons were served. The growth in the number and kinds of services accompanied that chapter growth:

	1971	1972	1973
No. of Services	612	882	1137

Government grants, particularly from the Developmental Disabilities program, is helping the chapter local organizations towards program development. An estimated $800,000 will be reported by the chapters in 1973.

	1971	1972	1973
Amount of Grant funds	$20,443	$272,399	$800,000

A firm requirement of affiliation with the Foundation is that the local organization have services and programs which have the input, the planning, and the review by professional persons, particularly the medical profession. The number of active professional advisory boards rose from 40 in 1971 to 88 in 1972. The 1973 count is expected to be 100. A chapter cannot continue to be affiliated with EFA nor will a local organization be granted affiliation without a functioning PAB.

In order to coordinate better with government, the Foundation in 1971 established its regional assignments to conform with the boundaries. Each regional office is responsible for two HEW regions, and this move has facilitated working with various governmental offices, particularly Rehabilitation Services Administration.

We have now moved to a service reporting system which will give the Foundation more detailed information -- on a quarterly basis -- as to just what is being accomplished by the chapters. The quarterly report on Services and Activities will tell us what age groups are being served and what services are being furnished. In addition, our chapters will report on those areas where program development is needed. Public education activities as well as professional education functions will also be reported on.

This reporting system, when fully utilized by the chapters, will provide the entire Foundation with current information, not only where and how the services are being rendered but also where the gaps are. This will permit headquarters to have its new program development section in gear with the needs of the chapters.

9. RECOMMENDATIONS TO THE SUBCOMMITTEE AND OTHER INTERESTED PARTIES

Let us then return to what I have understood to be the purpose of these hearings: To explore "whether existing legislation is adequate to protect the interest of the beneficiaries of and contributors to" the organization being invited to testify "and trying to determine if new legislation is needed."

On March 12, Carol Cochran, Director, Commission on Charitable Organizations, Commonwealth of Pennsylvania, stated that: "So my hope is that through the information gathered in hearings like these the public will be made aware of the magnitude of the problem, and will be motivated to support -- in fact, demand -- strong legislation for the regulation of charities on a nationwide basis."

Whether further "regulation" is called for is debatable. How does one regulate a charity or judge the worthiness of a voluntary? As Helen L. O'Rourke, Director, Philanthropic Advisory Department, Council of Better Business Bureaus, Inc., stated on February 4: "...What is a worthwhile cause for one person will be meaningless to another..."

Is Regulation What We are Really Talking About?

Or is it that we are seeking a national consensus as to appropriate cost ratios for administration and various forms of fund raising ... and more effective ways for getting such information to donors, potential donors, and the general public?

As another witness has pointed out "Fund raising restrictions exist in various states and localities ... this legislation varies from state-to-state and municipality-to-municipality." Can this be the source of the confusion?

Presently, the Foundation prepares reports for the Internal Revenue Service, the National Health Council, the National Information Bureau, the Council of Better Business Bureaus, the Federal Combined Giving Campaign, at least 24 state governmental agencies (see "Giving USA"), a growing number of local jurisdictions, and an innumerable number of magazines and journalists, many of whom need to be educated as regards basic standards, terminologies and reporting practices. Our Administration and Finance Departments estimate a requirement of: 2-man years to prepare such reports! I think their estimate is low ... and the cost is high.

This, despite the fact, that EFA publishes -- and widely distributes -- a detailed Annual Report made up in strict and meticulous conformity with National Health Council standards. This is available to any donor -- or to any member of the general public -- who requests same.

What to do? The report required by the New York State Board of Social Welfare has been hailed as a model by many. Mr. Mal Gross, a partner in Price Waterhouse & Co. -- our auditors -- has suggested that it be adopted by other states. This would be helpful ... although I will have more to say on this in a moment.

On February 5, Philip J. Sgarlata stated that the New York State Board "does not approve, or disapprove, any organization or indicate whether it is a 'worthy cause'. The purpose is to give the facts to the public and let the public decide on whether to make a contribution."

Are the Right Facts Reaching the Public?

And, if not, what can be done about the situation? Equally important, who is -- or should be -- responsible for delivery of the facts?

Helen L. O'Rourke stated on February 4:

> "The IRS is responsible for making Form 990 filed by a tax-exempt organization available to the public."

If this is correct (I am not sure it is for IRS makes a charge for Xeroxing information obtained from the Philadelphia Center), then perhaps we need to take a new look at Form 990. And I will address myself to that subject very shortly.

But first let me comment upon at least one of the more intelligent proposals now receiving consideration, namely ...

Bill H.R. 1191 introduced December 17, 1973, by Congressman Lionel Van Deerlin, of California. This bill would require the solicitating organization, upon request, to furnish complete and accurate financial and program disclosure about it and the person making the solicitation. This bill was drafted, as I understood it, with the help of a number of interested organizations; including the National Health Council, the American Association of Fund Raising Counsel, National Foundation, Direct Mail Marketing Association, National Catholic [illegible]pment Conference, United Way, and the National Assembly for Social Po[illegible]nd Development.

EFA has already put into the mail 50,000 letters (two tests of 25,000 each) in response to this development and I would like to read into the Record the following letter dated March 19 from Siegmund W. Smith, Administrative Assistant to Congressman Van Deerlin.

> "I was pleased indeed to receive the copy of the Epilepsy Foundation appeal which you sent to me with your letter of March 18. Congressman Van Deerlin and I are delighted to note that you incorporate in this appeal all the requirements contained in legislation the Congressman has introduced to provide for the dissemination of financial information by charitable organizations soliciting funds through the mail.
>
> "As I told you, our attempts to draft suitable legislation to provide for such disclosure met with considerable resistance on the part of many charitable organizations. Some contended that the requirements would be too onerous and impossible to fulfill. These contentions have been demonstrated to be groundless by the actions of the Epilepsy Foundation of America which has fulfilled them almost exactly.

> "I shall be in Los Angeles on March 21 to speak on behalf of Congressman Van Deerlin to the Southern California Society of Fund-Raisers, Inc. I shall take great pleasure in citing the actions of the Epilepsy Foundation as an example of what can be done to generate confidence in the charitable organization."

Copies of the letter and data sheet are available to anyone requesting same.

EFA Views

EFA has long been concerned with the development of national consensus in regard to fund raising standards for our very existence depends upon this matter getting resolved...and soon. Under date of January 31, for example, I wrote all members of our Board of Directors as follows:

> "Over the past year I have several times referred to the rising tide of criticism, commentary and 'investigation' with which we and other voluntaries are currently confronted at local, state and national levels. This reality warrants the most careful consideration as the Foundation plans for the future.
>
> "The enclosed article appears in the February issue of multi-million circulation READER'S DIGEST and is one of the more objective stories which have been appearing in various publications. But the net result, I fear, may still further 'dry up' donor contributions.
>
> "Carl Bakal visited us here in Washington (presently, we receive visits and/or calls from at least two journalists a week) and he now believes that 'the situation is far more complex than I believed it to be at the time I wrote the article' but even so we and other voluntaries have a major task ahead of us.
>
> "The definitive article -- or book -- on fund raising and appropriate cost ratios has yet to be written. And the 'standards' thus far developed leave much to be desired.
>
> "'High' fund raising cost ratios continue to be equated, ipso facto, with 'inefficiently managed' organizations. And in our own case, little or no consideration is given to the fact that epilepsy is still a stigmatizing condition and the thousands and thousands of people who serve as volunteers for other causes hesitate to publicly work for this one for fear of being identified as epileptic persons.
>
> "What few standards exist -- whether they be NIB's subjective '8 points' or the more specific National Health Council or Council of Better Business Bureaus standards make no meaningful distinction between revenues derived from patient fees ... or government funding ... or major gifts from foundations or wealthy donors. All is treated as 'revenue' and the cost of securing same as 'fund raising' costs.
>
> "Cost ratios are also viewed as sums organizations elect to spend prior to a fund raising event, and a measure of 'efficiency' -- rather than a

measure of the public's awareness of need ... or the public's generosity ... or the inherent appeal of the cause. In truth, of course, ratios are known only after the fact, not before.

"Perhaps the following will put what I am trying to say in sharper perspective:

-- If EFA were to derive $20 per person from those we attempt to serve ... our fund raising cost ratio would drop by about 25% ... although we would have changed absolutely nothing in our operation.

-- If a major foundation were to fund the organization in an amount of $2,000,000 ... our fund raising cost ratio would drop to about 27% ... although we would have changed absolutely nothing in our operation.

-- If EFA were to receive $5,000,000 in government funding (and such sums are being devoted to education on alcoholism alone!) our fund raising cost ratio would drop to about 15% although we would have changed absolutely nothing in our operation.

"The problem is a frustrating one and is debilitating to the headquarters staff, to the 138 paid staff members we now have in the field, to the officers and directors of our 156 chapters and to would-be volunteers everywhere.

"Decisive action is essential to the future of the organization, and after many perplexing hours, I conclude that there are probably only three ways to go to improve the situation:

a. Drastically accelerate our chapter fund raising operations. We are currently doing this to the full extent affordable.

b. Drastically accelerate our solicitation of foundations and major donors. Recent experience and current contacts, however, give me no reason to count on significant results.

c. Drastically reduce our mail solicitation (probably limiting it to house list mailings only) and reduce our operations to a level supportable by the resultant income. Preliminary studies indicate this would require halving headquarters staff and programs ... and would make a and b above far more difficult.

"The alternative is to 'tough it out' in the conviction that what we are doing is of extreme importance to four million of our fellow citizens and that there is as yet no viable programs in sight to significantly ameliorate their problems."

What I did not point out is that our direct mail solicitation is handled by the very same man who handled subscription solicitations for READER'S DIGEST for eight years so that we could obtain efficient management of this function. His assistant, incidentally, is an equally talented person who previously handled direct mail solicitations for Common Cause.

I could have added -- with deep gratitude -- that the Reader's Digest Foundation is one of our major contributors, one of nearly 200 foundations which support the work of EFA.

Endorsements

We have followed with interest the testimony of Arthur "Jack" Grimes of the National Health Council. Our organization supports the views he advanced including:

-- Providing increased incentives through our tax system for voluntary citizen support of reputable voluntary organizations.

-- Correcting the existing severe restrictions on the right of public charities to participate in legislative dialogue.

-- Strengthening provisions of the current requirements for organizations that are granted tax-exempt status under Sec. 501(c)3 of the IRS Code.

- Establishing an Assistant Commissioner of the IRS for charitable organizations.

Indeed we would go further and we would sincerely urge that this Subcommittee goes further. Despite the efforts of the Health Council, the United Way of America, the National Assembly for Social Development and other organizations --all of whom have made worthwhile progress -- there is still no totally satisfactory financial report which has been developed, in our judgment.

Like the Council of Better Business Bureaus, EFA believes "any organization which solicits funds from the public should provide a full accounting of their activities and financial standing to potential or actual donors..." The new "Standards for Charitable Solicitations" being worked on by the CBBB together with almost 50 representatives of fund-raising organizations, media and donor groups are a step in the right direction, and we support them. But here again we do not believe they go far enough.

Utilization of Contemporary Techniques for Establishing Needs and Public Ratings of Same

In a day and age when it is possible to measure the popularity of presidential aspirants as closely as 3%, I am concerned that no similar effort is made to assess public attitudes and the degree of public concern about many other problems with which the nation is confronted. Sociological/marketing research techniques for doing this are available, in my judgment.

It is our contention that the general public needs to have a means of expressing itself and, in return, receiving authoritative information about the seriousness of national health problems and conditions. We could hope that some such mechanism is developed through cooperation with business, government and voluntary sections. As we see it, it would require an appraisal of need conducted by at least three groups:

-- A consumer panel of at least three thousand names pulled at intervals utilizing contemporary marketing research techniques such as those regularly employed by persons running for office.

-- Some mechanism of the American Medical Association.

-- An appropriate interdepartment committee of HEW with representation on it of all the many bureaus, sections and divisions of that department.

These annual surveys would give us a picture of professional appraisal and consumer interest in various health problems. They would also give us a benchmark against which to measure the "efficiency" of various organizations in raising funds.

No such benchmark exists at the present time.

And yet, as Mr. Gene Pulliam, Vice President of the Riggs National Bank and Chairman of EFA's Fund Raising Committee points out:

> "--the harder it is to raise money, the more it costs. And I think you've got to realize the influence that stigma has on fund raising. People avoid our cause as they seek to avoid those who have the condition. It takes more effort to reach people, more appeals, more staff, more costs.
>
> "...suppose you have a stigmatizing condition that people don't want other people to think they have, or are associated with. Then try to get a large volunteer force to march or go door to door. Your turnout will not be large; your total will be correspondingly less, and whatever printing or materials costs you have will be the same. Result: a higher cost ratio, (i.e., the percentage of income spent on raising money).
>
> "And the cost ratio will also depend on the kind of fund raising which is, for a variety of complex reasons, most successful for your agency. For EFA, direct mail appeals succeed as no other fund raising instrument does -- and we have tried many. It is unfortunately, a relatively costly method (printing, postage, paper), though we believe we put letters into the mail at as low a cost as any agency, and would be happy to compare them. It may well be that the anonymous, private nature of the mailed gift is directly related to the stigma which still attaches to epilepsy. It allows 900,000 people to help the cause without being identified with it. However, it does not, unfortunately, trigger the kind of per gift response that Common Cause or a red hot political campaign can."

Let there be no mistake about it: any problem that afflicts 4,000,000 Americans and costs the nation at least $4.3 billion a year, is a major national problem. Something must be done about it. And, if not by the people who have epilepsy and the Epilepsy Foundation of America, then by whom?

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Need to Separate "Apples" and "Oranges"

One of my concerns about fund raising costs is that such standards as now exist are simple ratios which tend to "put into one pot" all revenues received by an organization including patient service fees, profit from [illegible] sales, government grants, gifts from foundations and major donors, and $2 contributions from the general public. We would hope that in the future such distinctions will be made between these categories and that the basis for evaluation will be the cost at which these activities are conducted, as well as the results obtained.

I think that standard cost ranges should be established for each.

For example, let us take direct mail which is very important to the fund raising activities of our organization. I think it appropriate for us to report the cost at which we put 1,000 pieces into the mail. Moreover, I think it appropriate that we report response rate and size of average gift as well as the total raised. And I would hope that we could do this in a way that enables the citizen to make comparisons with the cost of other fund raising direct mail such as that employed routinely in political fund raising and in fund raising on behalf of educational institutions, museums and other organs of our society.

Much the same is true with the solicitation of United Funds. I would like to see a top range established to cover the time of personnel, cost of presentation materials, cost per call, and so forth, and I would like to see this equated with end results.

The size of staff and the activities carried in pursuit of government grants should, in my judgment, be evaluated in similar fashion.

Finally, we come to contributions from the general public. Obviously, sharp distinctions should be made between revenues obtained from patient service fees or revenues through the resale of materials and services. I do not know that these are presently separated sufficiently.

Funding Needs of National Headquarters and Local Citizen Volunteer Units

Still another concern is the seeming increase in various jurisdictions attempting to expand their range of control. For example, certain states would appear to be trying to limit mail solicitation within their boundaries even when the letters are mailed from outside the state. This raises interesting legal complications, for the mails are federal. Can a state decide what can or cannot be mailed to its citizens?

The truth of the matter, of course, is that organizations dealing with large patient populations have a need for a national headquarters, state organizations, and local units.

And funding must be secured for all. All of which leads me to my major recommendation to this Subcommittee...

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Urgent Need for One Uniform National Report Acceptable to all Jurisdictions

In the absence of simple faith that major organizations -- governed by responsible citizen volunteers -- are somehow less concerned and trustworthy than others, it is my considered judgment that we probably need to develop more stringent and detailed fund raising and financial reports.

But there should be ONE report -- not one hundred.

This report should probably be IRS Form 990, modified in any way that our society deems necessary or desirable. I have already indicated my own thoughts with regard to some of the elements that should go into the report.

FUND RAISING

	Numbers of Presentations, Calls, Letters or Other	Cost per 100 - Calls, Letters or Other	Response Rate	Average Gift	Total Revenues	Cost Ratio
Fund Raising Activity #1						
Fund Raising Activity #2						
Etc.						
Etc.						

INDEX

National Priorty Established by Polling → ☐

Comparative Fund Raising Index Established by Actual Results → ☐

FINANCIAL REPORTS

	Consolidated	National HQ Only	State Organizations	Local Units
Revenue Detail				
Revenue Detail				
Expenditure Detail				

But there are apparently other things which should to into the report. Dozens of them. So many, in fact, that it boggles the mind. I recently gave to Price Waterhouse & Co. the assignment of inventorying all items of information requested by all of the people who ask us for reports. The worksheets already compiled are astounding! The requirements are so voluminous as to not be believed. I further asked them to work with EFA in developing one uniform national report form acceptable to all jurisdictions.

Our President, Mr. Paul D. Holland, a leading West Coast attorney, has recently called for "a standardized method of collecting specific data on a voluntary's operation. .... such things as the size of staff, sources of funds with cost ratios per source, functions of the organization, etc." He would like to see this freely available to all.

Mr. Holland has further stated:

> "I believe there should be a movement towards some national system -- into which organizations could feed standard, detailed data about themselves and their work. I would advocate a uniform -- and more detailed -- report. The data would then be available to any citizen or potential donor who wished to see it. Our whole political system is based upon the idea of informed choices, made freely. I think the same philosophy applies to voluntaries. The important thing is to make sure that the citizen is truly informed."

EFA is happy to make this contribution to national dialogue on this subject.

Some Further Observations on Reports and "Administrative" Costs

Unfortunately, very little is known about "Administrative Costs" as they are defined in National Health Council Standards. Writing a "thank you" letter to a donor is an administrative cost. As is, renting a room to hold a board meeting, publicizing the organization, paying dues to the Health Council, preparing reports for various states, paying the switchboard operator, advertising for a new secretary, and many other necessary activities. Writing and publishing an annual report and paying an organization's auditor are administrative costs.

We would all agree that organizations such as EFA should have input from "consumer" representatives (See NHC pamphlets, "Consumer Input - Why" and "Consumer Input - How") and yet paying the cost for them to attend board meetings is still another "administrative cost."

Indeed, preparing testimony for these hearings and responding to queries from the various states as a result of the activities of the Subcommittee are "administrative costs." Legal fees in the amount of $60,000 or more are already in sight for the current year.

In my judgment, we are dealing with considerable hypocrisy in regard to administrative costs. For example, in the same mail that brought EFA word that the U.S. Civil Service Commission had turned down its application for the Federal Combined Giving Campaign because of "high administrative costs" came the news that the nation's 2.2 million armed forces were backed up with one million civilians...all busily engaged, no doubt, in non "administrative" activity.

Needless to say, FSA continues to serve federal employees as it does all other citizens.

Helen O'Rourke had it right, I suspect, when she recently indicated that the American public has not yet accepted the need for any fixed or administrative costs. That this is unrealistic in no way changes the validity of the statement.

10. SUMMARY

EFA has covered quite a number of topics in this statement; far more than we intended when we originally set about the task. We have done so for many reasons, not the least of which is that the mere mention of the name of a charity in connection with a Senate "study" unfortunately seems to carry with it, in this day and age, the possible implication of wrongdoing. And retractions and apologies never really correct rumors or erroneous impressions or statements. Organizations that depend upon the public for support can very easily be injured.

During the last two weeks, for example, newspapers and television programs in the Commonwealth of Pennsylvania have carried stories to the effect that the Foundation has been prohibited from soliciting funds in that great state. This is not true.

Under date of April 2, I have the following letter from EFA's legal counsel, Gordon and Healy of Washington, D.C.

> "You have requested an opinion of this office as to the status of the Epilepsy Foundation of America in the Commonwealth of Pennsylvania since the recent hearings and litigation.
>
> "As you know the Foundation filed for a charitable solicitation permit before the Commission on Charitable Solicitations in Harrisburg. The application was denied without hearing by mail.
>
> "A meeting was held with Commonwealth Officials who indicated that the Director of the Commission did not have the power to stay her action until hearing by the full Commission and that there was no discretion to allow the exemption provided in the statute to exceed the 35% fund raising cost limitation.
>
> "An appeal was immediately taken to the Commission and was heard on March 26, 1974. The Commission insisted that the letter denial would stay in effect while they had the matter under advisement. They felt they did not have authority to grant a stay.
>
> "Faced with a dilemma of an outstanding denial and being unable to advise the Foundation to continue under these conditions, we asked the Commission to make a final determination even if adverse so that the matter could be placed before the courts. The Commission did render an adverse decision and application was immediately made to the Commonwealth Court in Pennsylvania for an appeal of the decision and a supersedeas, which under Pennsylvania law is in effect a stay of the adverse decision of the Commission on Charitable Soliciations.
>
> "The petition for a supersedeas was granted and the order of the Commonwealth Court issued on March 29, 1974 by Judge Crumlish stated in pertinent part:

> "'The Epilepsy Foundation of America is permitted to solicit funds and engage in fund raising activities in the Commonwealth of Pennsylvania permitting final disposition of the appeal in this matter.'
>
> "Thus, the Foundation is presently able to operate in the Commonwealth of Pennsylvania as it did heretofore and no restrictions are placed on it with regard to its activities and it is our opinion that the chances of prevailing on the merits are good."

I will not comment further on this matter for it is presently at law.

One of the predecessor organizations of EFA was involved with Congressional hearings nearly 20 years ago. These were hearings on "Federal Agencies and Philanthropies" before a Subcommittee of the Committee on Government Operations of the House of Representatives. And -- although no misfeasance, malfeasance or wrongdoing was established -- the epilepsy movement has, I fear, paid a price for this for many years and a great number of sincere, compassionate and hard working citizen-volunteers were hurt by it. I believe that the Honorable Joel T. Broyhill of Virginia and a member of EFA's Honorary Board of Directors can supply details on this if it is deemed desirable.

EFA wants there to be no mistake about what it is, what it does, how it operates, how it raises funds, and how it expends those funds. We have, therefore, opted for completeness.

Let me attempt to summarize, however, the main points with which we have dealt:

A. We have endeavored to illuminate a major national health problem by defining the kinds, causes, epidemiology, care and treatment of the epilepsies. For all EFA activities stem from the nature of the disorder with which we are concerned.

B. We have addressed ourselves to the history, growth and development of an increasingly effective advocate organization. We have described where and how the organization operates and the manner in which the views of our constituencies and our citizen-volunteers are translated into programs and how those programs are budgeted and accounted for.

C. We have been as specific as we know how to be about the nature and cost of services provided and the manner in which funding for them is presently secured.

D. Finally we have addressed ourselves to recommendations which we believe might be helpful not only to EFA but to all similar organizations.

In conclusion, EFA wants to convey to the Subcommittee warm good wishes for the success of these hearings and their translation into meaningful legislation beneficial to our society. For our part we are delighted at the opportunity to once again focus the attention of this great deliberative body -- and the public -- on the epilepsy movement in the United States. For epilepsy is, unfortunately, primarily an invisible affliction.

We would most humbly request of the Subcommittee that if there is anything we can be doing better, or more effectively in our dedicated mission as spokesmen and advocates for those with epilepsy, we would be most grateful for your guidance. In our view the hearings provide a fine service to the country by making clear your genuine interest and leadership in the well-being of the 4,000,000 people with epilepsy, the 12,000,000 or more members of their families, and the additional millions of doctors, educators, research scientists, vocational rehabilitation workers, social workers and just plain Americans who are seeking to overcome this age-old disorder.

For them -- and in their name -- we thank you for inviting us to be here today.

11. INDEX AND PARTIAL BIBLIOGRAPHY

For the convenience of the Subcommittee -- and the press -- the following index to contents of this document has been prepared to facilitate referring to various subjects.

For much the same reasons, the pages which follow list pamphlets, brochures, articles, and other references cited in this document.

INDEX TO CONTENTS

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ADDENDUM: National Board of Directors and Professional Advisory Board Members Follow Section 4

PARTIAL BIBLIOGRAPHY

American Association of Fund-Raising Counsel. *Giving USA*: 1973 Annual Report: A compilation of facts and trends on American philanthropy for the year 1972. New York, American Association of Fund Raising Counsel, 1973.

Bakal, Carl. "Charities: Which Ones are Worth Giving To?" *The Reader's Digest* (February, 1974), 82-86.

Epilepsy Foundation of America. *Affiliation Agreement Between Epilepsy Foundation of America and ____________________ (Chapter)*. Washington, D.C., Epilepsy Foundation of America.

________. *Affiliation Agreement Between Epilepsy Foundation of America and ____________________ (State Organization)*. Washington, D.C., Epilepsy Foundation of America.

________. *Annual Report 1972*. Washington, D.C., Epilepsy Foundation of America, 1973.

________. *The Cost of the Epilepsies to Individuals, Families and to the Nation*. Washington, D.C., Epilepsy Foundation of America, 1974.

________. *Covenant Between Epilepsy Foundation of America and ____________________ (Chapter)*. Washington, D. C., Epilepsy Foundation of America.

________. *Emerging Manpower Needs for the Social and Medical Management of the Epilepsies*. Washington, D.C., Epilepsy Foundation of America, 1974.

________. *EFA Bylaws & Board Committee Practices*. Washington, D. C. Epilepsy Foundation of America, 1974.

________. *EFA Staff*. Information in regard to structure, Board and PAB interfaces, departmental functions, reporting channels, work flows, career planning, training and basic personnel policies (including compensation practices, performance reviews, insurance, leaves and pension arrangements). Washington, D. C., Epilepsy Foundation of America, 1973.

________. *Epilepsy and the Military*. Washington, D. C., Epilepsy Foundation of America, 1974.

________. *Facts and Figures on the Epilepsies and other Neurological Dysfunctions*. Washington, D. C., Epilepsy Foundation of America, 1974.

________. *History of the Epilepsy Movement in the United States*. Washington, D. C., Epilepsy Foundation of America, 1974.

________. *The Legal Rights of Persons with Epilepsy: A Survey of State Laws and Administrative Policies Relating to Persons with Epilepsy*. Washington, D. C., Epilepsy Foundation of America, 1972.

_______. *Materials and Services Available Through Regional Chapter Service Centers.* Washington, D. C. Epilepsy Foundation of America, 1974.

_______. *National Directory of Chapter Program Services.* Washington, D.C., Epilepsy Foundation of America, 1973.

_______. *National Directory of Clinic Facilities for the Diagnosis and Treatment of Epilepsy.* Washington, D. C., 1973.

_______. *National Spokesman.* Washington, D. C., Epilepsy Foundation of America, March, 1974, April, 1974.

_______. *The Next Three Years: 1974, 1975, 1976:* A Review of 1973, A Detailed Plan and Budget for 1974, and Some Projections into the Future. Washington, D. C., Epilepsy Foundation of America, 1973.

_______. *1973-1974 School Alert: A National Educational Annual Program to Foster Better Understanding of Epilepsy Among Teachers, Students, Parents and the Entire School Community.* Washington, D. C., Epilepsy Foundation of America, 1973.

_______. *1974 Operating Budget.* Washington, D. C. Epilepsy Foundation of America, 1974.

_______. PAB Bylaws & Guidelines: Information in regard to mission, membership, officers, committees and practices of the total professional advisory structure. Washington, D. C., Epilepsy Foundation of America, 1974.

_______. *A Preliminary Exploration of Awareness of the Epilepsies Among Educators.* Washington, D. C., Epilepsy Foundation of America, 1974.

_______. *Problems of Epilepsy as Viewed by Parents and Patients.* Washington, D. C. Epilepsy Foundation of America, 1973.

_______. *Professional Advisory Board Statement on Prevalence.* Washington, D. C.,Epilepsy Foundation of America, n.d.

_______. *Program/EFA Activities to Help People with Epilepsy.* Washington, D. C., Epilepsy Foundation of America, 1973.

_______. *Program Working Guides* (list). Washington, D. C., Epilepsy Foundation of America, 1974.

_______. *Provisional Chapter Agreement Between Epilepsy Foundation of America and ____________________ (Chapter).* Washington, D. C., Epilepsy Foundation of America, n.d.

_______. *A Report on 10 Years of Research and Training.* Washington, D. C., Epilepsy Foundation of America, 1973.

________. What It's Like to Have Epilepsy. Washington, D. C., Epilepsy Foundation of America, 1973.

________. What's Your Opinion. Washington, D. C., Epilepsy Foundation of America, 1972.

National Health Council. Consumer Input - How. New York, National Health Council, n.d.

________. Consumer Input - Why?: A Statement of rationale for gaining participation in health services decision-making from "Consumers" -- Persons not employed in the health service field -- by Health Service Planning and Provider Organizations. New York, National Health Council, n.d.

________. Fifteen NHC Member Voluntary Health Agency Executive Personnel Salary Ranges (National Office) 1972-73. New York, National Health Council, n.d.

Priestland Associates. Association Executive Compensation Study 1974. Washington, D. C., American Society of Association Executives, 1974.

U. S. Congressional Record. Senate. v. 119, no. 178. November 19, 1973.

U. S. Department of Health, Education and Welfare, National Institutes of Health, National Institute of Neurological Diseases and Stroke. Neurological and Sensory Disabilities: Estimated Numbers and Cost. DHEW Publication (NIH) 73-152, Washington, D. C., U. S. Government Printing Office, 1973.

________. NINDS Research Profiles: 1973: Summary of Research at the National Institute of Neurological Diseases and Stroke. DHEW Publication No. (NIH) 74-323, Washington, D. C., U. S. Government Printing Office, 1974.

________. Trend in Public Attitudes Toward Epilepsy in the United States 1949-1969. Washington, D. C. n.d.

________. Office of Mental Retardation Coordination. Programs for the Handicapped. (January 30, 1974), DHEW Publication No. (OHD) 74, 22000, Washington, D. C., 1974.

U. S. Department of Labor. Bureau of Labor Statistics. Employment and Earnings. (v 20, No. 8, February 1974)

U. S. Library of Congress. Congressional Research Service. Federal Support for Epilepsy Programs. Washington, D. C., Library of Congress, January 22, 1974.

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12/31/73

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WHAT THE EPILEPSY FOUNDATION OF AMERICA IS AND DOES

The Epilepsy Foundation of America, with national headquarters at 1828 L Street, N.W., Washington, D.C., was formed in 1968 by a group of citizen volunteers, many of whom were persons with epilepsy or parents of children with epilepsy. All were active in two predecessor organizations (Epilepsy Association of America, and The Epilepsy Foundation) anxious to create one strong, unified national organization devoted to solving a major national health problem affecting at least 4,000,000 Americans.

EFA's GOAL

EFA's goal is to improve the lot of the person with epilepsy by:

—Promoting, conducting and supporting research into the causes and treatment of Epilepsy;

—Making known the available treatments for Epilepsy;

—Improving educational and vocational opportunities for persons with Epilepsy,

—Educating and providing information to the general public with a view toward eradicating misconceptions about Epilepsy;

—Promoting and supporting clinics, schools, and other facilities or means for treating, educating, training, obtaining employment for, caring for or otherwise helping persons with Epilepsy;

—And providing financial support to individuals and other organizations engaged in activities that further any of the purposes of the Foundation;

EFA ACTIVITIES

The Foundation's activities, under its latest by-laws adopted November 30 1973, are charted and guided by a 43 member Board of Directors. The Board consists of 10 directors elected by 156 local chapters throughout the United States; 10 directors elected by a Professional Advisory Board made up of 50 distinguished physicians and specialists; 19 representing the general public, and 4 who are directors by virtue of their positions in the organization.

Incorporated under the laws of the State of Delaware, the Epilepsy Foundation of America is a 501(c)(3) tax exempt corporation and contributions to it are deductible for federal income tax purposes under the Internal Revenue Code of 1954.

MANAGEMENT AND FINANCES

Dues from local chapters and contributions from 1,037,000 individual private citizens — averaging $3.13 each — numerous firms, and 230 charitable foundations support the work of EFA headquarters in research, fellowships, training programs, counseling, vocational rehabilitation, and public information and education.

The Foundation has no contract or agreement between persons making solicitation and persons on whose behalf the solicitation is made which in any manner —

(a) bases the amount of receipts received by the person on whose behalf the solicitation is made on the amount or number of contributions received from the solicitation; or

(b) bases the fee or other charge of the person making the solicitation on the amount or number of contributions received.

PROGRAM AND OPERATING EXPENDITURES

The total income and total expenditures of the Foundation vary from year-to-year, but the most recent financial statement audited by Price Waterhouse & Co., and as published in the Annual Report released in May, 1973, shows the following as categorized by the standards of the National Health Council, of which EFA is a member.

REVENUES (including all chapters)	$4,147,162
Costs of solicitations, administrative, managerial and certain fixed costs of doing business and running programs	$1,976,904
NET AVAILABLE INCOME	$2,170,258

PROGRAM EXPENDITURES

	Total	Percent Revenues Allocated
Research	$ 176,004	8.1%
Professional Education & Training	188,019	8.7%
Public Health Education	364,161	16.8%
Community Services	1,059,536	48.8%
Patient Services	318,029	14.6%
Transferred to Reserves & Capital Fund	64,509	3.0%
TOTAL EXPENDITURES	$2,170,258	100.0%

1974 Operating Budget

Professional Advisory Board

Fund Raising

Chapter & Field Services

Vocational Rehabilitation

Public Information & Education

Other Board Committees

Program and Long Range Planning Committee

[illegible]

Finance Committee

[illegible] 1973

Executive Committee

[illegible] 1973

Board of Directors

[illegible]

[illegible] January 21 1974

Epilepsy
Foundation of America

As reviewed and approved by the
EXECUTIVE COMMITTEE and the full
BOARD OF DIRECTORS
meeting in Washington D.C. on
November 30 1973

PREMISE:

This budget was originally predicated — first of all — upon the following revenue objectives as developed by the Fund Raising Committee and approved by the Finance Committee of the Board of Directors in the expectation of "normal growth" and a reasonably stable economic climate.

REVENUE OBJECTIVES:

Direct Mail	$3,415,000
Proceeds from Affiliates	310,000*
Commerce and Industry	35,000
Wills and Bequests	115,000
Foundations and Major Donors	235,000
Memorials and Special Gifts	20,000
Miscellaneous, Recovered Costs (& Government Grants)	50,000
TOTAL REVENUES	**$4,180,000**

The above table sets forth Fund Raising *objectives*

*It includes revenues from Affiliates which were originally estimated at $130,000, but are now projected as $310,000 or more. This substantial increase is based on Jan. 8 actions in assigning five (5) senior staff members to the field system to promote chapter development, and on acceptance by the latter of a minimum goal — over and above previous plans — of at least 40 additional special events netting at least $10-20,000 each.

By decision of the Executive Committee and the Board, Affiliate revenues for at least another year are expended only for chapter activities. But, a like — or larger — amount from other sources is required for direct support of the chapter system and the regional offices serving same.

All materials and services provided to the chapters have been costed and a price list prepared. At least some of these materials and services *must be charged for* on an "at cost" basis at the *earliest* possible date. And fiscal reality makes clear that the only sound principle to be considered is: a man in the field must generate revenues to the headquarters at least equal to his salary and expenses. Even this would result in a 100% cost ratio! Which is not defensible . . . long range.

NOTE: The budget is structured — primarily — by headquarters departmental categories. See back cover for a summary of expenditures by National Health Council categories.

REVISED PREMISE:

As of this date, the economic outlook in 1974 *is not promising* and "normal growth" will be difficult to achieve despite increased efforts and arrangements for recovering costs. Hence objectives should not be confused with pragmatic projections as to actuals likely to be attained in view of the present economic climate.

SUMMARY OF BUDGET ACTIONS:

Original Expenditure Budget approved by Program and Long-Range Planning Committee, Finance Committee, and Executive Committee		$3 691 200
Plus	Board Reserve ($178,800) and basic CEO contingency ($50 000) included in original plan	228 800
Plus	Affiliate revenues originally anticipated	130 000
Plus	Additional Affiliate revenues from ten (10) men in the field	180 000
TOTAL REVENUES TO BE CONSIDERED		**$4.180.000**
Less	10% expenditure reduction recommended	369.100
New Plan (still including Board Reserve and basic CEO contingency)		$3 810 900
Less	Board reserve and basic CEO contingency fund	228 800
		$3 582 100
Less	"below-the-line" items being held in contingency status	200 000
		$3.382 100
Less	Reserve for chapter bad debts	30 000
FINAL EXPENDITURE BUDGET WHICH SHOULD BE POSSIBLE		**$3.352.100**

In short, all seems well from the above. For in between the "revenue objectives" of $4,180,000 and the final firmly committed expenditure budget of $3,176,000 there is a theoretical "cushion" of $1,004,000. But with the current economic outlook, this could well prove illusionary.

FINANCIAL REALITIES GOVERNING BUDGETING

After a series of actions and decisions by the Board of Directors — and the Treasurer, President, and Chief Executive Officer — only $3,176,000 has been firmly committed for 1974 expenditure. All other expenditures and activities are being held in abeyance "below-the-line", meaning they will be carried out only "if additional funding is secured." Latest revenue projections — for budgeting purposes only — are conservatively stated at (or under) formulas based upon actual past history.

NATIONAL CHILDREN'S REHABILITATION CENTER

BUDGET CODE NO.	DESCRIPTION OR ACTIVITY	OFFICIAL ANNUAL BUDGET as approved by Board 11/30/73	REVISED BUDGET as of ____ Amount From-To	REVISED BUDGET as of ____ Amount From To	YEAR TO DATE Expenditures/ Commitments as of ____	BALANCE REMAINING	DEPARTMENT RESPONSIBLE	REQUIRES WATCHING OR ACTION
BASIC ACTIVITIES	Page 1 of 1							
901	National Children's Rehabilitation Center	170.0					GP	

998

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RESEARCH, PROFESSIONAL EDUCATION, GOVERNMENT LIAISON, NEW PROGRAM DEVELOPMENT & INFORMATION SERVICES

Page 1 of 5

BUDGET CODE NO	DESCRIPTION OR ACTIVITY	OFFICIAL ANNUAL BUDGET as approved by Board 11-30-73	REVISED BUDGET as of Amount From To	REVISED BUDGET as of Amount From To	YEAR TO DATE Expenditures & commitments as of	BALANCE REMAINING	DEPARTMENT RESPONSIBLE	REQUIRES WATCHING OR ACTION
801	PROFESSIONAL ADVISORY BOARD	7.5					RPE/ALL	
	-Full Board Mtg. 4.0 -Exec. Com. Mtg. 2.0 -12 Bulletins, Agenda, Minutes & Reports .6 -Misc.,PAB Travel Exp. .9							
	RESEARCH, FELLOWSHIP, TRAINING, PARA-MEDICAL, & SOCIAL SERVICES -GRANTS & AWARDS							
802	Research Training Grants	65.0		(+ 40.0 anticipated in restricted funds)			RPE/FR	
803	Training Grants	4.6		(+ 14.0 anticipated in restricted funds)			RPE/FR	
804	Fellowship Grants	4.7		(+ 20.0 anticipated in restricted funds)			RPE/FR	
805	Para-medical Grants	.6					RPE	
806	Social Services Award	.7					RPE/I-E	
	PROFESSIONAL CONFERENCES, INSTITUTES, SYMPOSIA & SEMINARS							
807	EFA Western Institute	5.0					RPE/I-E	
808	Professional Conference	2.5					RPE/I-E	
	Exhibits:							
	-Ass'n for Children w/Learning Disorders		2-28-74					
	-American Academy of Neurology		4-22-74					
	-President's Comm. on Empl. of Handicap.		5-2-74					
	-National Congress Parent-Teacher Ass'n		5-14-74					
	-American Neurological Ass'n		6-10-74					
	-American EEG Society		7-25-74					
	-American Psychological Ass'n		8-30-74					
	-American Academy of Family Physicians		(date unknown)					
	-National Rehabilitation Ass'n		10-20-74					
	-American Epilepsy Society		12-5-74					

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BUDGET CODE NO	DESCRIPTION OR ACTIVITY		OFFICIAL ANNUAL BUDGET as approved by Board 11/30/73	REVISED BUDGET as of ... Amount From-To	REVISED BUDGET as of ... Amount From To	YEAR TO DATE Expenditures Commitments as of ...	BALANCE REMAINING	DEPARTMENT RESPONSIBLE	REQUIRES MATCHING OR ACTION
BASIC ACTIVITIES Page 2 of 5									
	PROFESSIONAL CONFERENCE, ETC		(cont'd)						
809	Psycho-Social Seminar		.6					RPE	
810	HQ Staff Travel (covers Budington, Hoxie, Atwell)		4.0					RPE	
811	Conference Registrations Fees		2.3					GLP	
	-Interagency Comm.CEC	.4							
	-Ass'n Child w/Learn. Disabilities	.4							
	-NNC Form (2 @ 35)	.7							
	-Am. Ass'n Mental Def.	.4							
	-Soc. Security Adm.	.4							
812	PROFESSIONAL EDUCATION & MAT'L		5.0						
	-RTI Sponsored short course	3.0			(+ grants & costs recovered)			RPE/FR	
	-UAF or-other-sponsored courses	2.0			(+ grants & costs recovered)			RPE/FR	
813	GLC PROJECTS		10.5						
	-GLC Tech. Adv. Com.	3.0						RPE	
	-Feasibility Study for Determination of Methodology for Major (25-50M)Study of Labs	3.5							
	-Other GLC Projects (+ anticipated 17.0 in restricted funds)	4.0							
	GOVERNMENT LIAISON								
814	Congressional Committee Witness Expenses		1.0					GLP	
815	Gov't Publ. & Subscriptions		.8					GLP	

RESEARCH, PROFESSIONAL EDUCATION, GOVERNMENT LIAISON, NEW PROGRAM DEVELOPMENT & INFORMATION SERVICES

BUDGET CODE NO	DESCRIPTION OR ACTIVITY	OFFICIAL ANNUAL BUDGET as approved by Board 11/30/73	REVISED BUDGET as of ___ Amount From/To	REVISED BUDGET as of ___ Amount From/To	YEAR TO DATE Expenditures/ Commitments as of ___	BALANCE REMAINING	DEPARTMENT RESPONSIBLE	REQUIRES MATCHING OR ACTION
BASIC ACTIVITIES	Page 3 of 5							
	GOVERNMENT LIAISON (cont'd)			SUBJECTS TO BE SELECTED FROM THIS LIST:				
816	-Fees and Travel for Consultants Preparing (10) Gov't Grant Applications: Arangio Brown Chiazze Goldin Johnson Sands Schlesinger Wright *Typical grant application requires 4 hours to 8 weeks and for budget purpose will be considered as ten (10) working days	14.5 --------------	--------------	-Conf. on Concerned Org. re Nat'l Plan -Exp. Projects (City Types) on Nat'l or Reg. Levels -Training package for VocRehab Counselors -School Alert Projects -Diagnostic Procedures in Screening Pre-Schoolers -Completion Cereghino Studies & State & Regional Plans -Specialized Trng Courses, i.e. 1-day, 3-day 1-wk, regionally and nationally -Development of pre-VocRehab Programs for Youths -Attitudinal & Behavioral Studies on Employers -Sheltered Workshop & VocRehab Demonstration Projects -Preparation for Job Development - Seminars -Development Cassettes for Families, Employers & Schools -GLC Projects -One Center of Excellence under Control of EFA -Basic Studies (see Info Center list) -New Elements to & Funding for Correspondence Room -Regional Workshops/Combinations Prof. & Chapter Operations -Films (Domestic and Foreign Projects) -National and/or Int'l Conference on the Epilepsies -Library Additions - EFA and Chapters -Model state legislation-drafts and work w/states -NCRC -Epidemiology Projects -Standards for Clinics			GLP	
817	-Other Program Consultants	10.0					GLP	
818	-Chapter Bulletins on Gov't Matters of Interest (12)	.5					GLP	

RESEARCH, PROFESSIONAL EDUCATION, GOVERNMENT LIAISON, NEW PROGRAM DEVELOPMENT & INFORMATION SERVICES

BUDGET CODE NO	DESCRIPTION OR ACTIVITY	OFFICIAL ANNUAL BUDGET as approved by Board 11/30/73	REVISED BUDGET as of ___ Amount From To	REVISED BUDGET as of ___ Amount From To	YEAR TO DATE Expenditures Commitments as of ___	BALANCE REMAINING	DEPARTMENT RESPONSIBLE	REQUIRES WATCHING OR ACTION
BASIC ACTIVITIES	Page 4 of 5							
	GOVERNMENT LIAISON (cont'd)							
819	Meetings w/other Voluntaries on Gov't Matters	1.9					GLP	
820	HQ Staff Travel & Expenses (covers Perlman&Paige)	3.0					GLP	
821	Memberships & Expenses of Coalitions Involved in Gov't Affairs -Nat'l Comm. for Research in Neurological Disorders -National Coalition for Health Funding -Alliance of Information & Referral Services -American Psychological Ass'n -Nat'l Rehabilitations Ass'n -American Epilepsy Society	8.0					GLP	
	LIBRARY AND INFORMATION CENTER							
822	New Acquisitions	1.5					GLP	
	TOTAL	154.2						
ADDITIONAL-IF FUNDING SECURED								
	Nat'l Conf. on the Epilepsies	8.2					RPE	
	Other Consultants' Serv.Exp.	2.5					GLP	
	Microfische Card File	7.0					GLP/A-F	

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RESEARCH, PROFESSIONAL EDUCATION, GOVERNMENT LIAISON, NEW PROGRAM DEVELOPMENT & INFORMATION SERVICES

BUDGET CODE NO	DESCRIPTION OR ACTIVITY	OFFICIAL ANNUAL BUDGET as approved by Board 11 30 73	REVISED BUDGET as of ____ Amount From/To	REVISED BUDGET as of ____ Amount From To	YEAR TO DATE Expenditures Commitments as of ____	BALANCE REMAINING	DEPARTMENT RESPONSIBLE	REQUIRES MATCHING OR ACTION
BASIC ACTIVITIES Page 5 of 5								
ADDITIONAL	IF FUNDING SECURED							
	Survey of Chapters to Determine Program Needs	.2					GLP/FS	
	Chapter Program Staff Training (course development)	1.0					GLP/FS	
	Chapter Personnel Program Travel & Expense	1.5					GLP/FS	
	Gov't Grant Matching Funds (90/100 on $145.0)	14.5					GLP/A-F	
	Program Planning Conference	4.0					GLP	
	Research Reports & Studies Including: -Impact of EFA Awards -Nat'l Research Thrust in Epilepsy -Physican's Education Survey	2.0					RPE	
	Individual Staff Conference Registration Fees	4.5					GLP	
	Sixth Intern'l Symposium	1.6					RPE/All	
	Board & PAB Govt. Liaison Committee Meetings	.9					GLP	
	TOTAL	47.9						

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FIELD SERVICES AND CHAPTER DEVELOPMENT

BUDGET CODE NO	DESCRIPTION OR ACTIVITY	OFFICIAL ANNUAL BUDGET as approved by Board 11-30-73	REVISED BUDGET as of Amount From-To	REVISED BUDGET as of Amount From-To	YEAR TO DATE Expenditures Commitments as of	BALANCE REMAINING	DEPARTMENT RESPONSIBLE	REQUIRES WATCHING OR ACTION
BASIC ACTIVITIES	Page 1 of 4							
701	Los Angeles Regional Office Rent 3.9 Telephone 4.1 *Travel 15.8 Other Off.Supp.&Equip. 1.0 Chapter Literature 8.0 films, TV spots, radio spots, exhibits fund raising material & distribution & handling costs	32.8	(All distribution, in chapter and non-chapter areas, is being transferred to regional office. Budget control is by memo invoices.)				FR/A-F	
702	Houston Regional Office Rent 4.0 Telephone 4.0 *Travel 13.9 Other Off.Supp.&Equip 1.0 Chapter Literature 8.0 films, TV spots, radio spots, exhibits, fund raising material & distribution & handling costs	30.9	(All distribution, in chapter and non-chapter areas, is being transferred to regional office. Budget control is by memo invoices.)				FR/A-F	
703	N.Y./Boston Regional Office Rent 4.0 Telephone 3.1 *Travel 15.9 Other Off.Supp.&Equip. 1.9 Chapter Literature, 10.0 films, TV spots, radio spots, exhibits, fund raising material & handling costs	34.9	(All distribution, in chapter and non-chapter areas, is being transferred to regional office. Budget control is by memo invoices.)				FR/A-F	

* To be detailed quarterly - in advance - and shared with chapters. (Covers Stevenson, Hay, Moore, Ross, Organ & Quinn.)

FIELD SERVICES AND CHAPTER DEVELOPMENT

BUDGET CODE NO	DESCRIPTION OR ACTIVITY	OFFICIAL ANNUAL BUDGET as approved by Board 11 30 73	REVISED BUDGET as of ____ Amount From/To	REVISED BUDGET as of ____ Amount From/To	YEAR TO DATE: Expenditures Commitments as of ____	BALANCE REMAINING	DEPARTMENT RESPONSIBLE	REQUIRES WATCHING OR ACTION
BASIC ACTIVITIES	Page 2 of 4							
704	Chicago Regional Office Rent 3.4 Telephone 3.4 *Travel 14.6 Other Off. Supp.&Equip. .8 Chapter literature, films, TV spots, radio spots, exhibits, fund raising mat'l & distribution & handling costs 8.0	30.2	(All distribution, in chapter and non-chapter areas, is being transferred to regional office. Budget control is by memo invoices.)				FR/A-F	
705	Atlanta Regional Office Rent 2.3 Telephone 4.2 *Travel 11.0 Other Off.Supp.&Equip. 1.0 Chapter literature, films, TV spots, radio spots, exhibits, fund raising mat'l & distribution & handling costs 8.0	24.9	(All distribution, in chapter and non-chapter areas, is being transferred to regional office. Budget control is by memo invoices.)				FR/A-F	
706	Chapter Bonding Insurance	3.0					FR/A-F	
707	Membership Materials	7.0					FR/I-E	
708	Chapter Membership Tests Paducah, Kentucky San Diego, California San Antonio, Texas Wichita, Kansas Boston Massachusetts	2.5					FR/I-E	

* To be detailed quarterly - in advance - and shared with chapters. (Covers Ennis, Petry, Ostrom and Sutherland)

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FIELD SERVICES AND CHAPTER DEVELOPMENT

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BASIC ACTIVITIES	Page 3 of 4							
709	Membership Mailings House List #1 House List #2 Patient Service Names Prospect List #1 Prospect List #2 SPOKESMAN list	4.3					FS/FR	
710	Other Chapter Materials -39 Local Organiz.Bulletins -24 Regional Off. Directives -Secretary Manual -Chapter Service Ctr Forms -Model Bylaws, Patient forms, etc.	2.0					FS/I-E	
711	Chapter and Volunteer Awards	.8					FS/I-E	
712	Chapter Manual Additions & Revisions	1.0					FS/I-E	
	TOTAL	175.3						
ADDITIONAL	- IF FUNDING SECURED							
	Regional Managers Meetings	2.2					FS	
	Regional Workshops	20.0					FS/GLP/PE	
	Chapter Visits to HQ	2.0					FS	
	State Organization Support	20.0					FS/R-F	

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FIELD SERVICES AND CHAPTER DEVELOPMENT

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BASIC ACTIVITIES	Page 4 of 4							
ADDITIONAL	- IF FUNDING SECURED (cont'd)							
	Chapter Committee Meetings	1.4					FS	
	National Chapters Workshop	75.0					FS/ALL	
	Additional Chapter Materials	10.0					FS/I-E	
	TOTAL	130.6						

INFORMATION AND EDUCATION

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BASIC ACTIVITIES	Page 1 of 13							
	CONSUMER LITERATURE-PAMPHLETS							
601	Literature Reprinting for Inventory (Not covered in Chapter or Patient Service Consumption)	6.5					I-E	
602		2.0					I-E	
	-Help Wanted (Employment, Occupational Guides, Workman's Compensation, Second Injury) .5						I-E	
	-Understanding & Living w/Epilepsy (Patient) .5						I-E	
	-Understanding & Living w/Epilepsy (Parent) .5						I-E	
	-Facts and Figures .5						I-E	
	CONSUMER LITERATURE-BROCHURES							
603	This is EFA	.8					I-E	
604	EFA Chapter Services Center	.6					I-E	
	BOOKS							
605	What Everyone Should Know About Epilepsy	2.0					I-E	
606	Physician's Handbook	2.0					I-E	

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INFORMATION AND EDUCATION

BUDGET CODE NO	DESCRIPTION OR ACTIVITY	OFFICIAL ANNUAL BUDGET as approved by Board 11-30-73	REVISED BUDGET as of ___ Amount From/To	REVISED BUDGET as of ___ Amount From To	YEAR TO DATE Expenditures/ Commitments as of ___	BALANCE REMAINING	DEPARTMENT RESPONSIBLE	REQUIRES WATCHING OR ACTION
BASIC ACTIVITIES	Page 2 of 13							
	KITS/PRESENTATIONS/OTHER MAT'LS							
607	Epilepsy Month	4.0					I-E	
608	School Alert	7.0					I-E/GLP	
	OTHER LITERATURE & POSITION PAPERS							
609	-Legislative Information Paper (Appendix) .5 -Emerging Manpower Needs Paper .5 -Spectrum (Consensus) .2	1.2					I-E/GLP I-E/GLP I-E/	
610	-EFA Board By-Laws .2 -PAB By-Laws .2 -Annual Report 7.8	8.2					I-E/A- I-E/GLP I-E/A-	
611	Mobilizing Volunteers	.3					I-E/A-	
	BROADCAST/AUDIO VISUALS/OTHER MAT'L							
612	Equipment Purchases	.3					I-E	
613	Presentation to TV Producers & Networks	.5					I-E	
615	Four (4) TV Spots	16.0					I-E	
615	TV Spot Promotion	.5					I-E	
616	TV Spot Prints	1.8					I-E	

INFORMATION AND EDUCATION

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BASIC ACTIVITIES	Page 3 of 13							
	FILMS & VIDEO TAPES							
	<u>New Films</u>							
617	28 Min./General 17.5	77.5					I-E	
	28 Min./"The 50%" 17.5						I-E	
	28 Min./"The 30%" 17.5						I-E	
	28 Min./"The 20%" 17.5						I-E	
	10 Min./Parents 7.5							
618	10 Min./Teachers 7.5	37.5					I-E	
	10 Min./V.R. Counselors 7.5						I-E	
	10 Min./Physicians 7.5						I-E	
	10 Min./Employers 7.5						I-E	
	10 Min./Nurses 7.5						I-E	
619	New Film Library Prints	3.2					I-E	
620	-Film Library Refurb. .5	1.5					I-E	
	-Film Library Distribution Service 1.0						I-E	
	SLIDES							
621	Routine Slides	2.0					I-E	
	EXHIBITS							
622	Exhibit Handling	1.0					I-E	
623	New Exhibit Design & Prod.	1.5					I-E	
	GENERAL							
624	Art Room Supplies	.8					I-E	
* 625	Art Director	25.5					I-E	

*Will try to revise basic arrangements

INFORMATION AND EDUCATION

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BASIC ACTIVITIES Page 4 of 13								
	GENERAL (cont'd)							
626	I & E Committee Meetings	.7					I-E	
627	I & E Staff Travel (Funk, Scherer, Brown)	2.2					I-E	
628	Copyright	.5					I-E	
629	Miscellaneous Photography	1.0					I-E	
630	Writers & Consultants	4.0					I-E	
	NATIONAL SPOKESMAN							
631	-Circulation List Dev. & Maintenance 2.5	38.0					I-E	
	-Photos and Art 1.5						I-E	
	-Typeset'g & Print'g 34.0						I-E	
	NEWS BUREAU							
632	Basic Releases	2.7					I-E	
633	Jornalism Award	.8					I-E	
634	Press Clipping Service	2.1					I-E	
	TOTAL	256.2						

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INFORMATION AND EDUCATION

BUDGET CODE NC	DESCRIPTION OR ACTIVITY	OFFICIAL ANNUAL BUDGET as approved by Board 11 30 73	REVISED BUDGET as of ___ Amount From To	REVISED BUDGET as of ___ Amount From To	YEAR TO DATE Expenditures Commitments as of ___	BALANCE REMAINING	DEPARTMENT RESPONSIBLE	REQUIRES WATCHING OR ACTION
BASIC ACTIVITIES	Page 5 of 13							
ADDITIONAL - IF FUNDING SECURED								
	Epilepsy and Pregnancy	.5					I-E	
	Epilepsy & Health Routine	.5					I-E	
	Poster Child Promotion	1.0					I-E	
	Additional Activity for Epilepsy Month	3.0					I-E	
	CONSUMER LITERATURE-PAMPLETS							
	Directory I & E Ed. Mat'ls	.5					I-E	
	A Consumer's Guide to Ins.	.5					I-E/GLP	
	GLC: A New Technique	.5					I-E/GLP	
	Civil, Legal & Human Rights	.5					I-E/GLP	
	Directory of Allied Organiz.	.5					I-E/A-F	
	Government & the Epilepsies	.5					I-E/GLP	
	Directory of GLC Facilities	.5					I-E /GLP	
	School Alert (secondary schls)	.5					I-E	
	Because You Are My Friend(Adult)	.5					I-E	
	Because You Are My Friend(Span.)	.5					I-E	
	Answers to Questions (Span.)	.5					I-E	
	Kinds and Causes	.5					I-E	

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INFORMATION AND EDUCATION

BUDGET CODE NO	DESCRIPTION OR ACTIVITY	OFFICIAL ANNUAL BUDGET as approved by Board 11.30 73	REVISED BUDGET as of ——— Amount From To	REVISED BUDGET as of —— Amount From To	YEAR TO DATE Expenditures Commitments as of ——	BALANCE REMAINING	DEPARTMENT RESPONSIBLE	REQUIRES WATCHING OR ACTION
BASIC ACTIVITIES Page 6 of 13								
ADDITIONAL - IF FUNDING SECURED (cont'd)								
	CONSUMER LITERATURE-PAMPHLETS (cont'd)							
	Professional Specialists	.5					I-E	
	For Those Who Help People w/ Epilepsy	.5					I-E	
	Massachusetts State Pamphlet	.5					I-E	
	Glossary Pamphlet	.5					I-E	
	CONSUMER LITERATURE-BROCHURES							
	New Literature Development:							
	The EFA Chapter System	.6					I-E/FS	
	Research Brochure (Rev.)	4.0					I-E/RPE	
	Research Brochure (Pub.)	2.0					I-E/GLP	
	Legal Rights of the Person w/Epilepsy (Rev.)	4.0					I-E/GLP	
	Centers of Excellence	4.0					I-E/RPE	

INFORMATION AND EDUCATION

BUDGET CODE NO	DESCRIPTION OR ACTIVITY	OFFICIAL ANNUAL BUDGET (as approved by Board 11/30/73)	REVISED BUDGET as of Amount From To	REVISED BUDGET as of ___ Amount From To	YEAR TO DATE Expenditures Commitments As of ___	BALANCE REMAINING	DEPARTMENT RESPONSIBLE	REQUIRES WATCHING OR ACTION
BASIC ACTIVITIES	Page 7 of 13							
ADDITIONAL -	IF FUNDING SECURED (cont'd)							
	OTHER LITERATURE & POSITION PAPERS							
	New Literature Development						I-E	
	Residential Facilities for Those w/Epilepsy	.5					I-E	
	What It's Like to Have Epilepsy	.2					I-E	
	Statistics on the Epilepsies	.5					I-E/GLP	
	Epilepsy & the Military	.3					I-E/GLP	
	A National Plan Paper	.6					I-E/GLP	
	Behind the Stigma	.3					I-E/GLP	
	Annotated Subject Bibliography	.3					I-E/GLP	
	Guide to Government Programs	.3					I-E/GLP	
	Knowledge of Epilepsy Among Professionals	.3					I-E/GLP	
	Sheltered Workshops Survey	.2					I-E/GLP	
	EFA Staff Document	.2					I-E/A-P	
	Model Legislation	.3					I-E/GLP	

INFORMATION AND EDUCATION

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BASIC ACTIVITIES	Page 8 of 13							
ADDITIONAL	IF FUNDING SECURED (cont'd)							
	OTHER LITERATURE & POSITION PAPERS (cont'd)							
	Educational Facilities	2.0					I-E	
	Cassette Slip Sheet	.1					I-E	
	Book Slip Sheet	.1					I-E	
	Library Manual	.2					I-E/GLP	
	Impact of Awards Paper	.3					I-E/RPE	
	Research Thrusts	.3					I-E/RPE	
	Physician's Educational Survey	.5					I-E/RPE	
	WORKING GUIDES							
	Seminars on Employment & Job Recruitment	.3					I-E/GLP	
	Survey for Screening Pre-School Children	.3					I-E/GLP	
	Planning Chapter Advocacy Programs	.3					I-E/GLP	
	Vocational Rehabilitation Programs	.3					I-E/GLP	

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INFORMATION AND EDUCATION

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BASIC ACTIVITIES	Page 9 of 13							
ADDITIONAL -	IF FUNDING SECURED (cont'd)							
	WORKING GUIDES (cont'd)							
	Professional Conferences & Seminars	.3					I-E/GLP	
	Grant Applications & Admin.	.3					I-E/GLP	
	Teenage Counseling/Individual Group	.3					I-E/GLP	
	Vocational & Sheltered Workshops	.3					I-E/GLP	
	Counseling Services	.3					I-E/GLP	
	Insurance Coverage for those w/Epilepsy	.3					I-E/GLP	
	Model Legislation	.3					I-E/GLP	
	Local Speakers Bureau	.3					I-E/GLP	
	BROADCAST/AUDIO VISUALS/OTHER MAT'LS							
	Consumer Audio Tapes	3.0		(+ anticipated recovered costs)			I-E/RPE	

INFORMATION AND EDUCATION

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BASIC ACTIVITIES	Page 10 of 13							
ADDITIONAL -	IF FUNDING SECURED cont'd							
	TELEVISION							
	New TV Spots							
	1-Minute	4.0					I-E	
	30-Second	4.0					I-E	
	30-Second	4.0					I-E	
	RADIO							
	Broadcast Committee Meeting	.7					I-E	
	Recorded Spots	7.0					I-E	
	FILMS & VIDEO TAPES							
	Video Tapes for Staff Trng	1.2					I-E	
	Re-editing & Piecing of Existing Film Footage	6.0					I-E	
	Videotape Verson 1-Week Course on Epilepsies	4.0					I-E/RPE	
	Videotape Version of 1-Day Physician's Course	3.4					I-E/RPE	

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INFORMATION AND EDUCATION

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BASIC ACTIVITIES	Page 11 of 13							
ADDITIONAL	- IF FUNDING SECURED (cont'd)							
	SLIDES							
	Slide Presentations	6.0					I-E	
	Status '74 - Chapter Mtgs	.9					I-E	
	Recruitment-Volunteers & Fund Raisers	.9					I-E/FS/FR	
	Medical, Research, Professional Development	.6					I-E	
	Illustrated Q & A	.6					I-E	
	Community & Nat'l Problems	.6					I-E	
	Employment	.6					I-E	
	Teacher	.6					I-E	
	How to Make Your Voice Heard	.6					I-E	
	Why You Should be a Member	.5					I-E	

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INFORMATION AND EDUCATION

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BASIC ACTIVITIES	Page 12 of 13							
ADDITIONAL -	IF FUNDING SECURED (cont'd)							
	NEWS BUREAU							
	News Releases	9.0					I-E	
	Western Institute	.7					I-E/RPE	
	National Conference	.7					I-E/GLP	
	PAB Meeting	.7					I-E/RPE	
	Board Meetings	.7					I-E/A-F	
	Special Reports	.7					I-E	
	RTI Courses	.7					I-E/RPE	
	Development & Maintenance	.7					I-E	
	Regional Workshops	.7					I-E/FS/GLP	
	Miscellaneous	2.7					I-E	
	White House Visit	1.0					I-E	
	Poster Child Tour	6.0					I-E	
	TV News Releases	3.0					I-E/FS	
	Speakers Bureau-Speeches	.5					I-E	
	Magazine Articles	2.0					I-E	

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BASIC ACTIVITIES	Page 13 of 13							
ADDITIONAL	IF FUNDING SECURED							
	NEWS BUREAU (cont'd)							
	Celebrity Recruitment	1.0					I-E	
	Stringer-Freelance	3.0					I-E	
	GENERAL							
	Additional Staff Travel	2.2					I-E	
	Misc. Props For Board, PAB & Other Prof. Meetings	.8					I-E/A-F	
	Reprints	.7					I-E	
	Governor's Conference	7.0					I-E	
	National Conf. on Epilepsy for Sc. & Health Writers	7.0					I-E/RPE	
	Mayor's Conference	7.5					I-E/FS	
	Testing	2.0					I-E	
	Membership (PRSA, NCPR, SPEA, Press Club, etc. & Publications)	1.2					I-E	
	TOTAL	156.0						

FUND RAISING

BUDGET CODE NO	DESCRIPTION OR ACTIVITY	OFFICIAL ANNUAL BUDGET as approved by Board 11/30/73	REVISED BUDGET as of ___ Amount From To	REVISED BUDGET as of ___ Amount From To	YEAR TO DATE Expenditures Commitments as of ___	BALANCE REMAINING	DEPARTMENT RESPONSIBLE	REQUIRES WATCHING OR ACTION
BASIC ACTIVITIES	Page 1 of 4							
501	Direct Mail (16.3M) letters	1125.6					FR	
	-Postage & Shipping 301.4						FR	
	-Copywriting (10 top writers x .7/letter accepted for tests, plus others as needed) 14.0						CEO	
	-Artwork & Mech'ls 4.0						FR	
	-Photos & Prints -0-						FR	
	-Printing 6.1						FR	
	-Outgoing Envelopes 82.0						FR	
	-Preparing Direct Mail 128.4						FR	
	-Seal 97.2						FR	
	-Appeal Letters 69.0						FR	
	-Coins 108.0						FR	
	-Return Envelopes 64.4						FR	
	-List Rentals-Gross 127.0						FR	
	-Data Process:							
	Computer letters 4.2						FR	
	List Maint. & Fulfillment 48.0						FR	
	Key Punching 41.5						FR	
	Dup Removal 25.0						FR	
	Miscellaneous 5.4						FR	
	MAILINGS AS FOLLOWS:							
	A)House Mailing "Valentine"		I	1/15/74	900M		FR	
	B)House Mailing TBD Against	best past	II	3/12/74	900M		FR	
	C)House Mailing TBD Against	best past	III	5/14/74	850M		FR	
	D)House Mailing TBD Against	best past	IV	8/13/74	850M		FR	
	E)House Mailing TBD Against	best past	V	9/24/74	900M		FR	
	F)House Mailing TBD Against	best past	VI	11/19/74	900M		FR	

FUND RAISING

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BASIC ACTIVITIES	Page 2 of 4							
	MAILINGS AS FOLLOWS (cont'd)							
	G)RTI Mailing I			4/30/74	20M		RPE	
	H)RTI Mailing II			6/30/74	20M		RPE	
	I)House Copy Test		I	5/14/74			FR	
	J)"Long Copy"		II	5/14/74	50M		FR	
	K)"SPOKESMAN Digest"		III	5/14/74			FR	
	L)"New Research"		IV	8/13/74			FR	
	M)"Prevention/Children		V	8/13/74	50M		FR	
	N)"Counseling/Referral"		VI	8/13/74			FR	
	O)Prospect Copy		Test I	6/15/74	10M		FR	
	P)"Your Brain"		Test II	6/15/74	10M		FR	
	Q)"How You Can Incur"		Test III	6/15/74	10M		FR	
	R)"What Would You Do"		Test IV	6/15/74	10M		FR	
	S)"Neurological Exam"		Test V	6/15/74	10M		FR	
	T)"GLC Today"		Test VI	6/15/74	10M		FR	
	U) TBD		Test VII	6/15/74	10M		FR	
	V) TBD		Test VIII	6/15/74	10M		FR	
	W) TBD		Test IX	6/15/74	10M		FR	
	X)Continuous Prospect Mailings		January-December		10,740M		FR	
	Y)$25-Plus Mailing		I	4/30/74	15M		FR	
	Z)$25-Plus Mailing		II	9/30/74	15M		FR	
502	Social & Fraternal Org. -Mailing I -Mailing II -Personal Contact w/30 (at least)	1.7					FR	
503	Commerce & Industry Campaign -Mailing I/Dun & Bradstreet -Mailing II/Other Bus. Lists	2.1					FR	
504	Foundations Campaign -Mailing I - 3,000 -Mailing II- 3,000 -200 pers./tel. contacts (at least)	2.6					FR	

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FUND RAISING

BUDGET CODE NO	DESCRIPTION OR ACTIVITY	OFFICIAL ANNUAL BUDGET as approved by Board 11/30/73	REVISED BUDGET as of ___ Amount From/To	REVISED BUDGET as of ___ Amount From To	YEAR TO DATE Expenditures/ Commitments as of ___	BALANCE REMAINING	DEPARTMENT RESPONSIBLE	REQUIRES WATCHING OR ACTION
BASIC ACTIVITIES	Page 3 of 4							
505	Major Donors Campaign -Mailing I - 1,500 -Mailing II - 1,500	1.7					FR	
506	Deferred Giving Campaign -Mailing I - 1,250 -Mailing II - 1,250 (Trust officers & attys)	1.5					FR	
507	Writers & Consultants (for other than direct mail)	4.0					FR	
508	Dues -Direct Mail Marketing Ass'n (EFA) -FRI (Fund Raising Inst.) -KRC Letter -Mail Adv. Club of Wash. (Flemma & Price) -Foundation Center/Information Quarterly -National Society of Fund Raisers [National & Local] (Membership: Flemma, Organ, Sutherland) [National Membership] (Funk, Shannon, Moore Ennis) -Foundation News -Monthly MACW Meetings	.9					FR	
509	Focus Group Interviews	2.1					FR	
510	Travel (HQ-FR)	7.0					FR	

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FUND RAISING

BUDGET CODE NO	DESCRIPTION OR ACTIVITY	OFFICIAL ANNUAL BUDGET as approved by Board 11/30/73	REVISED BUDGET as of ___ Amount From:To	REVISED BUDGET as of ___ Amount From To	YEAR TO DATE Expenditures/ Commitments as of ___	BALANCE REMAINING	DEPARTMENT RESPONSIBLE	REQUIRES WATCHING OR ACTION
BASIC ACTIVITIES Page 4 of 4								
511	United Fund Presentation	.6					FR	
512	New Fund Raising Concepts	3.0					FR	
513	Acknowledgement Program	37.0					FR	
	TOTAL	1189.8						
ADDITIONAL - IF FUNDING SECURED								
	Additional Fund Raising Kits	10.0					FR	
	Foundation Reporting Serv.	6.0					FR	
	Services from American Ass'n of Fund Raising Counsel member firm	15.0					FR	
	Additional Staff Travel	10.0					FR	
	TOTAL	41.0						

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ADMINISTRATION & FINANCE

BUDGET CODE NO	DESCRIPTION OR ACTIVITY	OFFICIAL ANNUAL BUDGET as approved by Board 11/30/73	REVISED BUDGET as of ___ Amount From To	REVISED BUDGET as of ___ Amount From To	YEAR TO DATE Expenditures Commitments as of ___	BALANCE REMAINING	DEPARTMENT RESPONSIBLE	REQUIRES WATCHING OR ACTION
BASIC ACTIVITIES Page 1 of 3								
401	President's Expenses	2.0					CEO	
402	Liability & Casualty Ins.	3.5					A-F	
403	Officer & Director Ins.	1.5					A-F	
404	Legal Fees	30.0					A-F	
405	Armored Car Service	3.4					A-F	
406	Dues (National Health Council)	3.0					A-F	
407	Employments Costs	7.0					A-F/FS	
408	Travel (Internal Auditor)	7.0					A-F/FS	
409	Other Travel (A-F: Shannon & Smith)	2.0					A-F	
410	Board of Directors - 2 Meetings -12 Bulletins -Agendas, Minutes, Travel	12.0					A-F/All	
411	Executive Committee - 2 Meetings -12 Bulletins -Agendas, Minutes, Travel	3.0					A-F/All	
412	Annual Report Filing Fees	.3					A-F	
413	Computerized Acc't'g Exp.	6.5					A-F	
414	Outside MT/ST Services	3.5					A-F	
* 415	D.C. Space Rental	61.8						

*Will try to reduce by 9.0 through sub-lease

ADMINISTRATION & FINANCE

BUDGET CODE NO	DESCRIPTION OR ACTIVITY	OFFICIAL ANNUAL BUDGET as approved by Board 11/30/73	REVISED BUDGET as of ____ Amount From-To	REVISED BUDGET as of ____ Amount From-To	YEAR TO DATE Expenditures/ Commitments as of ____	BALANCE REMAINING	DEPARTMENT RESPONSIBLE	REQUIRES WATCHING OR ACTION
BASIC ACTIVITIES	Page 2 of 3							
416	D.C. Telephone	13.0					A-F	
417	D.C. Equipment Leases	9.8					A-F	
418	HQ/Chapter Audit Fees	16.0					A-F	
419	D.C. Office Supplies	17.0					A-F	
420	D.C. Xerox	15.0					A-F	
421	Postage	19.0					A-F	
422	Interest Expenses	6.0					A-F	
424	Salaries & Wages (63 people)	836.6					A-F	
425	Reserve for Salary Increases	20.0					A-F	
426	Payroll Taxes)						A-F	
427	Employee Group Insurance)	94.6					A-F	
428	Pension)						A-F	
429	Temporary Help & O.T.	9.0					A-F	
430	Consultants - Personnel	15.0					A-F	
431	Staff Relocation Costs	2.0						
432	Literature required to service national information & referral program (including inventory and distr. handlg)	8.0					A-F/I-E	
423	Misc. Printing	.5					A-F/PS	

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ADMINISTRATION & FINANCE

BUDGET CODE NO	DESCRIPTION OR ACTIVITY	OFFICIAL ANNUAL BUDGET as approved by Board 11-30-73	REVISED BUDGET as of ___ Amount From/To	REVISED BUDGET as of ___ Amount From To	YEAR TO DATE Expenditures Commitments as of ___	BALANCE REMAINING	DEPARTMENT RESPONSIBLE	REQUIRES WATCHING OR ACTION
BASIC ACTIVITIES	Page 3 of 3							
424	D. C. Maintenance & Repairs	3.0					A-F	
	TOTAL	1231.0						
ADDITIONAL - IF FUNDING AVAILABLE								
	System-wide Audit by PW	31.0					A-F/FS	
	Printing 1975 Forward Plan	1.4					A-F/All	
	Further Computerization of Accounting	20.0					A-F	
	Administrative Seminars for Chapter Paid Staff	12.0					A-F	
	Standard Accounting Forms for Chapters	4.0					A-F/FS	
	Additional Employee Fringe Benefits	25.0					A-F	
	Eleven Additional Staff	170.0					A-F/All	
	Staff Tuition	1.0					A-F	
	Staff Training	3.0					A-F/RPE	
	Christmas Cards	.3					A-F/I-E	
	D.C. Capital Expenditures	10.0					A-F/All	
	Consultants	7.0					A-F	
	G & A Meetings	.2					A-F	
	TOTAL	284.9						

.STAFF AUTHORIZATIONS

(From minutes of the April 24, 1971 Board of Directors' Meeting)

"(a) The Chief Executive Officer is strictly enjoined to make downward adjustments in expenditures whenever actual income drops below budgeted projections. In this process, he has complete discretion and may adjust any or all accounts downward

(b) The Chief Executive Officer may make adjustments within accounts within the budget at any time and without limit as long as the total budget is not exceeded and the general goals of the approved budget are maintained.

Mr. Green, Chairman of the Finance Committee, recommended the Board approve those statements as an expression of Board policy and then discussed the possibility of the Chief Executive Officer being given authority to make interim upward adjustments in the expenditures budget between Board/Executive Committee meetings provided that receipts were exceeding budget by a specified percentage. Mr. Green indicated that the Finance Committee was in favor of allowing a reasonable degree of operating flexibility to the Chief Executive Officer."

(From the minutes of the November 17, 1972 Executive Committee Meeting).

". . . the budget surplus should be considered a line item in the budget and not be reduced unless other accounts are reduced accordingly."

(From the minutes of the November 30, 1973 Board of Directors' Meeting)

"Mr. O'Neil pointed out that . . . the Finance Committee had decided to recommend that the Board approve the 1974 Budget in the members' folders as presented, but to direct Mr Funk to reduce expenditures by 10 percent and at the same time to retain a quarter of a million dollars in unallocated contingency funds under the control of the Chief Executive Office to be spent as resources permit and circumstances require . . .

"Following a brief discussion, approval of the report of the Finance Committee, including all the recommendations therein, was moved, seconded and passed."

The Chief Executive Officer requires staff members recommending changes in the expenditure budget to specify the account to be *increased* and the one to be *decreased* He retains authority for all change approvals

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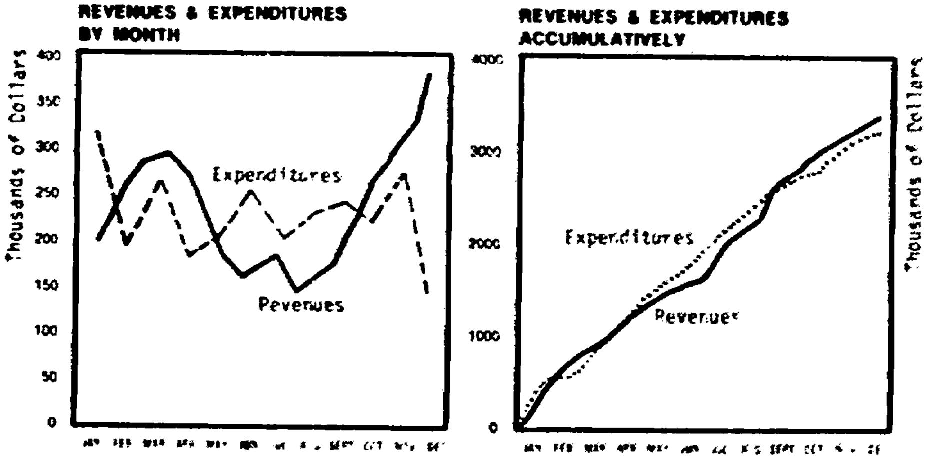
CASH FLOW PROJECTIONS



GENERAL FUND PROGRAM EXPENDITURE SUMMARY BUDGET – 1974 BY NATIONAL HEALTH COUNCIL CATEGORIES

	Salary & Related	Indirects	Out of Pocket Expenses	1974 Total	Percent of net Available Revenues
Research	43.4	8.2	87.4	139.0	9.4
Professional Education & Training	45.0	8.6	63.2	116.8	7.9
Public Health Education	119.5	22.7	174.6	316.8	21.4
Community Services					
Chapter Dev. & Field Services	266.4	50.7	186.6	503.7	34.0
Govt Liaison & Program Dev.	95.3	18.1	58.1	171.5	11.6
N C R C			170.0	170.0	11.5
Patient Services	42.1	8.2	12.0	62.3	4.2
TOTAL PROGRAM EXPENDITURES	611.7	116.5	751.9	1480.1	100.0
CEO Contingency				50	
Fund Raising Cost Ratio (HQ only)				37.4	

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Epilepsy
FOUNDATION OF AMERICA
Suite 406 • 1828 L Street N.W. • Washington D.C. 20036 • (202) 293-2930
MEMBER NATIONAL HEALTH COUNCIL

January 28, 1974

The Honorable Walter Mondale
United States Senate
Washington, D. C. 20510

Dear Senator Mondale:

On Saturday, January 26, Mr. Harvey M. Katz of your staff visited this office for a period of about three hours and reviewed financial records, including the 1973 general ledger and a portion of the voucher register. During this visit he requested the following items:

-- A copy of the organization's contract with our Executive Vice President

-- A copy of the lease covering the Foundation's motor vehicle, and

-- A copy of the employment contract with consultant Hans Scherner.

Although the Foundation normally regards compensation of its staff members and consultants a private matter between the organization and the individual concerned, Mr. Funk has authorized and directed me to furnish you with a copy of his contract, which is enclosed.

Also enclosed is a copy of the rental agreement on the Foundation's automobile which is utilized by several staff members, but principally by Mr. Funk. Mr. Funk also makes some use of this vehicle for personal driving. You will note that the lease fee is $2580 per year. For your information Mr. Funk paid $549.90 of this personally in 1973.

Honorable Walter Mondale
January 28, 1974
Page 2

Also enclosed is a copy of our contract with Mr. Hans Scherner which is largely self-explanatory as to his duties. His resume is included for further information as are his working papers on the last assignment completed for us. His current assignment has to do with relationships between our regional offices and key individuals in local chapters.

As covered by other staff members in other correspondence with you, this is a quasi-public organization and all of us, including the headquarters staff, professional advisers, national Board of Directors and local chapters stand ready to provide you with all possible help and assistance.

Sincerely yours,

James A. Shannon
Associate Executive Director

JAS/smv
Enclosures
cc: Paul E. Funk, Executive Vice President
Paul D. Holland, President
A. B. Baker, M.D., Chairman of the Board
Harold Gordon, General Counsel

Harvey Katz

[EDITORS NOTE.—Letter to page 737 in Part 2 of this hearing series follows:]

THE INTERPUBLIC GROUP OF COMPANIES, INC.

Neal Gilliatt
Vice Chairman

June 25, 1973

Mr. Hugh S. Gage
Epilepsy Foundation of America
1828 L Street, N. W., Suite 406
Washington, D. C. 20036

Dear Hugh:

Your proposals about the films using Dave Gilbert sound fine. I am quite sure you would find it difficult to get a better price. I know you would find it impossible to find someone as experienced as Dave in the epilepsy field.

I wish you well with this project. If there's anything I can do to help, please let me know.

Sincerely,

Neal Gilliatt

NG:th

COPY

National
Directory of

CHAPTER PROGRAM SERVICES

Epilepsy
FOUNDATION OF AMERICA

1828 L Street, N.W. • Washington, D.C. 20036

WHAT IS AN EFA CHAPTER?

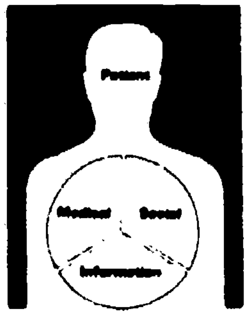
The local chapter is one of the most important units in the Epilepsy Foundation of America. This is where a lot of the work for which the Foundation was established, is carried out . . . where the actual delivery of services to the epilepsy patient takes place . . . in the community where the patient lives.

CHAPTER ROLES

Foundation chapters are groups of concerned lay and professional citizens who, acting as *counselors*, carry out a variety of services and activities in their community to help those with epilepsy help themselves; as *spokesmen*, help remove the obstacles that prevent patients from fulfilling their own potential; as *ombudsmen*, safeguard their civil, legal and human rights; and as *advocates*, support programs designed to eliminate epilepsy as a major national health problem.

CHAPTER PROGRAM SERVICES

Overall Foundation program activities, national and local, encompass 19 categories of services covering (1) medical, (2) social and (3) informational areas as illustrated below. These are further subdivided into 73 specific program activities, many of which are provided at the chapter level.



Major Program Areas of the Foundation

Medical Assistance
Evaluation
Comprehensive Health Planning
Research
Education and Training (Medical)
Treatment (Medical)
Diagnosis
Maternal and Child Care
Mental Health
Education and Training (Social)
Protective and Socio-legal
Transportation
Treatment (Social)
Employment and Vocational Rehabilitation
Financial and Public Assistance
Counseling
Referral Services
Public Education
Information Management

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LOCAL ORGANIZATIONS

	REGION (EFA & NEW)	COUNSELING						PATIENT INFORMATION		PUBLIC INFORMATION								FINANCIAL AND PUBLIC ASSIST.	TRANSPORTATION	EMPLOYMENT AND VOCATIONAL REHABILITATION			TREATMENT						EDUCATION AND TRAINING
		ADULT		TEEN		PARENT																	SOCIAL			MEDICAL			
		Individual	Group	Individual	Group	Individual	Group	Info. & Referral	Directory of Clinics	Films on Epilepsy	Speakers' Bureau	Exhibits	Press, Radio, TV Materials	School Alert	Police, Fire, Transport Alert	Medical Alert ID	Public Meetings	Drug Assistance Program	Transportation	Employment Seminars	Voc./Sheltered Workshops	Voc./Rehab. Counseling	Special Living Arrangements	Residential & Day Camps	Recreation	Case Workups	Out Patient Seizure Clinic	Gas Liquid Chromatography	Physicians' Cont. Education
ALA - Alabama Council on Epilepsy Inc (Birmingham)	(4)	●		●		●		●					●	●	●	●	●					●							
Epilepsy Chapter of Mobile and Gulf Coast Inc	(4)	●		●		●		●				●	●		●		●					●							
ALASKA - Anchorage Area Epilepsy Society	(10)	●		●		●		●		●	●	●	●				●					●							
ARIZONA Central Ariz Regional Epilepsy Soc (Phoenix)	(9)							●			●		●	●			●				●	●				●		
ARK - Arkansas Epilepsy Society (Little Rock)	(6)							●			●		●			●													
CALIF California Epilepsy Society (Sherman Oaks)	(9)							●		●	●	●	●	●	●	●	●	●				●				●			
Contra Costa Alameda Epilepsy League (Richmond)	(9)	●		●		●		●		●	●	●	●	●	●	●	●	●		●	●	●				●			●
Fresno County Epilepsy Society	(9)			●		●		●			●		●	●		●	●												
Kern County Epilepsy Society (Bakersfield)	(9)	●	●	●		●		●		●	●		●	●	●	●	●	●	●		●	●				●			
Los Angeles County Epilepsy Society	(9)	●	●	●		●		●		●	●	●	●	●	●	●	●	●	●			●			●	●			●
Orange County Epilepsy Society (Santa Ana)	(9)	●		●		●		●		●	●	●	●	●	●	●	●	●	●		●	●		●		●	●		
Riverside-Imperial Counties Epilepsy Society	(9)	●		●		●		●		●	●	●	●	●	●	●	●	●				●				●			●
Sacramento Metropolitan Area Epilepsy Society	(9)			●		●		●		●	●	●		●		●	●	●				●				●			
San Bernardino County Epilepsy Society	(9)	●		●		●		●		●	●	●	●	●	●	●	●	●				●				●			
San Diego County Epilepsy Society	(9)	●		●		●		●		●	●	●	●	●	●		●	●				●		●			●		●
San Francisco County Epilepsy Society	(9)			●		●		●				●																	
Santa Barbara County Epilepsy Society (Santa Maria)	(9)			●		●		●		●	●	●	●	●	●	●	●	●				●				●			
Santa Clara County Epilepsy Society (San Jose)	(9)			●		●		●			●	●	●	●		●	●	●		●		●				●			●
Tulare-Kings County Epilepsy Society (Visalia)	(9)							●					●				●												
Ventura County Epilepsy Society	(9)			●		●		●		●	●	●	●	●	●	●	●	●				●				●			●
COLO Colorado Epilepsy Association (Denver)	(8)	●		●		●		●		●	●	●		●		●	●	●		●		●							
Southeastern Colorado Chapter (Pueblo)	(8)							●						●															
Western Colorado Chapter (Grand Junction)	(8)							●		●	●			●															
CONN Epilepsy League of Greater Hartford	(1)							●																					
Southern Connecticut Chapter (Bridgeport)	(1)							●																					
DEL - Delaware Epilepsy Association (Wilmington)	(3)	●		●		●		●			●	●	●				●	●	●			●		●			●		●
DC - Washington D C Area Chapter	(3)	●		●		●		●	●		●	●	●	●	●	●													
FLA - Epilepsy Association of Central Florida Inc (Orlando)	(4)	●		●		●		●		●	●	●	●	●	●	●		●				●	●						
Florida Epilepsy Federation (State Organization) Tallahassee	(4)							●																					
Greater Miami Epilepsy Foundation, Inc (Hialeah)	(4)	●		●		●	●	●			●		●				●					●							
Gulf Coast Chapter (Tampa)	(4)	●		●		●		●				●	●									●							
Jacksonville Chapter Inc	(4)	●		●		●		●				●	●		●	●	●					●							
Palm Beach County Chapter (Delray Beach)	(4)	●		●		●		●			●		●		●	●	●					●							
Sarasota Council on Epilepsy	(4)	●		●		●		●	●		●		●	●		●		●	●			●				●	●	●	
GA - Georgia Chapter EFA (Atlanta)	(4)	●		●		●		●		●	●	●	●	●		●	●	●		●		●	●						
HAWAII Hawaii Epilepsy Society (Honolulu)	(9)	●		●		●		●		●	●	●	●	●	●	●	●			●									
IDAHO - Idaho Epilepsy League (Boise)	(10)							●			●	●	●	●		●	●												
ILL - Heart of Illinois Epilepsy League Inc (Peoria)	(5)	●		●			●	●				●	●	●		●	●												
Epilepsy Foundation of America - Chicago Metropolitan Chapter	(5)	●						●		●			●				●	●											
Rock River Valley Epilepsy Association (Rockford)	(5)	●		●		●		●		●	●	●	●	●	●		●	●				●							
IND - Tri-State Epilepsy Association Inc (Evansville)	(5)	●		●		●		●		●	●		●	●	●	●	●	●	●	●	●	●	●			●			●
IOWA Aligned Community of Epileptics, EFA (Cedar Falls)	(7)							●			●					●	●					●							
EFA Iowa Chapter (State Organization) Des Moines	(7)	●		●		●		●		●	●	●	●	●		●	●												
Siouxland Area Chapter (Sioux City)	(7)							●		●	●		●	●	●	●	●												●
Epilepsy Association of Area X (Cedar Rapids)	(7)							●																					
North Central Division of Iowa State Chapter (Clear Lake)	(7)							●																					
KANS - Kansas Chapter EFA (Wichita)	(7)	●						●			●		●				●												
KY - Central Kentucky Epilepsy Foundation (Lexington)	(4)							●																					
Epilepsia of Louisville	(4)	●		●		●		●			●	●	●	●			●					●							●
Jackson Purchase Chapter (Paducah)	(4)	●		●		●		●			●	●	●				●					●							
LA - Southwest Louisiana Chapter EFA (Lake Charles)	(6)					●		●		●	●	●	●	●		●		●				●							
Louisiana Epilepsy Association EFA (New Orleans)	(6)	●		●		●		●		●	●	●	●	●		●												●
MAINE - Epilepsy Inc, Bangor Chapter (Hampden Highlands)	(1)	●		●		●		●			●	●	●	●	●	●	●	●		●		●							●
MD Chesapeake Association for Epilepsy EFA (Baltimore)	(3)							●					●			●		●												

LO
ORGAN

MASS Epilepsy Federation of M
Greater Springfield Epile
MISS Mississippi Council on Epi
MO Greater Kansas City Epilepsy
Missouri Epilepsy Federation
MONTANA Big Sky Epilepsy A
NEB Nebraska Epilepsy League I
NEV No Nevada Epilepsy Leagu
So Nevada Epilepsy Societ
N H Epilepsy Society of the Gra
N J New Jersey Chapter of EFA
N M Epilepsy Foundation of Ne
N Y Epilepsy Association of Su
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Poughkeepsie
Nassau County Chapter, In
Oneida County Chapter (U
N C Epilepsy Association of N
N D Bismarck
OHIO EFA Greater Cleveland
Epilepsy Association of F
Greater Cincinnati Counc
OKLA Tulsa Area Council on E
OREGON Epilepsy League of O
Epilepsy League of L
PA Allegheny Plateau Chapter o
Epilepsy Society of Lycomi
Philadelphia Regional Chapt
R I Providence
S C Piedmont Epilepsy Associat
S D Sioux Falls Chapter
TENN Bi-State Chapter of EFA
Memphis Epilepsy Societ
TEX Dallas Epilepsy Associatio
El Paso Epilepsy Associati
Greenville Epilepsy Assoc
High Plains Epilepsy Asso
Houston Epilepsy Associat
San Antonio Epilepsy A
UTAH - Salt Lake City Epilepsy
VT Vermont Epilepsy Associati
VA Greater Tidewater Epilepsy
Epilepsy Foundation of Vi
WASH - Eastern Washington Epi
Western Washington Sta
W VA - Mountain State Epilepsy
Central W Va Epilepsy
WISC Wisconsin Epilepsy Asso
Wisconsin Epilepsy Leagu
WY Wyoming State Epilepsy A

REHABILITATION	TREATMENT						EDUCATION AND TRAINING
	SOCIAL			MEDICAL			
Voc./Rehab. Counseling	Special Living Arrangements	Residential & Day Camps	Recreation	Case Workups	Out Patient Seizure Clinic	Gas Liquid Chromatography	Physicians' Cont. Education
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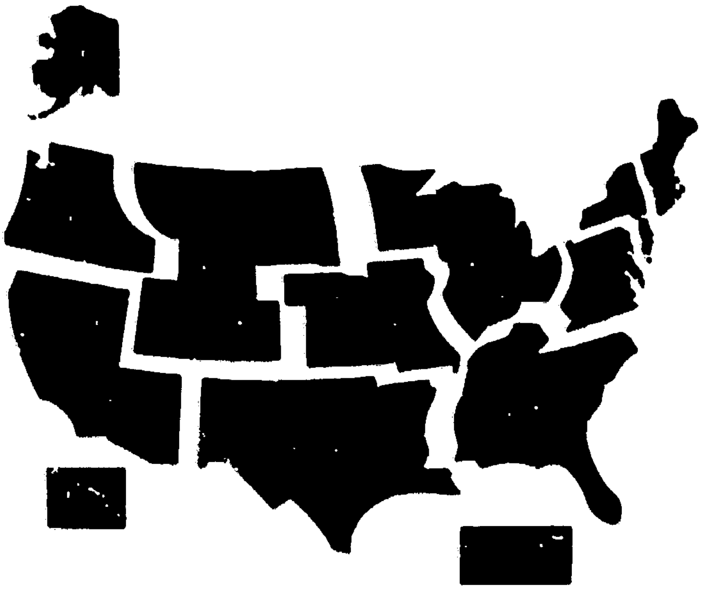
LOCAL ORGANIZATIONS

LOCAL ORGANIZATIONS	REGION (EFA & HEW)	COUNSELING						PATIENT INFORMATION		PUBLIC INFORMATION								FINANCIAL AND PUBLIC ASSIST.	TRANSPORTATION	EMPLOYMENT AND VOCATIONAL REHABILITATION			TREATMENT						EDUCATION AND TRAINING
		ADULT		TEEN		PARENT																	SOCIAL			MEDICAL			
		Individual	Group	Individual	Group	Individual	Group	Info. & Referral	Directory of Clinics	Films on Epilepsy	Speakers' Bureau	Exhibits	Press, Radio, TV Materials	School Alert	Police, Fire, Transport Alert	Medical Alert ID	Public Meetings	Drug Assistance Program	Transportation	Employment Services	Voc./Sheltered Workshops	Voc./Rehab. Counseling	Special Living Arrangements	Residential & Day Camps	Recreation	Case Workups	Out-Patient Seizure Clinic	Gas Liquid Chromatography	Physicians' Cont. Education
MASS Epilepsy Federation of Mass. Inc (State Org.) (Boston)	(1)	●		●		●		●	●	●	●	●	●		●		●	●		●		●		●			●	●	●
Greater Springfield Epilepsy Association	(1)	●		●		●		●		●	●	●	●	●	●	●	●												
MISS Mississippi Council on Epilepsy, Inc. (Jackson)	(4)	●		●		●		●			●	●	●	●	●	●	●	●		●		●							●
MO Greater Kansas City Epilepsy League (Kansas City)	(7)	●		●		●		●			●		●	●	●	●		●	●			●		●					
Missouri Epilepsy Federation Inc. (St. Louis)	(7)	●		●		●		●		●	●		●	●		●	●	●							●				
MONTANA Big Sky Epilepsy Association (Billings)	(8)							●			●																		
NEB Nebraska Epilepsy League Inc. (Omaha)	(7)	●		●		●		●		●	●	●	●	●		●		●				●				●	●	●	●
NEV No. Nevada Epilepsy League (Reno)	(9)	●		●		●		●			●		●	●			●					●							
So. Nevada Epilepsy Society (Las Vegas)	(9)	●		●		●		●		●	●	●	●	●			●	●											
N.H. Epilepsy Society of the Granite State (Manchester)	(1)	●		●		●		●	●	●	●	●	●	●	●	●	●	●		●		●							●
N.J. New Jersey Chapter of EFA (Union)	(2)	●		●		●		●	●		●	●	●		●	●	●	●		●		●							
N.M. Epilepsy Foundation of New Mexico (Albuquerque)	(6)							●					●	●			●					●							
N.Y. Epilepsy Association of Suffolk, Inc. (Greenlawn)	(2)	●		●	●	●		●		●	●			●	●		●												
Epilepsy Association of Western New York, Inc. (Buffalo)	(2)	●		●		●		●			●	●	●	●	●	●	●	●		●		●	●	●	●				
Epilepsy League of Tri Cities (Albany)	(2)		●	●	●	●	●	●			●	●	●	●	●	●	●	●	●			●							●
Epilepsy Society of Onondaga County (Syracuse)	(2)	●		●		●		●			●	●	●	●	●	●	●												●
Greater New York City Chapter EFA	(2)	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●			●		●						●	●
Binghamton	(2)							●																					
Poughkeepsie	(2)							●																					
Nassau County Chapter, Inc. (Hempstead)	(7)	●	●	●	●	●	●	●			●		●	●	●	●	●					●			●	●	●		
Oneida County Chapter (Utica)	(2)	●		●		●		●			●		●	●	●	●	●			●		●							
N.C. Epilepsy Association of N. Carolina (Charlotte)	(4)	●		●		●		●	●		●	●	●	●		●	●					●							
N.D. Bismarck	(8)							●																					
OHIO EFA Greater Cleveland Chapter	(5)	●		●		●		●				●	●	●	●		●	●				●							●
Epilepsy Association of Franklin County (Columbus)	(5)	●		●		●		●				●	●			●	●	●				●					●		●
Greater Cincinnati Council for Epilepsy, Inc. EFA	(5)	●		●		●		●		●	●		●	●		●	●					●							●
OKLA Tulsa Area Council on Epilepsy EFA	(6)							●						●		●						●							
OREGON Epilepsy League of Oregon (Portland)	(10)	●		●		●		●			●	●	●	●	●	●	●	●				●					●	●	●
Epilepsy League of Lane Co. (Eugene)	(10)							●			●		●	●															
PA Allegheny Plateau Chapter of EFA (Pittsburgh)	(3)	●		●		●		●			●	●	●	●								●							
Epilepsy Society of Lycoming County Inc. (Williamsport)	(3)	●		●		●		●		●	●	●	●	●		●		●				●				●	●		
Philadelphia Regional Chapter EFA	(3)	●		●		●		●			●		●	●			●					●							
R.I. Providence	(1)							●		●			●	●			●												
S.C. Piedmont Epilepsy Association (Pickens)	(4)	●		●		●		●			●	●	●	●	●		●		●			●							●
S.D. Sioux Falls Chapter	(8)							●					●	●															
TENN Bi-State Chapter of EFA (Clarksville)	(4)							●				●	●	●		●	●					●							
Memphis Epilepsy Society of EFA	(4)							●					●	●								●							
TEX Dallas Epilepsy Association	(6)	●		●		●		●					●	●	●	●	●	●	●			●							●
El Paso Epilepsy Association	(6)							●																					
Greenville Epilepsy Association (El Paso)	(6)							●					●	●			●												
High Plains Epilepsy Association (Amarillo)	(6)							●						●			●												
Houston Epilepsy Association	(6)	●		●		●		●		●	●	●	●	●	●	●	●	●				●							
San Antonio Epilepsy Association	(6)						●	●			●		●	●															
UTAH Salt Lake City Epilepsy Association	(8)							●					●																
VT Vermont Epilepsy Association, Inc. (Burlington)	(1)	●		●		●		●					●		●		●	●								●	●		
VA Greater Tidewater Epilepsy Assn. Inc. EFA (Chesapeake)	(3)	●		●		●		●			●	●	●	●	●	●	●	●				●							●
Epilepsy Foundation of Virginia (Richmond)	(3)	●		●		●		●					●																
WASH Eastern Washington Epilepsy Society (Spokane)	(10)	●		●		●		●		●	●	●	●	●			●	●				●							
Western Washington State Epilepsy Society (Seattle)	(10)	●		●		●		●		●	●	●	●	●		●	●	●				●							●
W. VA. Mountain State Epilepsy League (Huntington)	(3)	●		●		●		●				●	●	●			●					●							
Central W. Va. Epilepsy League (Clarksburg)	(3)							●																					
WISC Wisconsin Epilepsy Association (Madison)	(5)	●						●		●																●	●		●
Wisconsin Epilepsy League EFA (Milwaukee)	(5)	●		●		●		●		●	●	●	●	●		●	●												
WY Wyoming State Epilepsy Association (Cheyenne)	(8)							●					●	●															

EFA REGIONAL OFFICES



Northeastern Region
(HEW Regions 1 & 2)
Boston, Mass.

Southeastern Region
(HEW Regions 3 & 4)
1581 Phoenix Boulevard, Suite 10
Atlanta, Georgia 30349

North Central and Midwest Regions
(HEW Regions 5 & 7)
343 South Dearborn Street, Suite 1717
Chicago. Illinois 60604

South Central Region
(HEW Regions 6 & 8)
1625 Main Street, Suite 305
Houston, Texas 77002

Western Region
(HEW Regions 9 & 10)
5665 N. Las Virgenes Road
Calabasas, California 91302

CHAPTER PROGRAM SERVICES

EFA chapters vary in size from a nucleus, formative group, called "Information Contacts", to larger sophisticated local organizations with years of experience. The resources and capabilities of a local chapter determine the number of program activities it can support. Some activities, however, are basic throughout the chapter network. These are:

- **Community Resources Survey**
- **Information and Referral Program**
- **Speakers' Bureau**
- **Public Education Program**
- **"School Alert" Program**
- **Participation in Epilepsy Month (Nov.)**

This chart indicates the 29 most widespread Program Activities (out of 73 total) supported by individual chapters. A brief description of these 29 services follows.

- COUNSELING

  Life-long or Long-term Counseling for epilepsy patients whose needs cannot be met by immediate or intermediate service. Many epilepsy patients whose seizures are not completely controlled need counseling throughout their lives.

  Parental Counseling to help parents better understand the growth and development problems of their children with epilepsy.

  Teenage Counseling covers the special needs of teenagers with epilepsy, including some pre-vocational guidance and aid.

  Adult Counseling deals with the broad needs posed by the adult patient requiring multi-disciplinary solutions—vocational, medical, psychological and others. Some chapters offer counseling services on a group as well as an individual basis.

- INFORMATION AND REFERRAL

  From inquiries made through Foundation headquarters as well as those made directly to chapters, epilepsy patients are informed about resources available to them and their families, including physicians, neurologists, health and welfare organizations and other local facilities and services they may need.

- DIRECTORY OF CLINICS

  The Foundation publishes a national directory of clinic facilities to aid those with epilepsy. The directory lists, for each clinic facility, the numbers and kinds of personnel, types of testing and diagnostic equipment and other services. Many chapters supplement this directory with their own local directory which would list all available resources in the community.

- LIBRARY

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- **LIBRARY OF FILMS**
  Some EFA chapters provide films on epilepsy, made for a variety of public and professional audiences. Chapters which do not have their own films, as well as other chapters and individuals, utilize the Foundation's national film library service.
- **SPEAKERS' BUREAU**
  Speakers on various phases of epilepsy and the work of the Foundation are available through many EFA chapters for general lay audiences as well as for medical professionals and paraprofessionals, meeting in seminars, conferences and conventions.
- **EXHIBITS**
  Several types of lightweight, portable exhibits are available through many EFA chapters. Others are available through national headquarters. They are designed for the general public as well as for professional audiences.
- **PRESS, RADIO, TV MATERIALS**
  Local chapters can supply facts, figures and background material on epilepsy for newspaper and magazine writers, as well as for radio and TV producers. Chapters also have (or can obtain) recorded radio and TV informational spots as well as copy for live announcements.
- **SCHOOL ALERT**
  An educational program specifically designed for teachers, school nurses, pupils and others in the school community is conducted by most chapters annually. Chapters have access to a special School Alert Kit prepared by EFA containing a wide range of materials for use by schools and individuals.
- **POLICE, FIRE, TRANSPORTATION ALERT**
  Many chapters conduct an educational program for police, firemen, airline and other transportation personnel about epilepsy recognition and recommended first aid. Chapters also have printed and audio/visual materials for use in training classes and other groups.
- **MEDICAL ALERT IDENTIFICATION**
  Many EFA chapters provide sources for emergency medical identification jewelry or cards for epilepsy patients at minimum cost.
- **PUBLIC MEETINGS**
  A number of chapters conduct meetings for clubs, civic organizations, business groups and others who want to learn more about epilepsy.

Spearheading Foundation and individual chapter Program Services is the task of educating the general public about epilepsy. Chapter volunteers, above, provide information about epilepsy to a national group meeting in Dallas.

- **DRUG ASSISTANCE**
  More and more EFA chapters are providing, through cooperating druggists and drug wholesalers, medication for epilepsy patients at lower cost and on an emergency basis.
- **TRANSPORTATION**
  Chapters, often in cooperation with other voluntary health agencies, provide appropriate, economical and convenient public and private transportation for persons with epilepsy.
- **EMPLOYMENT SEMINARS**
  Some chapters initiate or work with employers and employer groups in disseminating information about epilepsy and the employee. Some subject areas are attendance, safety and productivity records of workers with epilepsy, workmen's compensation costs, and vocational rehabilitation training.
- **VOCATIONAL/SHELTERED WORKSHOPS**
  A number of EFA chapters cooperate with "Epi-Hab" workshops, which train and employ workers with epilepsy.
- **VOCATIONAL REHABILITATION COUNSELING**
  Most chapters conduct such programs, usually in conjunction with State Rehabilitation offices.

- **SPECIAL LIVING**
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- **RESIDENTIAL AND**
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- **SPECIAL LIVING ARRANGEMENTS**
  Pilot programs in some chapters provide alternatives to residential or domiciliary care for epilepsy patients in need of sheltered living environments. Some chapters are also developing services for the aged with epilepsy.

- **RESIDENTIAL AND DAY CAMPS**
  A few chapters offer residential and day summer camp programs for children with epilepsy, regardless of the degree of seizure control. Any chapter can provide information about the development and operation of such programs.

- **RECREATION**
  Some chapters conduct programs which provide recreational opportunities and activities for children and adults with epilepsy.

- **CASE WORKUPS**
  To improve the efficiency in medical evaluation of people with epilepsy, EFA headquarters collects and distributes to chapter Professional Advisory Boards various forms and procedures deemed appropriate by the medical community.

- **OUT-PATIENT SEIZURE CLINICS**
  Some chapters cooperate with and, in some cases, partially support out-patient clinics for the diagnosis and treatment of epilepsy. Information about these clinics is available for those considering establishment of new clinics.

- **GAS-LIQUID CHROMATOGRAPHY**
  "GLC" is a technique for blood serum analysis which provides new, more accurate and effective determination of anticonvulsant drug levels in epilepsy patients. The Foundation and a limited number of EFA chapters have funded GLC equipment for patient service and research.

- **CONTINUING PHYSICIAN EDUCATION**
  The Foundation and its chapters, in conjunction with medical societies and other professional organizations, sponsor vehicles for continuing the education of physicians about epilepsy. These include local, state and regional meetings and seminars, annual events such as the Western Institute on Epilepsy, grants and awards to support significant research projects and the training of young physicians.

Teenage counseling, provided by many chapters, meets the special needs of teenagers with epilepsy. It includes some pre-vocational guidance and aid. Some chapters offer both individual and group counseling, for adults as well as youngsters.

Epilepsy
FOUNDATION OF AMERICA

1828 L Street, N.W • Washington, D C 20036

What's Your Opinion? BEST COPY AVAILABLE

When we say these are the "official" PURPOSES OF EFA	*. . . Is this essentially what we mean?*	*. . . And is this approximately the percentage of net annual revenues we should allocate to each?*
To promote, conduct and support research into the causes and treatment of Epilepsy.	(a) monitoring all significant, world-wide investigations and disseminating the findings; (b) providing support for the NINDS and other government agency epilepsy research budgets; (c) providing to qualified researchers seed grants for needed projects unlikely to be started by other agencies; (d) maintaining a continuous "inventory" of references to studies by subject and making same available to all investigators.	**10%**
To make known the available treatments for Epilepsy.	(a) conducting at least two professional seminars each year; (b) publishing appropriate pamphlets and brochures; (c) engaging in cooperative educational programs (with other organizations) for professional and para-professional people; (d) operating a nation-wide information and referral system in conjunction with chapters to assist persons with epilepsy and their families in taking advantage of assistance available from government and private sources and engaging in related activities.	**10%**
To improve educational and vocational opportunities for persons with Epilepsy.	(a) working at local, state and federal levels to make certain that laws and school systems do not discriminate against persons with epilepsy; (b) encouraging the establishment of special educational facilities wherever needed; (c) sponsoring an annual "School Alert" program in cooperation with professional educational societies and government agencies; (d) working with employers and personnel management associations; (e) working with vocational rehabilitation agencies; (f) sponsoring pre-vocational training programs; (g) working to assure that sheltered workshops accept persons with epilepsy; (h) encouraging the establishment of special epi-hab facilities wherever needed and engaging in related activities as affordable.	**10%**
To educate and provide information to the general public about Epilepsy, with a view toward eradicating misconceptions about Epilepsy.	(a) issuing appropriate news releases to the nation's media; (b) maintaining a library of films and an inventory of pamphlets on various aspects of epilepsy; (c) conducting four to six special events each year which will generate widespread publicity; (d) encouraging writers, novelists, dramatists and other communications specialists to write about epilepsy through sponsorship of annual Journalism Awards and by engaging in appropriate related activities.	**20%**
To promote, establish, develop, maintain and conduct clinics, schools, camps and other facilities or means for treating, educating,	(a) providing financial support grants to selected institutions; (b) encouraging local organizations and affiliates to establish cooperative arrangements with medical schools and hospitals to include securing government grants and contracts for programs to be subcontracted to such medical institutions; (c) continuing to refine the concept of Regional Centers of Excellence; to seek funding and [illegible] for those	**20%**

training, obtaining employment for, caring for, or in any other manner helping persons with Epilepsy. **And to provide financial support by contributions, donations, grants or otherwise to individuals, partnerships, corporations and other organizations engaged in activities that further any of the purposes of the Foundation.**	(c) continuing to refine the concept of Regional Centers of Excellence; to seek funding and establishment of such centers to provide comprehensive treatment and rehabilitation for those with epilepsy; (d) working with the National Education Association and various of its 35 allied organizations, as well as other groups which further child and teacher training, to improve education and training programs and curricula; (e) working with the National Foundation, Easter Seal Society and other groups which operate recreation and camping facilities for handicapped children, and providing information on special needs of children with epilepsy; (f) encouraging EFA affiliates to establish recreation and camping programs; (g) encouraging EFA affiliates to provide social workers and professional vocational counseling, and to maintain information on firms which hire the handicapped; (h) encouraging EFA affiliates to establish sheltered workshop training programs; (i) working within statutory confines to secure adequate legislation to improve the condition of persons with epilepsy and insure that their human and legal rights are not abridged; (j) attempting to integrate all or part of EFA's programs into state and local governmental health care delivery systems and engaging in appropriate activities.	
To encourage, foster and cause to be established chapters and affiliated organizations or groups having similar purposes or whose activities would further the purposes of the Foundation.	(a) administering a nation-wide network of 140 to 220 local chapters with appropriate state and regional offices; (b) seeking widespread public membership in and support for these organizations; (c) training staff people for these organizations; (d) providing expert help to the organizations through visits of qualified EFA specialists no less often than three times a year; (e) enlisting the person with epilepsy in his own fight through participation in these organizations, and engaging in related appropriate activities.	**15%**
To cooperate and work with any health, welfare, educational or other organizations or groups having similar purposes or whose activities would further the purposes of the Foundation.	(a) working closely with appropriate professional societies which include, but are not limited to: the American Epilepsy Society, American Neurological Association, American Academy of Neurology, American Society of EEG Technologists, American Medical Association, Association for Research in Nervous and Mental Diseases, American Academy of Pediatrics and the International Bureau for Epilepsy; (b) recruiting and appointing liaison representatives to EFA's Professional Advisory Board from these and other appropriate organizations; (c) participating in, and establishing, cooperative relationships and projects with various voluntary health agencies, i.e. United Cerebral Palsy Association, National Association of Retarded Children, etc. through the vehicle of ad hoc and liaison committees; (d) keeping abreast of policies and positions of interest to EFA, and soliciting agreement or support for EFA policies and positions and engaging in appropriate related activities.	**5%**
In general to do all things necessary or convenient to effect any or all of the aforesaid purposes, to the extent permitted by law including, but not limited to	(a) being the repository for — and/or guide to — all existing data on the epilepsies; (b) filing class action suits and otherwise appearing as a "friend of the court" in all legal cases advancing the cause of persons with epilepsy; (c) taking the lead in making known to the Congress and the general public the cost of the epilepsies to the nation; (d) taking the lead in developing and continuously up-dating — in cooperation with other organizations and agencies of the government — a National Plan for the medical and social management of the epilepsies, and (e) acting as advocate, ombudsman, spokesman and trustee for both the person with epilepsy and the general public in an attempt to improve and expand services made available by both government and private sectors and engaging in appropriate related activities.	**10%**

Or — are these too many things to try to do with limited funds? How would YOU allocate our effort?

Your Ideas:...

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