### DOCUMENT RESUME

ED 308 673 EC 220 546

TITLE A Guide to Selected National Genetic Voluntary

Organizations.

INSTITUTION National Center for Education in Maternal and Child

Health, Washington, DC.

SPONS AGENCY Health Resources and Services Administration

(DHHS/PHS), Rockville, MD. Office for Maternal and

Child Health Services.

PUB DATE Jan 89

GRANT MCJ-117006-01-0

NOTE 192p.

PUB TYPE Reference Materials - Directories/Catalogs (132) --

Books (010)

EDRS PRICE MF01/PC08 Plus Postage.

DESCRIPTORS \*Congenital Impairments; \*Disabilities; \*Genetics;

Information Sources; \*Organizations (Groups);
Philanthropic Foundacions; \*Social Support Groups;

\*Voluntary Agencies

### ABSTRACT

The directory lists mutual support groups concerned with the medical and psychosocial impacts of genetic disorders and birth defects on affected individuals and families. Each organization included is dedicated to the ongoing emotional, practical, and financial needs of these populations. Entries are categorized by disorder, including: general, auditory, cancer, cardiovascular, chromosomal, connective tissue, craniofacial, developmental, gastrointestinal, hematologic, immunologic, kidney, mental, metabolic, muskoskeletal, neurologic, neuromuscular, short stature, skin, and visual disorders. Listings are also indexed by subject and organization name. Information provided in the organization listings includes the names of the executive director and a contact person, the chapters or satellites, if any, the purpose, publications, available audiovisuals, and newsletter title and/or frequency. (MSE)



Reproductions supplied by EDRS are the best that can be made

<sup>\*</sup> from the original document.

U.S. DEPARTMENT OF EDUCATION

Office of Educational Research and Improvement EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

- This document has been reproduced at received from the person or organization
- Minor changes have been made to improve
- Points of view or opinions stated in this document do not necessarily represent official OERI position or policy

# A Guide to Selected NATIONAL GENETIC VOLUNTARY ORGANIZATIONS



NCEMCH

National Center for Education in Maternal and Child Health

6

BEST COPY AVAILABLE

## A GUIDE TO SELECTED NA'...NAL GENETIC VOLUNTARY ORGANIZATIONS

January 1989



National Center for Education in Maternal and Child Health (NCEMCH)
38th & R Streets, N.W.
Washington, D.C.
20057
(202) 625-8400

This publication is not copyrighted. Readers are free to duplicate and use all or part of the information contained in it. In accordance with accepted publishing standards, the Center requests acknowledgement, in print, of any information reproduced in another publication.

NCEMCH provides information services, educational materials, and technical assistance to organizations, agencies, and individuals with maternal and child health interests.

The Center was established in 1982 at Georgetown University, within the Department of Obstetrics and Gynecology. NCEMCH is primarily funded by the U.S. Department of Health and Human Services through its Bureau of Maternal and Child Health and Resources Department.

THIS PUBLICATION WAS MADE POSSIBLE THROUGH GRANT NUMBER MCJ-117006-01-0 FROM THE OFFICE OF MATERNAL AND CHILD HEALTH, BUREAU OF MATERNAL AND CHILD HEALTH AND RESOURCES DEPARTMENT, PUBLIC HEALTH SERVICE, DEPARTMENT OF HEALTH AND HUMAN SERVICES



Foreword —		
1. General —	11	
Alliance of Genetic Support Groups	13	
March of Dimes Birth Defects Foundation	14	
National Association of Radiation Survivors (NARS)	15	
National Easter Seal Society	16	
National Foundation for Jewish Genetic Diseases, Inc.	17	
National Organization for Rare Disorders (NORD)	18	
Sibling Information Network	19	
·		
2. Auditory	21	
•		
Alexander Graham Bell Association for the Deaf (AGBAD)	23	
American Society for Deaf Children (ADSC)	24	
2 0		
3. Cancer	25	
American Cancer Society	22	
Candlelighters Childhood Cancer Foundation	27	
Familial Polyposis Registry————————————————————————————————————	28	
Gastrointestinal Polyposis & Hereditary Colon Cancer Registry	29	
Intestinal Multiple Polyposis and Colorectal Cancer (IMPACC)	30	
Leukemia Society of America, Inc.	31	
National Cancer Care Foundation (NCCF)	32 33	
Tradional Cancel Care I outloation (IVCCI)	33	
4. Cardiovascular	35	
Council on Cardiovascular Disease in the Young	37	
5. Chromosomal	39	
Association for Children 11 D. C. 1. T. (1 CDC)		
Association for Children with Down Syndrome, Inc. (ACDS)	41	
5p- Society — Fragile X Foundation — Fragile	42	
Fragile X Support, Inc.	43	
National Association for Down Syndrome (NADS)	44	
National Down Syndrome Congress (NDSC)	45	
National Down Syndrome Congress (NDSC)	46 47	
Prader-Willi Syndrome Association (PWSA)		
Support Group for Monosomy 9P	48	
Support Organization for Trisomy 18/12 and other Related	49	
Disorders (S.O.F.T. 18/13)	50	
Turner's Syndrome Society	51	
,	٠.	

### Table of Contents



### Table of Contents (cont'd)

0.	Connective Tissue —
Ehi	lers-Danlos National Foundation (EDNF)
	tional Marfan Foundation (NMF)
IVa	tional Marian Poundation (INMP)
7.	Craniosacial ————————————————————————————————————
۸	engines Cloft Balata Association / The Cloft Balata Foundation
	nerican Cleft Palate Association/The Cleft Palate Foundation _ CES - The National Association for the Craniofacially
r.a.	Handicapped
Na	tional Foundation for Facial Reconstruction
	escription Parents, Inc.
8.	Developmental Disabilities
Ass	sociation for Children and Adults with Learning Disabilities
- 200	(ACLD)
	socation for Retarded Citizens of the United States (ARC) tism Society of America (ASA)
	nter for Hyperactive Child Information, Inc. (CHCI)
	rnelia de Lange Syndrome (CdLS) Foundation, Inc.
Lat	urence-Moon-Biedl Syndrome (LMBS) Support Network
Ort	on Dyslexia Society
Pro	geria International Registry
Rul	binstein-Taybi Sybdrome (RTS) Parent Contact Group
	re and Care
Uni	ited Cerebral Palsy Associations, Inc./UCP Research and
	Educational Foundation
۵	Gastrointestinal
7.	Gastrointestinai
Am	nerican Celiac Society
Am	nerican Liver Foundation (ALF)
Cel	iac Sprue Association/United States of America (CSA/USA) -
Chi	ildren's Liver Foundation, Inc. (CLF)
Glu	tten Intolerance Group of North America (GIG)
Nat	tional Foundation for Ileitis and Colitis, Inc. (NFIC)
10.	Hematologic ————————————————————————————————————
	•
	oley's Anemia Foundation, Inc.
	nconi Anemia Support Group ————————————————————————————————————
	reditary Hemorrhagic Telangiectasia Foundation, Inc.
	tiocytosis-X Association of America, Inc.
Iro	n Overload Diseases Association, Inc. (IOD)
Nat	tional Association for Sickle Cell Disease, Inc. (NASCD)



National Hemophilia Foundation (NHF)	
Thrombocytopenia Absent Radius Syndrome Association (TARSA)	
11. Immunologic	
Amonian I umus Cariota	
American Lupus Society	
Lupus Foundation of America, Inc. (LFA)	
Siggraph's Syndrome Foundation Inc. (CFR)	
Sjogren's Syndrome Foundation, Inc. (SSF)	
12. Kidney	
National Kidney Foundation Inc	
National Kidney Foundation, Inc.	
Polysystic Kidney Research (PKR) Foundation	
13. Mentzl	
Depression and Related Affective Disorders Association, Inc.	
(DRADA)	
(5.6.5.)	
14. Metabolic ——————————————————————	
American Diabetes Association, Inc.	
American Porphyria Foundation	
Association for Glycogen Storage Diseases	
Association of Neuro-Metabolic Disorders	
Cystic Fibrosis (CF) Foundation	
Cystinosis Foundation, Inc.	
Dysautonomia Foundation, Inc.	
Foundation for the Study of Wilson's Disease, Inc.	
Juvenile Diabetes Foundation International	
Lowe's Syndrome Association, Inc.	
Malignant Hyperthermia Association of the United States	
Maple Syrup Urine Disease (MSUD) Family Support Croup	
ML (Mucolipidosis) IV Foundation	
National Gaucher Foundation, Inc.	
National Mucopolysaccaridosis (MPS) Society, *ac.	
National Organization for Albinism and Hypopigmentation	
(NOAH)	
National Tay-Sachs and Allied Diseases Association, Inc. (NTSAD)	
Organic Acidemia Association, Inc.	
United Leukodystrophy Foundation, Inc. (ULF)	
Williams Syndrome Association (WSA)	
Wilson's Disease Association ————————————————————————————————————	
Zain Hansen M.P.S. Foundation ————————————————————————————————————	

### Table of Contents (cont'd)



### Table of Contents (cont'd)

15.	Muskoskeletal
Art	hritis Foundation/American Juvenile Arthritis Organization
	(AJAO)
Fre	eman- Sheldon Parent Support Group
	tional Scoliosis Foundation, Inc.
	eogenesis Imperfecta Foundation, Inc. (OIF)
	eogenesis Imperfecta-National Capital Area, Inc. (OI-NCA)
	get's Disease Foundation, Inc. (PDF)
	liosis Association, Inc.
	·
16.	Neurologic —————
Acc	eustic Neuroma Association
	heimer's Disease and Related Disorders Association, Inc.
	(ADRDA)
Am	erican Narcolepsy Association (A.N.A.)
	erican Parkinson Disease Association (APDA)
	ten's Disease Support and Research Association
	lepsy Foundation of America (EFA)
	edrich's Ataxia Group in America, Inc. (FAGA)
	reditary Disease Foundation
	ntington's Disease Society of America, Inc. (HDSA)
	ernational Joseph Diseases Foundation, Inc. (ISDF)
	ernational Rett Syndrome Association, Inc. (IRSA)
	tional Hydrocephalus Foundation (NHF)
	tional Neurofibromatosis Foundation, Inc.
	tional Parkinson Foundation, Inc. (NPF)
	tional Spasmodic Torticollis Association
	tional Tuberous Sclerosis Associatio, Inc. (NTSA)
	kinson's Disease Foundation, Inc. (PDF)
	kinson Educational Program (PEP) USA
	lex Sympathetic Dystrophy Syndrome Association (RDSA)
Spi	na Bifida Association of America (SBAA)
	rge-Weber Foundation
Tou	rette Syndrome Association, Inc. (TSA)
Tut	perous Sclerosis Association of American, Inc. (TSAA)
	•
17	Neuromuscular
1/.	IACH, OHIOSCHIAL
Am	yotrophic Lateral Sclerosis Association, Inc. (ALSA)
	ENUES - National Support Group for Arthrogryposis
	Multiplex Congenita
Ren	nigr. Essential Blepharospasm Research Foundation, Inc. (BEBRF)
CM	T (Charcot-Marie-Tooth) International, Inc.
	Stonia Medical Research Foundation (DMRF)
	nilies of S.M.A. (Spinal Muscular Atrophy)
	scular Dystrophy Association (N DA)
	asthenia Gravis Foundation Inc (MGF)



Myoclonus Families United
National Ataxia Foundation
National Multiple Sclerosis Society
18. Short Stature
Human Growth Foundation (HGF)
Little People of America, Inc. (LPA)
Parents of Dwarfed Children —
19. Skin Disorders
Dystrophic Epidermolysis Bullosa Research Association of America, Inc. (D.E.B.R.A.)
Foundation for Ichthyosis and Related Skin Types, Inc. (F.I.R.S.T.)
National Congenital Port Wine Stain Foundation
National Foundation for Ectodermal Dysplasias (NFED)
United Scleroderma Foundation, Inc. (ÚSF)
Xeroderma Pigmentosum Registry
20. Visual Disorders
American Foundation for the Blind, Inc. (AFB)
Association for Macular Diseases Inc.
Blind Children' Fund
National Association for Parents of the Visually Impaired, Inc. (NAPVI)
National Society to Prevent Blindness
Parents and Cataract Kids (PACK)
RP Foundation Fighting Blindness
Indexes
Subject Index
Title Index

### Table of Contents (cont'd)



A Guide to Selected National Genetic Voluntary Organizations is a directory of mutual support groups concerned with the medical and psychosocial impacts of genetic disorders and birth defects on affected individuals and families. Each of the organizations listed in this directory is dedicated to serving the ongoing emotional, practical, and financial needs of these populations.

By presenting descriptions of these groups, we hope to further public awareness of their existence and their representative disorders. All information has been obtained from an organizational spokesperson, either through mail questionnaires or telephone inquiries. The entries are arranged according to categories of disorders. An organizational index and a subject index are also included.

The efforts of each organization are greatly appreciated. We regret any inadvertent omissions. Notification of changes, additions, or deletions should be sent to the Publications Coordinator, The National Center for Education in Maternal and Child Health, 38th and R Streets, N.W., Washington, D.C. 20057.

### **FOREWORD**



Part One
General
11



Jayne Mackta, President

### **CONTACT PERSON (S):**

**Brett Emmerson** 

### **CHAPTERS/SATELLITES:**

None

**Alliance of Genetic** 

**Support Groups** 

20057 (202) 625-7853

38th and R Streets, N.W.

Washington, D.C.

### **PURPOSE:**

The Alliance of Genetic Support Groups is dedicated to fostering a partnership among consumers and professionals in order to represent the needs of families and individuals affected by genetic disorders. Activities include developing and disseminating information to enhance public and professional awareness; working to improve the availability and appropriateness of genetic services; making resources and referrals available; encouraging communication among support groups; and enhancing awareness of cross-disability similarities.

### **PUBLICATIONS:**

**Brochure** 

### **AUDIOVISUALS:**

None

### **NEWSLETTER:**

Quarterly

### March of Dimes Birth Defects Foundation

1275 Mamaroneck Avenue White Plains New York 10605 (914) 428-7100

### **EXECUTIVE DIRECTOR:**

Charles S. Massey, President

### CONTACT PERSON (S):

Natalie Paul and Mary Bayha

### **CHAPTERS/SATELLITES:**

150 chapters nationwide

### **PURPOSE:**

The March of Dimes Birth Defects Foundation works toward the prevention of birth defects through the support of research and the provision of medical services and education.

### **PUBLICATIONS:**

Contricte catalog available upon request

### **AUDIOVISUALS:**

Complete catalog available upon request

### **NEWSLETTER:**

• Genetics in Practice (Quarterly)



Dorothy Legarreta, Ph.D.

### **CONTACT PERSON (S):**

Dorothy Legarreta, Ph.D.

### CHAPTERS/SATELLITES:

Arizona, California, Colorado, Maine, Montana, Mississippi, New Jersey, New Mexico, Nevada, New York, Oregon, Utah, and Virginia

### **PURPOSE:**

The National Association of Radiation Survivors provides medical, legal, and mutual support to veterans and civilians exposed to ionizing radiation in the Nuclear Weapons Testing Program. The association supports research into late onset effects of exposure, including genetic defects. With 13 chapters nationwide, the association is very active in bringing the issue to light, appearing in documentaries, spearheading legal claims, and testifying before Congress. The association offers an extensive network of health and legal professionals, as well as a computer-based databank with statistics on every military exposure site.

### **PUBLICATIONS:**

None

### **AUDIOVISUALS:**

- NARS slide show
- Shadow of Death (photography show)

### **NEWSLETTER:**

Quarterly

National
Assocation of
Radiani
Survivors
(NARS)

78 El Camino Road Berkeley California 94705 (415) 658-6056, 652-4400, ext. 441



Part One / 15

### National Easter Seal Society

2023 West Ogden Avenue Chicago Illinois 60612 (312) 243-8400

### **EXECUTIVE DIRECTOR:**

John Garrison

### **CONTACT PERSON (S):**

Jan Bakker

### CHAPTERS/SATELLITES:

Over 820 state and local affiliates

### **PURPOSE:**

The National Easter Seal Society pioneered attempts to identify the needs of disabled people and to provide rehabilitation services. Direct services are provided to persons with disabilities and their families through more than 820 state and local affiliates, operating some 2000 facilities and programs across the country. The society also advocates, provides public health education, and funds both research into the causes of disabling conditions and rehabilitation services for disabled people.

### **PUBLICATIONS:**

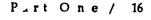
Complete catalog available upon request

### **AUDIOVISUALS:**

None

### **NEWSLETTER:**

• Communicator (Quarterly)





Joan Samsen

### **CONTACT PERSON (S):**

George Crohn

### **CHAPTERS/SATELLITES:**

None

### **PURPOSE:**

The National Foundation for Jewish Genetic Diseases supplies educational materials and conducts professional symposia.

### **PUBLICATIONS:**

• Fact Sheet: You Have a Right to Know...About Jewish Genetic Diseases

### **AUDIOVISUALS:**

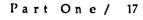
None

### **NEWSLETTER:**

None

National Foundation for Jewish Genetic Diseases, Inc.

250 Park Avenue Suite 1000 New York New York 10177 (212) 682-5550



### National Organization for Rare Disorders, Inc. (NORD)

P.O. Box 8923 New Fairfield Connecticut 06812 (800) 447-6673 (203) 746-6518

### **EXECUTIVE DIRECTOR:**

Abbey S. Meyers

### **CONTACT PERSON (S):**

Abbey S. Meyers

### **CHAPTERS/SATELLITES:**

None

### **PURPOSE:**

The National Organization for Rare Disorders is dedicated to the identification, control, and cure of rare disorders. To achieve these goals, NORD operates programs of education, service, and research.

### **PUBLICATIONS:**

**Brochure** 

### **AUDIOVISUALS:**

None

### **NEWSLETTER:**

• The Orphan Disease Update (Quarterly)

Part One / 18



Kathleen Bradley

### **CONTACT PERSON (S):**

Kathleen Bradley

### **CHAPTERS/SATELLITES:**

None

### **PURPOSE:**

The Sibling Information Network serves as a clearinghouse of information, ideas, projects, literature, and research regarding siblings and other issues related to the needs of families with disabled members. The network helps its membership through the central dissemination of materials and by establishing linkages among members with common interests.

### **PUBLICATIONS:**

Complete catalog available upon request

### **AUDIOVISUALS:**

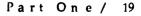
None

### **NEWSLETTER:**

Quarterly

### Sibling Information Network

University Affiliated
Program on
Developmental
Disabilities
University of Connecticut
249 Glenbrook Road
Box U-64
Storrs
Connecticut
06268
(203) 486-3783



## TASH: The Association for Persons with Severe Handicaps

7010 Roosevelt Way, N.E. Seattle Washington 98115 (206) 523-8446

### **EXECUTIVE DIRECTOR:**

Liz Lindley

### **CONTACT PERSON (S):**

Dian McKernan, Information Specialist

### **CHAPTERS/SATELLITES:**

Over 40 chapters

### **PURPOSE:**

The Association for Persons with Severe Handicaps is concerned with the issues of human dignity, education, and independence for individuals with physical handicaps and profound mental retardation. Members include parents, administrators, teachers, medical and legal personnel, researchers, speech pathologists, and occupational and physical therapists.

### **PUBLICATIONS:**

Complete catalog available upon request

### **AUDIOVISUALS:**

None

### **NEWSLETTER:**

Monthly



Part One / 20

1	
	Part Two
	Auditory
	21



Donna McCord Dickman, Ph.D.

### **CONTACT PERSON (S):**

Susan Coffman, Director of Professional Programs & Services

### CHAPTERS/SATELLITES:

Alabama, California, Connecticut, Florida, Indiana, Kentucky, Massachusetts, Michigan, Pennsylvania, Virginia, Washington, and Saskatchewan, Canada

### **PURPOSE:**

The Alexander Graham Bell Association for the Deaf helps hearing-impaired persons function independently in the hearing world. The association promotes universal rights and optimum opportunities, from infancy through adulthood, for individuals to learn, use, maintain, and process spoken language. The International Parents' Organization, a support group for parents of hearing-impaired children, has been established. Contact with this group can be made via the association at the above Washington address.

### **PUBLICATIONS:**

Catalog available upon request

### **AUDIOVISUALS:**

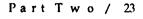
Catalog available upon request

### **NEWSLETTER:**

- Newsounds (Monthly)
- Our Kids Magazine (Quarterly)
- The Volta Review

Alexander
Graham Bell
Association for
the Deaf
(AGBAD)

3417 Volta Place, N.W. Washington, D.C. 20007 (202) 337-5220 (Voice and TTY)





### American Society for Deaf Children (ASDC)

814 Thayer Avenue Silver Spring Maryland 20910 (301) 535-5400 (Voice and TDD)

### **EXECUTIVE DIRECTOR:**

Roberta Thomas

### **CONTACT PERSON (S):**

Millie Maisel

### **CHAPTERS/SATELLITES:**

96 throughout the United States

### **PURPOSE:**

The American Society for Deaf Children provides information and support to parents and families with deaf or hearing impaired children. Services are also available to the general public. The society offers assistance with educational or legal problems related to the rearing of a hearing-impaired child.

### **PUBLICATIONS:**

Catalog available upon request

### **AUDIOVISUALS:**

None

### **NEWSLETTER:**

• The Endeavor (Bimonthly)

EBIC.

Part Three
Cancer
25

William Tipping

### **CONTACT PERSON (S):**

Ruth Donnelly Corcoran

### **CHAPTERS/SATELLITES:**

58 divisons

American Cancer Society, Inc.

3340 Peachtree F N.E. Atlanta Georgia 30026 (404) 320-3333

### **PURPOSE:**

The American Cancer Society's long-range objective is to eliminate cancer. The immediate goal is to save more lives and to diminish suffering from cancer. The society provides educational materials and information for the patient, family, and professional.

### **PUBLICATIONS:**

Catalog available upon request

### **AUDIOVISUALS:**

Catalog available upon request

### **NEWSLETTER:**

• Cancer News (Triannually)



### Candlelighters Childhood Cancer Foundation

1901 Pennsylvania Avenue, N.W. Suite 1011 Washington, D.C. 20006 (202) 659-5136

### **EXECUTIVE DIRECTOR:**

Julie Sullivan

### **CONTACT PERSON (S):**

Julie Sullivan

### **CHAPTERS/SATELLITFS:**

250 groups or contacts throughout the world

### **PURPOSE:**

Candlelighters Childhood Cancer Foundation is an international network of parents of children/adolescents with cancer. The foundation identifies patient and family needs so that medical and social systems can respond adequately; eases frustrations and fears through sharing of feelings and experiences; exchanges information on research, treatment, medical institutions, and community resources; breaks down the social isolation of families; and provides guidance in coping with childhood cancer's effect on the child, parents, and siblings.

### **PUBLICATIONS:**

Catalog available upon request

### **AUDIOVISUALS:**

None

### **NEWSLETTER:**

- Quarterly Newsletter
- Youth Newsletter (Quarterly)



Zane Cohen, M.D.

### **CONTACT PERSON (S):**

Teresa Berk, Clinical Coordinator

### **CHAPTERS/SATELLITES:**

Multiple registries around the world

### **PURPOSE:**

The Familial Polyposis Registry provides information and assistance to all patients and at-risk family members about a premalignant genetic disease, familiar adenomatous polyposis, through a national family study center in Canada. The registry also seeks to ascertain families with a diagnosis of juvenile polyposis and Peutz-Jeghers syndrome.

### **PUBLICATIONS:**

- Familial Polyposis: A Guide for Patients and their Families
- The Pelvic Pouch Procedure
- Ileostomy Surgery: What Does It Mean For Me?

### **AUDIOVISUALS:**

• The Pelvic Pouch Procedure

### **NEWSLETTER:**

• GI Polyposis & Related Conditions (Quarterly)

Familial Polyposis Registry

Toronto General Hospital 200 Elizabeth Street Eaton Building 10-315 Toronto Ontario MFG 2C4 Canada (416) 595-3934



### G.I. Polyposis and Hereditary Colon Cancer Registry

The Moore Clinic
Johns Hopkins Hospital
600 North Wolfe Street
Baltimore
Maryland
21205
(301) 955-4040 or
(301) 955-3875

### **EXECUTIVE DIRECTOR:**

Anne Krush, Coordinator

### **CONTACT PERSON (S):**

Anne Krush and Susan Booker

### CHAPTERS/SATELLITES:

Additional registries in Georgia, Illinois, Minnesota, Nebraska, New York (3), Ohio, Pennsylvania, Texas, Utah (2), Washington, Australia (2), Canada, Denmark, England, Finland, Holland, Italy, Japan, Mexico (2), Norway, Poland, Spain, Sweden.

### **PURPOSE:**

A network of C.I. Polyposis and hereditary colon cancer registries serves to link kindreds in all parts of the United States. Branches of a large kindred may therefore be included in one o. 'everal registries. Each registry includes physicians, a coordinator, and other para-medical professional persons who are dedicated to finding families with the heritable condition alerting them to risks, communicating with their physicians, and, through education, helping families to a better understanding of the physical and emotional problems that may result from a heritable diagnosis.

### **PUBLICATIONS:**

- Family Studies in Genetic Disorders by A.J. Krush and K.A. Evans
- · Ostomy Quarterly

### **AUDIOVISUALS:**

None

### **NEWSLETTER:**

• G.I. Polyposis & Related Conditions (Quarterly)



Dolores Boone, Administrator

### **CONTACT PERSON (S):**

Dolores Boone, Administration

### CHAPTERS/SATELLITES:

Planning to have a coordinator in each state in the United States and in each province in Canada

**PURPOSE:** 

Intestinal Multiple Polyposis and Colorectal Cancer is a support group for persons and families with one of the hereditary gastrointestinal polyposes or hereditary colon cancer. Its goals are to increase public awareness and education, to enlist volunteers and encourage membership in IMPACC, to encourage research, and to seek ongoing funding.

### **PUBLICATIONS:**

- Hereditary Intestinal Polyps: A Guide For Patients & Families
- Family Studies in Genetic Disorders by A.J. Krush and K.A. Evans
- · Ostomy Quarterly

### **AUDIOVISUALS:**

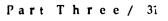
 Two videotaped segments concerning the eye/jaw lesions associated with Gardner syndrome

### **NEWSLETTER:**

• G.I. Polyposis & Related Conditions (Quarterly)

Intestinal
Multiple
Polyposis
and
Colorectal
Cancer
(IMPACC)

1006-1001 Brinker Drive Hagerstown Maryland 21740 (301) 791-7526





### Leukemia Society of America, Inc.

733 Third Avenue New York New York 10017 (212) 573-8484

### **EXECUTIVE DIRECTOR:**

Peter N. Cakridas

### **CONTACT PERSON (S):**

Mariana Jordan

### **CHAPTERS/SATELLITES:**

57 chapters in 31 states and in the District of Columbia

### **PURPOSE:**

The Leukemia Society of America provides financial aid to patients and sponsors investigators in studies directed against leukemia, lymphomas, and multiple myeloma. In addition, a national program of public and professional education is conducted.

### **PUBLICATIONS:**

Catalog available upon request

### **AUDIOVISUALS:**

Catalog available upon request

### **NEWSLETTER:**

• Society News (Bimonthly)



Harvey Newman

### **CONTACT PERSON (S):**

Diane Blum

### **CHAPTERS/SATELLITES:**

Satellite offices in New Jersey and New York

### National Cancer Care Foundation (NCCF)

1180 Avenues of the Americas New York New York 10036 (212) 221-3300

### **PURPOSE:**

The National Cancer Care Foundation helps cancer patients and their families cope with the impact of cancer by providing a program of psychological, social, and educational services.

### **PUBLICATIONS:**

Catalog available upon request

### **AUDIOVISUALS:**

None

### **NEWSLETTER:**

None



Part Four
Cardiovascular

**Dudley Hafner** 

### **CONTACT PERSON (S):**

Kathryn Taubert, Ph.D.

### **CHAPTERS/SATELLITES:**

None

### PURPOSE:

The purpose of the Council on Cardiovascular Disease is to reduce the incidence of mortality and disability among children with cardiovascular disease.

### **PUBLICATIONS:**

- Safeguarding Your Health During Pregnancy
- Innocent Heart Murmurs
- If Your Child Has A Congenital Heart Defect
- Your Child and Rheumatic Fever
- Feeding Infants With Congenital Heart Disease
- Abnormalities of Heart Rhythm A Guide for Parents

### **AUDIOVISUALS:**

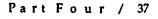
None

### **NEWSLETTER:**

None

Council on Cardiovascular Disease in the Young

American Heart
Association National
Center
7320 Greenville Avenue
Dallas
Texas
75231
(214) 373-6300





1	
	Part Five
	Chromosomal
	39

Fredda Stimell

### **CONTACT PERSON (S):**

Fredda Stimell

### CHAPTERS/SATELLITES:

None

2616 Martin Avenue Bellmore Long Island New York

11710 (516) 221-4700

Association for Children with

Down Syndrome,

Inc. (ACDS)

### **PURPOSE:**

The goals of the Association for Children with Down syndrome are to provide to children with Down syndrome and their families a preschool environment that will aid children's abilities to participate in mainstream schooling and community activities; to provide continued resources to the older child with Down syndrome through social and recreational programs; to advocate and promote parental advocacy for persons with Down syndrome; to educate the community through a newsletter and other publications, workshops, and conferences; and to conduct ongoing research.

### **PUBLICATIONS:**

Catalog available upon request

### **AUDIOVISUALS:**

Catalog available upon request

### **NEWSLETTER:**

• Spot Lite (Bimonthly)



Part Five / 41

### 5p-Society

11609 Oakmont Overland Park Kansas 66210 (913) 469-8900

### **EXECUTIVE DIRECTOR:**

Kent W. Nicholls

### **CONTACT PERSON (S):**

Kent W. Nicholls

### **CHAPTERS/SATELLITES:**

None

### PURPOSE:

The 5p- Society is a support organization for families who have a child with 5p- syndrome (also known as Cri-du-Chat and Cat Cry syndrome). The society is dedicated to facilitating the flow of information between families and interested medical professionals.

### **PUBLICATIONS:**

• North American 5p- Syndrome Listing

### **AUDIOVISUALS:**

None

### **NEWSLETTER:**

• 5p- Newsletter (Quarterly)

Part Five / 42



Tad Jackson

### **CONTACT PERSON (S):**

Tad Jackson

### **CHAPTERS/SATELLITES:**

Pursues active involvement in the organization of parent support groups across the United States.

### **PURPOSE:**

The Fragile X Foundation educates professionals, parents, and the public regarding diagnosis and treatment of the fragile X syndrome and other forms of X-linked mental retardation. The foundation promotes research pertaining to X-linked mental retardation in the areas of biochemistry, genetics, and clinical applications.

### **PUBLICATIONS:**

• Fragile X Foundation (brochure)

### **AUDIOVISUALS:**

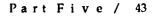
None

### **NEWSLETTER:**

Quarterly

Fragile X
Foundation

P.O. Box 300233 Denver Colorado 80203 (800) 835-2246, Ext. 58



### Fragile X Support, Inc.

1380 Huntington Drive Mundelein Illinois 60060 (312) 680-3317

#### **EXECUTIVE DIRECTOR:**

David Franklin

#### **CONTACT PERSON (S):**

David and Jackie Franklin

#### **CHAPTERS/SATELLITES:**

None

#### **PURPOSE:**

Fragile X Support informs educators and the general public about fragile X syndrome. It assists parents whenever possible by helping them enhance the lives of children with this syndrome.

#### **PUBLICATIONS:**

• Fragile X Syndrome (brochure)

#### **AUDIOVISUALS:**

None

#### **NEWSLETTER:**

None

Part Five / 44



Sheila Hebein

#### **CONTACT PERSON (S):**

Sheila Hebein

#### **CHAPTERS/SATELLITES:**

Encourages the formation of community support groups

## National Association for Down Syndrome (NADS)

P.O. Box 4542 Oak Brook Illinois 60521 (312) 325-9112

#### **PURPOSE:**

The National Association for Down Syndrome promotes the growth and development of persons with Down syndrome; disseminates information; provides family support; provides educational programs and seminars for parents and professionals; develops and sustains local parent groups; and encourages research into Down syndrome.

#### **PUBLICATIONS:**

- Parent Support Program (brochure)
- NADS (brochure)

#### **AUDIOVISUALS:**

- Down's Syndrome: New Expectations
- You Don't Outgrow Down's Syndrome: Counseling Parents

#### **NEWSLETTER:**

• NADS Newsletter (Bimonthly)



## National Down Syndrome Congress (NDSC)

1800 Dempster Street Park Ridge Illinois 60068-1146 (800) 232-NDSC (Outside Illinois) (312) 823-7550

#### **EXECUTIVE DIRECTOR:**

Diane M. Crutcher

#### **CONTACT PERSON (S):**

Diane M. Crutcher

#### CHAPTERS/SATELLITES:

More than 500 chapters in the United States and in many foreign countries

#### **PURPOSE:**

The National Down Syndrome Congress serves as a clearing-house for all aspects of Down syndrome and makes referrals to local chapters or resource people routinely. The NDSC chapters provide local parent support and enhance public awareness regarding all facets of Down syndrome including the enhancement of services.

#### **PUBLICATIONS:**

- Down Syndrome (pamphlet available in English and Spanish)
- Facts About Down Syndrome
- Bibliography of materials relating to Down syndrome

#### **AUDIOVISUALS:**

None

#### **NEWSLETTER:**

• Down Syndrome News (Ten issues a year)



Part Five / 46

Donna M. Rosenthal

#### **CONTACT PERSON (S):**

Donna M. Rosenthal

#### **CHAPTERS/SATELLITES:**

None

#### **PURPOSE:**

The National Down Syndrome Society was established to promote public awareness and education about Down syndrome, to support research related to this genetic disorder, and to provide services for families and individuals affected by Down syndrome.

#### **PUBLICATIONS:**

- Bibliography on Down syndrome
- Fact Sheet: Down Syndrome
- Questions and Answers about Down Syndrome
- The Connection Between Down Syndrome and Alzheimer's Disease
- This Baby Needs You Even More

#### **AUDIOVISUALS:**

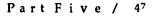
• Gifts of Love

#### **NEWSLETTER:**

• National Down Syndrome Society Update (Biannually)

## National Down Syndrome Society (NDSS)

141 Fifth Avenue Suite 75 New York New York 10010 (800) 221-4602 (212) 460-9330





#### Prader-Willi Syndrome Association (PWSA)

6490 Excelsior Boulevard E-102 St. Louis Park Minnesota (612) 926-1947

#### **EXECUTIVE DIRECTOR:**

Marge A. Wett

#### **CONTACT PERSON (S):**

Marge A. Wett

#### **CHAPTERS/SATELLITES:**

Alabama, Arizona, Connecticut, Colorado, Georgia, Illinois, Indiana, Kansas, Kentucky, Massachusetts, Michigan, Missouri, Montana, New York, Ohio, Pennsylvania, South Carolina, Texas, Utah, Virginia; Australia, Canada (3), Denmark, England, The Netherlands, Norway, and West Australia

#### **PURPOSE:**

The Prader-Willi Syndrome Association is a parent and professional support group organized as a source of support and education for anyone dealing with Prader-Willi syndrome.

#### **PUBLICATION'S:**

Catalog available upon request

#### **AUDIOVISUALS:**

- PWSA Audio/visual Presentation (60 slides and cassette tape)
- Oakwood Residence: A Home for People with PWS
- Television shown interviews

#### **NEWSLETTER:**



Part Five/

• The Gathered View (Bimonthly)

Jonathan C. Storr

#### CONTAC PERSON (S):

Jonathan C. Storr

#### CHAPTERS/SATELLITES:

None

#### **PURPOSE:**

The Support Group for Monosomy 9P links families with children with monosomy 9p, provides non-clinical, up-to-date information on the developmental aspects via distribution of the histories and stories of the group's children; facilitates the gathering of published clinical reports; and promotes research on the 9th chromosome.

#### **PUBLICATIONS:**

- Informatio ten by parents about their child with monosomy 9p is provided to other parents and those caring for a child or adult with the condition.
- Approximately 20 reports from medical journals are distributed to anyone requesting them.
- A roster of families is maintained.

#### **AUDIOVISUALS:**

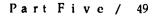
None

#### **NEWSLETTER:**

None

### Support Group for Monosomy 9P

43304 Kipton Nickle Plate Road La Grange Ohio 44050 (216) 775-4255





Support
Organization for
Trisomy 18, 13
And Other
Related
Disorders
(S.O.F.T. 18/13)

5030 Cole Pocatello Idaho 83202 (208) 237-8782

#### **EXECUTIVE DIRECTOR:**

Pat Farmer, President

#### **CONTACT PERSON (S):**

Pat Farmer

#### **CHAPTERS/SATELLITES:**

Arizona, California (2), Florida (2), Idaho. Illinois, Massachusetts, Michigan, New York, North Carolina, Ohio, Oklahoma, Pennsylvania, Texas, Utah, Wisconsin, and Ontario, Canada

#### **PURPOSE:**

The Support Organization for Trisomy 18, 13 and Other Related Disorders supports and educates families and persons involved in the care of a child with trisomy 18 or 13.

#### **PUBLICATIONS:**

• Trisomy 18: A Book for Families

#### **AUDIOVISUALS:**

None

#### **NEWSLETTER:**

• S.O.F.T. Touch (Bimonthly)

Part Five / 50



Sandi Hofbauer

#### **CONTACT PERSON (S):**

Sandi Hofbauer

#### **CHAPTERS/SATELLITES:**

California, Georgia, Idaho, Kentucky, Maryland, Massachusetts, New Jersey, Pennsylvania, Virginia, and Washington. Also Vancouver, Edmonton, Halifax, Montreal, and Toronto in Canada.

#### **PURPOSE:**

The Turner's Syndrome Society provides services to individuals with Turner syndrome and the families. The society also provides medical information in the hope of reducing the isolation and dispelling the myths surrounding this condition.

#### **PUBLICATIONS:**

• The X's & O's of Turner Syndrome

#### **AUDIOVISUALS:**

• Turner Syndrome

#### **NEWSLETTER:**

Quarterly

### Turner's Syndrome Society

York University
Administrative Studies
Building #006
4700 Keele Street
Downsview
Ontario M3J 1P3
Canada
(416) 736-5025





Part Six	
Connective Tissue	

Nancy A. Rogowski

#### **CONTACT PERSON (S):**

Nancy A. Rogowski

#### **CHAPTERS/SATELLITES:**

Arkansas, California, Illinois, Indiana, and Virginia

## Ehlers-Danlos National Foundation (EDNF)

P.O. Box 1212 Southgate Michigan 48195 (313) 282-0180

#### **PURPOSE:**

The Ehlers-Danlos National Foundation provides emotional support, knowledge, and understanding to those with Ehlers-Danlos syndrome and their families. The foundation also serves as an informational link with the medical community.

#### **PUBLICATIONS:**

• EDNF Fact Sheet

#### **AUDIOVISUALS:**

Plans are being made to produce instructional audiovisuals for members and for the medical community.

#### **NEWSLETTER:**

• Loose Connections (Quarterly)



Part Six / 55

#### National Marfan Foundation (NMF)

382 Main Street Port Washington New York 11050 (516) 838-8712

#### **EXECUTIVE DIRECTOR:**

Priscilla Ciccariello

#### **CONTACT PERSON (S):**

Priscilla Ciccariello

#### CHAPTERS/SATELLITES:

California (4), Florida (2), Indiana, Michigan, Minnesota, Ohio, and Texas

#### **PURPOSE:**

The National Marfan Foundation provides accurate and timely information about Marfan syndrome to patients, family members, and physicians; provides means for patients and relatives to share experiences, support one another, and improve their medical care; and supports and fosters research.

#### **PUBLICATIONS:**

- The Marfan Syndrome (2nd ed.) by Drs. Reed E. Pyeritz and Julia Conant
- How John Was Unique by Joe and Nancy Hathaway (Children's picture book)
- Various reprints of newspaper, magazine, and medical journal articles

#### **AUDIOVISUALS:**

- Do You Know Marfan?
- People Are Talking
- 1984 & 1986 National Conference videotapes

#### **NEWSLETTER:**



Part Six /

• Connective Issues (Quarterly)

Part Seven
Craniofacial
 57



Nancy C. Smythe

#### **CONTACT PERSON (S):**

Nancy C. Smythe

#### CHAPTERS/SATELLITES:

None

American Cleft Palate Association (ACPA)/ The Cleft Palate Foundation

1218 Grandview Avenue University of Pittsburgh Pittsburgh Pennsylvania 15211 (800) 24-CLEFT (412) 481-1376

#### **PURPOSE:**

The American Cleft Palate Association/The Cleft Palate Foundation educates patients, their families, and the general public about clefts and sources of treatment and support.

#### **PUBLICATIONS:**

Catalog available upon request

#### **AUDIOVISUALS:**

Catalog available upon request

#### **NEWSLETTER:**

• ACPA Newsletter (Triannually)

Part Seven / 59



# FACES The National Association for the Craniofacially Handicapped

P.O. Box 11082 Chattanooga Tennessee 37401 (615) 266-1632

#### **EXECUTIVE DIRECTOR:**

Phyllis S. Casavant, Ed.D.

#### **CONTACT PERSON (S):**

Phyllis S. Casavant, Ed.D.

#### **CHAPTERS/SATELLITES:**

None

#### **PURPOSE:**

The National Association for the Craniofacially Handicapped assists persons with severe craniofacial deformities with travel expenses to comprehensive medical centers, provides information and referrals, and serves as the national voice for the craniofacially handicapped.

#### **PUBLICATIONS:**

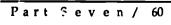
- · A Face for Me
- Brochure
- Craniofacial Deformity
- Craniofacia! Surgery

#### **AUDIOVISUALS:**

- MASK videotape
- Slide presentation for fund raising

#### **NEWSLET IER:**

Biannually





Robert E. Bochat

#### **CONTACT PERSON (S):**

Robert E. Bochat

#### CHAPTERS/SATELLITES:

None

#### **PURPOSE:**

The National Foundation for Facial Reconstruction supports facilities for the treatment and rehabilitation of individuals who require constructive surgical care; assists in the training and education of personnel engaged in reconstructive plastic surgery; initiates, stimulates, and encourages research in this field; and conducts public education campaigns which promote awareness of the problems of facial disfigurement and of the treatment methods available.

#### **PUBLICATIONS:**

• Out of the Shadows...into a Bright New Future (brochure)

#### **AUDIOVISUALS:**

• Face Value (Film and Video)

#### **NEWSLETTER:**

• SFD News

National
Foundation for
Facial
Reconstruction

P.O. Box 426 Quincy Massachusetts 02269 (617) 479-2463





Prescription Parents, Inc.

P.O. Box 426 Quincy Massachusetts 02269 (617) 479-2463

#### **EXECUTIVE DIRECTOR:**

Laura Cohen

#### **CONTACT PERSON (S):**

Laura Cohen

#### **CHAPTERS/SATELLITES:**

None

#### **PURPOSE:**

Prescription Parents directs its services to parents of children born with cleft lip and/or palate and to affected adults.

#### **PUBLICATIONS:**

- Caring for Your Newborn
- Hearing and Behavior in Children Born with Cleft Palate

#### **AUDIOVISUALS:**

• Growing Up: Young Adults with Parents (Audiotape)

#### **NEWSLETTER:**

Biannually



	H
	Part Eight
	Developmental Digabilities
53	63

Jean Petersen

#### **CONTACT PERSON (S):**

Jean Petersen

#### **CHAPTERS/SATELLITES:**

800 local chapters, with affiliates in every state.

#### **PURPOSE:**

The Association for Children and Adults with Learning Disabilities is an international organization of parents, professionals, and persons with specific learning disabilities. The association works for the accurate identification and remediation of persons with learning disabilities, and the sharing of innovative ideas and teaching techniques. The association also disseminates data, evaluates programs, promotes research, and works to make society aware of the problems of persons with learning disabilities.

#### **PUBLICATIONS:**

Catalog available upon request

#### **AUDIOVISUALS:**

Catalog available upon request

#### **NEWSLETTER:**

• ACLD Newsbriefs (Five issues a year)

Association for Children and Adults with Learning Disabilities, Inc. (ACLD)

4156 Library Road Pittsburgh Pennsylvania 15234 (412) 341-1515

Part Eight/ 65

#### Association for Retarded Citizens of the United States (ARC)

2501 Avenue J Arlington Texas 76006 (817) 640-0204

#### **EXECUTIVE DIRECTOR:**

Alan Abeson, Ed.D.

#### **CONTACT PERSON (S):**

Sharon Davis, Ph.D., Director of Research and Program Services

#### CMAPTERS/SATELLITES:

1300 state and local chapters

#### PURPOSE.

The Association for Retarded Citizens of the United States is the largest volunteer organization solely devoted to improving the welrare of all children and adults with mental retardation and their families. The association also provides service to parents and other individuals, organizations, and communities for jointly meeting the needs of the mentally retarded. The ARC's constitution defines its mission as the improvement of the quality of life of all people and the mental retardation, the prevention of this handicapping condition, and the search for cures.

#### **PUBLICATIONS:**

Catalog available upon request

#### **AUDIOVISUALS:**

Catalog available upon request

#### **NEWSLETTER:**

• The ARC (Bimonthly)



**David Lorms** 

#### CONTACT PERSON (S):

Ken Laureys, Director of Information and Referral

#### CHAPTERS/SATELLITES:

200 local chapters throughout the United States

#### Autism Society of America (ASA)

1234 Massachusetts Avenue, N.W. Suite 1017 Washington, D.C. 20005-4599 (202) 783-0125

#### **PURPOSE:**

The Autism Society of America provides emotional support for the parents and families of individuals with autism and promotes advocacy and education through various publications.

#### **PUBLICATIONS:**

Catalog available upon request

#### **AUDIOVISUALS:**

Mone

#### **NEWSLETTER:**

• Advocate (Quarterly)

Part Eight/ 67



Center for Hyperactive Child Information, Inc. (CHCI)

P.O. Box 66272 Washington, D.C. 20035-6272 (703) 920-7495 **EXECUTIVE DIRECTOR:** 

John C. Malloy

**CONTACT PERSON (S):** 

John C. Malloy

CHAPTERS/SATELLITES:

None

**PURPOSE:** 

The Center for Hyperactive Child Information provides information on the diagnosis and medical and educational requirements of hyperactive children to parents, teachers, and others.

#### **PUBLICATIONS:**

- Helping the Hyperactive Chila (National Institute of Imental Health)
- CHCI brochure

**AUDIOVISUALS:** 

None

**NEWSLETTER:** 

None

Part Eight/ 68



Julie A. Mairano

#### **CONTACT PERSON (S):**

Julie A. Mairano

#### **CHAPTERS/SATELLITES:**

None

#### **PURPOSE:**

The Cornelia de Lange Syndrome Foundation seeks to ensure early and accurate diagnosis of Cornelia de Lange syndrome and to enable parents, friends, and health professionals to make responsible decisions about the affected child's present and future.

#### **PUBLICATIONS:**

- Cornelia de Lange Syndrome: A Book for Families
- Facts About Cornelia de Lange Syndrome
- · CdLS Directory

#### **AUDIOVISUALS:**

• Unto Us This Child

#### **NEWSLETTER:**

• Reaching Out (Bimonthly)

Cornelia de Lange Syndrome (CdLS) Foundation, Inc.

60 Dyer Avenue Collinsville Connecticut 0€'922 (800) 223-8355 (Outside Connecticut) (203) 693-0159



#### Laurence-Moon-Biedl Syndrome (LMBS) Support Network

122 Rolling Road Lexington Park Maryland 20653 (301) £63-5658

#### **EXECUTIVE DIRECTOR:**

Barbara Mielcarek

#### **CONTACT PERSON (S):**

Barbara Mielcarek

#### **CHAPTERS/SATELLITES:**

None

#### **PURPOSE:**

The LMBS Network provides information and support to individuals and families affected by LMBS (also referred to as Bardet-Biedl syndrome); increases public and professional awareness of LMBS; and helps foster research into the cause, detection, diagnosis, and treatment of LBMS.

#### **PUBLICATIONS:**

- Brochure describing LMBS and the LMBS Network
- Bibliography of articles written about LMBS (1960 to the present)

#### **AUDIOVISUALS:**

None

#### **NEWSLETTER:**

• LMBS Network News (Quarterly)

Part Eight/70



Anne L. O'Flanagan

#### CONTACT PERSON (S):

Anne L. O'Flanagan

#### **CHAPTERS/SATELLITES:**

California (6), Colorado, the District of Columbia, Florida, Hawaii, Illinois, Indiana, Iowa, Maryland, Michigan, Nebraska, New Jersey, New Mexico, New York (3), Nevada, North Carolina, Ohio (2), Oregon, Pennsylvania, Rhode Island, South Carolina, Texas (3), Virginia, Washington, Wisconsin (2), Bermuda, and Canada

#### **PURPOSE:**

The Orton Dyslexia Society is concerned with specific language difficulty or developmental dyslexia. The society promotes research, shares knowledge, and encourages appropriate teaching.

#### **PUBLICATIONS:**

Catalog available upon request

#### **AUDIOVISUALS:**

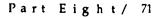
None

#### NEWSLETTER.

• Perspectives on Dyslexia (Quarterly)

Orton Dyslexia Society (ODS)

724 York Road Baltimore Maryland 21204 (301) 296-0232





#### Progeria International Registry

New York State Institute for Basic Research Department of Human Genetics 1050 Forest Hill Road Staten Island New York 10314 (718) 494-5230

#### **EXECUTIVE DIRECTOR:**

W. Ted Brown, M.D., Ph.D.

#### **CONTACT PERSON (S):**

W. Ted Brown, M.D., Ph.D.

#### **CHAPTERS/SATELLITES:**

None

#### **PURPOSE:**

The Progeria International Registry attempts to identify all persons affected with progeria. Information, counseling, and mutual support are then made available to patients and their families. Statistical analyses on these data also serve to further research.

#### **PUBLICATIONS:**

Fact sheet

#### **AUDIOVISUALS:**

None

#### **NEWSLETTER:**

Quarterly



Lorrie and Garry Baxter

#### **CONTACT PERSON (S):**

Lorrie and Garry Baxter

#### **CHAPTERS/SATELLITES:**

None

#### **PURPOSE:**

The Rubinstein-Taybi Syndrome Parent Group promotes contact among parents who have children with Rubinstein-Taybi syndrome.

#### **PUBLICATIONS:**

None

#### **AUDIOVISUALS:**

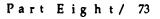
None

#### NEWSLETTER:

Periodic newsletter about families in the group and group activities.

Rubinstein-Taybi Syndrome (RTS) Parent Group

> 414 East Kansas Smith Center Kansis 66967 (913) 282-6237





#### **Share and Care**

1294 "S" Street North Valley Stream New York 11580 (516) 825-2284 **EXECUTIVE DIRECTOR:** 

Pat Cahill

CONTACT PERSON (S):

Pat Cahill

CHAPTERS/SATELLITES:

None

**PURPOSE:** 

Share and Care supports families of children with Cockayne syndrome.

**PUBLICATIONS:** 

None

**AUDIOVISUALS:** 

None

**NEWSLETTER:** 

Monthly

Part Eight/74



Allin Proudfoot

#### **CONTACT PERSON (S):**

Allin Proudfoot

#### **CHAPTERS/SATELLITES:**

Approximately 200 State and local affiliates in the United States

#### **PURPOSE:**

The United Cerebral Palsy Associations serve, support, and advocate for persons with cerebral palsy and their families.

#### **PUBLICATIONS:**

Catalog available upon request

#### **AUDIOVISUALS:**

Catalog available upon request

#### **NEWSLETTER:**

Catalog available upon request

United Cerebral
Palsy
Associations, Inc.
(UCPA)/UCP
Research and
Educational
Foundation

66 East 34th Street New York New York 10016 (800) USA-1UCP (212) 481-6300

Part Nine	
Gastrointestinal	



Anita Garrow

#### **CONTACT PERSON (S):**

Anita Garrow

#### **CHAPTERS/SATELLITES:**

None

### American Celiac Society

45 Gifford Avenue Jersey City New Jersey 07304 (201) 432-1207

#### **PURPOSE:**

The American Celiac Society provides educated and informational materials on gluten-free diets to patients, physicians, nutritionists, and others. The society responds to information requests and provides referrals to a gluten intolerance group.

#### **PUBLICATIONS:**

Catalog available upon request

#### **AUDIOVISUALS:**

None

#### **NEWSLETTER:**

None

Part Nine/79



#### American Liver Foundation (ALF)

998 Pompton Avenue Cedar Grove New Jersey 07009 (201) 857-2626

#### **EXECUTIVE DIRECTOR:**

Thelma King Thiel, President

#### **CONTACT PERSON (S):**

Fran Weiss, Public Relations Director

#### **CHAPTERS/SATELLITES:**

Arizona, California (3), Connecticut, the District of Columbia, Georgia, Illinois (2), Massachusetts, Michigan, New York (4), Ohio, Oklahoma, Pennsylvania, Tennessee, Texas (2), Washington, and Wisconsin

#### **PURPOSE:**

The American Liver Foundation is dedicated to fighting the more than 100 liver diseases by promoting research, education, and patient self-help groups.

#### **PUBLICATIONS:**

Catalog available upon request

#### **AUDIOVISUALS:**

- The Liver and Its Diseases: The Knowledge Crisis (slide show)
- You Can Make A Difference (videotape)

#### **NEWSLETTER:**

• Progress (Quarterly)



Part Nine / 80

None

#### **CONTACT PERSON (S):**

Tracey Mohns

#### CHAPTERS/SATELLITES:

Chapters in 16 states and 40 resource units, with information provided upon request

#### **PURPOSE:**

The Celiac Sprue Association offers information and referral services to patients with celiac sprue, their families, and health care professionals.

#### **PUBLICATIONS:**

- Celiac Sprue
- On The Celiac Condition

#### **AUDIOVISUALS:**

- A Basic Primer On Celiac Sprue
- Celiac Sprue in Adults & Children (slides)

#### **NEWSLETTER:**

• Lifeline (Quarterly)

Celiac Sprue Association/ United States of America, Inc. (CSA/USA)

2313 Rocklyn Drive Suite 1 Des Moines Iowa 50322 (515) 270-9689



## Children's Liver Foundation, Inc. (CLF)

76 South Orange Avenue Suite 202 South Orange New Jersey 07079 (201) 761-1111

#### **EXECUTIVE DIRECTOR:**

Maxine Turon, President

#### **CONTACT PERSON (S):**

Maxine Turon

#### **CHAPTERS/SATELLITES:**

Alabama, California (3), Connecticut, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maryland, Massachusetts, Michigan, New York, Ohio, Virginia, and Wisconsin

#### **PURPOSE:**

The Children's Liver Foundation provides family support, education, and advocacy for children with liver disease and their families, and it promotes funding of research bybindividual contacts referrals publications, media events, conferences, medical symposia, and fund development.

#### **PUBLICATIONS:**

Catalog available upon request

#### **AUDIOVISUALS:**

Catalog avai' ble upon request

#### **NEWSLETTER:**

• CLF Lifeline (Quarterly)



Part Nine / 82

Elaine I. Hartsook, Ph.D., R.D

#### **CONTACT PERSON (S):**

Elaine I. Hartsook, Ph.D., k.D.

#### CHAPTERS/SATELLITES:

Support groups and affiliates throughout the United States

#### Gluten Intolerance Group of North America (GIG)

P.O. Box 23055 Seattle Washington 98102-0353 (206) 325-6980

#### **PURPOSE:**

The Gluten Intolerance Group of North America offers assistance to persons with celiac sprue and/or dermatitis herpetiformis, their families, and health care professionals. Services include counseling, referrals, and a variety of publications and videotapes.

#### **PUBLICATIONS:**

- Diet instruction
- Fact sheet on celiac sprue
- Gluten-free bread recipes
- GIG cookbook
- Introductory brochure

#### **AUDIOVISUALS:**

Catalog available upon request

#### **NEWSLETTER:**

• GIG Newsletter (Quarterly)



# National Foundation for Ileitis And Colitis, Inc. (NFIC)

44 Park Avenue New York New York 10016-7374 (212) 685-3440

#### **EXECUTIVE DIRECTOR:**

George Theobald, Jr.

#### **CONTACT PERSON (S):**

Terry Jennings, Director of Communications

#### **CHAPTERS/SATELLITES:**

Chapters throughout the United States

#### **PURPOSE:**

The National Foundation for Ileiti3 and Colitis is committed to a nationwide coordinated research and education program aimed at conquering ileitis and colitis.

#### **FUBLICATIONS:**

Catalog available upon request

#### AUT OVISUALS:

Catalog available upon request

#### **NEWSLETTER:**

- IBD News (Quarterly)
- National Newsletter (Quarterly)

Part Nine/84



	Part Ten
	Hematologic
72	85

Teresa G. Piropato

#### **CONTACT PERSON (S):**

Teresa G. Piropato

#### **CHAPTERS/SATELLITES:**

California, Florida, Illinois, Massachusetts, New Jersey (2), New York (9), Pennsylvania, and Tennessee Cooley's Anemia Foundation, Inc.

105 East 22nd Street Suite 911 New York New York 10010 (212) 598-0911

#### PURPOSE:

The Cooley's Anemia Foundation promotes research; supports the training of health personnel; and promotes the training, vocational guidance, and occupational placement of children with Cooley's anemia. The foundation also disseminates information about Cooley's anemia and allied diseases.

#### **PUBLICATIONS:**

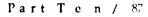
- Cooley's Azemia A Psychosocial Directory
- Cooley's Anemia A Medical Review
- Assessment of Cooley's Anemia Research and Treatment
- Cooley's Anemia Prevention Through Understanding and Testing

#### **AUDIOVISUALS:**

- A Little Hurt
- Precious Gift of Time

#### **NEWSLETTER:**

• Lifeline (Quarterly)





# Fanconi Anemia Support Group

2875 Baker Boulevard Eugene Oregon 97403 (503) 686-0434

#### **EXECUTIVE DIRECTOR:**

David B. Frohnmayer

### **CONTACT PERSON (S):**

ynn and David Frohnmayer

#### **CHAPTERS/SATELLITES:**

None

#### **PURPOSE:**

The Fanconi Anemia Support Group facilitates the sharing of information concerning this rare disorder among parents of affected children and offers support to affected families.

#### **PUBLICATIONS:**

None

#### **AUDIOVISUALS:**

None

#### **NEWSLETTER:**

• FA Family Newsletter (Annually)

Part Ten/88



Margaret A. Krikker, M.D., President

#### **CONTACT PERSON (S):**

Margaret A. Krikker, M.D.

#### CHAPTERS/SATELLITES:

Now being formed

Hemochromatosis Research Foundation, Inc. (HRF)

> P.O. Box 8569 Albany New York 12208 (518) 489-0972

#### PURPOSE:

The Hemochromatosis Research Foundation promotes public and medical community awareness of the disorder, identifies families with the disorder through screening, and solicits funds for screening and research. Patients are offered educational materials, counseling, and physician referrals.

#### **PUBLICATIONS:**

- Some Facts About...Hemochromatosis
- Hereditary Hemochromatosis A Publication for Patients
- Hereditary (Genetic or Idiopathic)

  Hermcchromatosis A Publication for Physicians

#### **AUDIOVISUALS:**

- Three reels of an April 1987 Family Teaching Conference
- Tape of August 1986 Radio Teaching Conference for Physicians

#### **NEWSLETTER:**

• Hemochromatosis Awareness (Quarterly)

Part Ten/89



# Hereditary Hemorrhagic Telangiectasia (HHT) Foundation, Inc.

Biochemistry
Department
University of
Massachusetts
Amherst
Massachusetts
01003
(413) 545-2048, 259-1515
(Massachusetts)
(415) 328-4854
(California)

#### **EXECUTIVE DIRECTOR:**

Bruce Johnson, Ph.D.

#### **CONTACT PERSON (S):**

Sharon Victor (Palo Alto, California)

#### **CHAPTERS/SATELLITES:**

California

#### **PURPOSE:**

The Hereditary Hemorrhagic Telangiectasia Foundation gathers and disseminates information about new forms of treatment and progress in research on the disease; provides a network of support for affected individuals and their families; and raises funds to encourage and support research.

#### **PUBLICATIONS:**

Brochure on HHT

#### **AUDIOVISUALS:**

None

#### **NEWSLETTER:**

None



Part Ten / 90

Jeffrey M. Toughill

#### **CONTACT PERSON (S):**

Jeffrey M. Toughill

#### **CHAPTERS/SATELLITES:**

None

Histiocytosis-X Association of America, Inc.

609 New York Road Glassboro New Jersey 08028 (609) 881-4911

#### **PURPOSE:**

The Histocytosis-X Association provides a source of reference information to all those interested in histiocytosis-X, provides support to affected persons and their families, and encourages research into the causes and best treatment of histiocytosis-X.

#### **PUBLICATIONS:**

None

#### **AUDIOVISUALS:**

None

#### **NEWSLETTER:**

Bimonthly

Part Ten/91

# Iron 'werload Diseases Association, Inc. (IOD)

224 Datura Street
Suite 311
West Path Beach
Florida
33401
(305) 659-5616, 5677

#### **EXECUTIVE DIRECTOR:**

Roberta Crawford

#### **CONTACT PERSON (S):**

Roberta Crawford

#### CHAPTERS/SATELLITES:

Alabama and Wisconsin

#### **PURPOSE:**

The Iron Overload Diseases Association promotes research, conducts education programs for the medical profession and the public, sponsors annual symposiums, organizes chapters, acts as a clearinghouse for patients and doctors, sponsors screening programs, publicizes the problem through the media, maintains a computerized information center, and raises necessary funds.

#### **PUBLICATIONS:**

- · Overload, An Ironic Disease
- Iron Overload Alert
- Fact Sheet

#### **AUDIOVISUALS:**

- Videotapes of symposia
- Slides of 1984 survey

#### **NEWSLETTER:**

• Ironic Blood (Bimonthly)



Dorothye Boswell

#### **CONTACT PERSON (S):**

Dorothye Boswell

#### **CHAPTERS/SATELLITES:**

Alabama (5), Arkansas, California (6), Connecticut, District of Columbia, Florida (12), Georgia, Illinois (2), Indiana (2), Iowa, Kansas, Louisiana (7), Maryland, Massachusetts, Michigan (2), Mississippi (2), Missouri (3), Nevada, New Jersey (3), New Mexico, New York (5), North Carolina (4), Ohio (3), Oklahoma, Pennsylvania South Carolina (2), Tennessee, Texas (5), Virginia (2), and Washington

#### **PURPOSE:**

The National Association for Sickle Cell Disease prepares and distributes educational materials to increase awareness of the impact of sickle cell disease. It is also dedicated to promoting the resolution of issues that might adversely affect patients. The association actively participates in national and regional conferences and in the development of local chapters.

#### **PUBLICATIONS:**

Catalog a ailable upon request

#### **AUDIOVISUALS:**

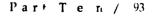
Catalog available upon request

#### **NEWSLETTER:**

• Sickle Cell News (Quarterly)

National
Association for
Sickle Cell
Disease, Inc.
(NASCD)

4221 Wilshire Boulevard Suite 360 Los Angeles California 90010-3503 (800) 421-8453 (213) 936-7205





# National Hemophilia Foundation (NHF)

The Soho Building 110 Greene Street Room 406 New York New York 10012 (212) 219-8180

#### **EXECUTIVE DIRECTOR:**

Alan P. Brownstein

#### **CONTACT PERSON (S):**

Alan P. Brownstein

#### **CHAPTERS/SATELLITES:**

Alabama, California (3), Colorado, Connecticut, District of Columbia, Georgia, Hawaii, Illir Jis, Indiana, Kansas, Kentucky, Louisiana, Maryland, Massachusetts, Michigan, Minnesota, Mississippi, Missouri, Nebraska, New Jersey, New York (4), North Carolina, Ohio (5), Oklahoma, Oregon, Pennsylvania (3), Rhode Island, South Carolina, Tennessee (2), Texas (2), Utah, Virginia, Washington, and Wisconsin

#### **PURPOSE:**

The National Hemophilia Foundation promotes opportunities for improving the quality of life for all affected by hemophilia and related bleeding disorders. The foundation is committed to provide and support programs of research; patient, public and professional education; and patient, family, and community services.

#### **PUBLICATIONS:**

Catalog available upon request

#### **AUDIOVISUALS:**

· loey

#### **NEWSLETTER:**

- Hemophilia Newsnotes (Quarterly)
- Hemophilia Nursing Network News (Biannually)
- Nemophilia Psychosocial News (Biannually)



Part Ten/94

**Edward and Sandra Purinton** 

#### **CONTACT PERSON (S):**

**Edward and Sandra Purinton** 

#### **CHAPTERS/SATELLITES:**

None

Thrombocytopenia
Absent
Radius
Syndrome
Association
(TARSA)

312 Sherwood Drive R.D. 1 Linwood New Jersey 08221 (609) 927-0418

#### **PURPOSE:**

The Thrombocytopenia Absent Radius Syndrome Association is a support and education association dedicated to supporting families affected by thrombocytopenia absent radius syndrome.

#### PUBLICATIONS:

• TARSA: A Very Special Organization With a Very Special Purpose (brochure)

#### **AUDIOVISUALS:**

None

#### **NEWSLETTER:**

• TARSA News (Biannually)



Part Ten/95

- 11 –	
	Part Eleven
	Immunologic
	97



Milton H. Abram, II, President

#### **CONTACT PERSON (S):**

Charlean Wakefield

#### CHAPTERS/SATELLITES:

25 chapters throughout the United States

# American Lupus Society

23751 Madison Street Torrance California 90505 (213) 373-1335

#### **PURPOSE:**

The American Lupus Society engages in programs aimed to increase public awareness about lupus and works to obtain funds for research. Patients and their families are provided with educational materials and support.

#### PUBLICATIONS:

Catalog available upon request

### AUPIOVISUALS:

None

#### **NEWSLETTER:**

• The Quarterly



Part Eleven/99

# Immune **Deficiency** Foundation (IDF)

P.O. Box 586 Columbia Maryland 21045 (301) 461-3127

Part Eleven/100

#### EXECUTIVE DIRECTOR:

Marcia Boyle, President

#### **CONTACT PERSON (S):**

Marcia Boyle

#### **CHAPTERS/SATELLITES:**

California, Illinois, Ohio, Oklahoma, Missouri, New York, and Texas

#### **PURPOSE:**

The Immune Deficiency Foundation promotes and supports scientific research into the causes, prevention, treatment, and cure of immune desciency diseases; promotes and supports training in medical research and clinical treatment of immune deficiency diseases; gathers, coordinates, and disseminates information concerning research and treatment of immune deficiency diseases and conducts education campaigns to increase public awareness and establish chapters in each state. The foundation sponsors an annual 'ellowship for the study of immune deficiency diseases.

#### **PUBLICATIONS:**

- Immune Deficiency Diseuses: An Overview
- Immune Deficiency Diseases: A Guide for Nurses
- Patient and Family Handbook
- List of Suggested Readings in Immunology
- The Immune Deficiency Foundation

#### **AUDIOVISUALS:**

• Moment to Moment: The Story of Immune Deficiency

#### **NEWSLETTER:**



• IDF Newsletter (Annually)

Margaret Gibelman, D.S.W.

#### **CONTACT PERSON (S):**

Margaret Gibelman, D.S.W.

#### CHAPTERS/SATELLITES:

98 chapters throughout the United States

#### **PURPOSE:**

The Lupus Foundation increases awareness of lupus; educates health care professionals and others; give emotional support to those with lupus and their families, and raise money for research

#### **PUBLICATIONS:**

Catalog available upon request

#### **AUDIOVISUALS:**

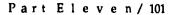
None

#### **NEWSLETTER:**

• Lupus News (Triannually)

Lupus Foundation of America, Inc. (LFA)

1717 Massachusetts Avenue, N.W. Suite 203 Washington, D.C. 20036 (202) 328-4550





# Sjogren's Syndrome Foundation, Inc. (SSF)

29 Gateway Drive Great Neck New York 11021 (516) 487-2243

#### **EXECUTIVE DIRECTOR:**

Elaine K. Harris, President

#### **CONTACT PERSON (S):**

Elaine K. Harris

#### **CHAPTERS/SATELLITES:**

United States, Canada, England, France, Holland, Japan, and Spain

#### **PURPOSE:**

The Sjogren's Syndrome Foundation helps patients and their families cope with the problems and frustrations of living with a chronic disease.

#### **PUBLICATIONS:**

• Sjogren's Syndrome Foundation, Inc.

#### **AUDIOVISUALS:**

None

#### **NEWSLETTER:**

• The Moisture Seekers (Monthly)

Part Eleven/102



ļ	1
	Part Twelve
	Kidney
-	103

John Davis

#### **CONTACT PERSON (S):**

Gigi Politoski, Public Information Director

#### **CHAPTERS/SATELLITES:**

50 affiliates throughout the United States

Two Park Avenue New York

**National Kidney** 

Foundation. Inc.

10016 (212) 889-2210

New York

#### **PURPOSE:**

The National Kidney Foundation provides patient publications, professional materials, transportation to facilities, and referrals in an attempt to improve the lives of patients. The foundation also supports research into the prevention and cure of kidney and urinary tract diseases.

#### **PUBLICATIONS:**

Catalog available upon request

#### **AUDIOVISUALS:**

Catalog available upon request

#### **NEWSLETTER:**

• Kianey '88 (Five issues a year)



Part Twelve/105

# Polycystic Kidney Research Foundation (PKR)

922 Walnut Kansas City Missouri 64106 (816) 421-1869

#### **EXECUTIVE DIRECTOR:**

Jean G. Bacon

#### **CONTACT PERSON (S):**

Judy Haines, Administrative Assistant

#### **CHAPTERS/SATELLITES:**

Four PKRF FRIENDS groups: Chicago Area, Mid-Atlantic (New York, New Jersey, Connecticut, and Pennsylvania), National Capital Area (Washington, D.C., Maryland, and Virginia), and Florida

#### **PURPOSE:**

The Polycystic Kidney Research Foundation promotes research into the cause and cure of polycystic kidney disease.

#### **PUBLICATIONS:**

- A Short History of the PKR Foundation
- Polycystic Kidney Disease?
- Problems in Diagnosis and Management of Polycystic Kidney Disease
- Your Diet and Polycystic Kidney Disease

#### **AUDIOVISUALS:**

None

#### **NEWSLETTER:**

• PKR Progress (Triannually)



Part Twelve/106

١	1
	Part Thirteen
	Mental
	107



Charles Peck, President

#### **CONTACT PERSON (S):**

Wendy Resnick

#### CHAPTERS/SATELLITES:

None

# Depression and Related Affective Disorders Association, Inc. (DRADA)

Johns Hopkins Hospital Meyer 4-181 601 North Wolfe Street Baltimore Maryland 21205 (301) 955-3246

#### **PURPOSE:**

The Depression and Related Affective Disorders Association is a group of patients, professionals, and families who are concerned about clinical depressions and manic depression and who have united to promote research, education, support services, and treatment.

#### **PUBLICATIONS:**

- Annotated bibliography for patients, families, and mental health professionals
- Handbook for developing and maintaining affective disorder support groups (in progress)
- I Am the Greatest. I Am Depressed. (brochure)

#### **AUDIOVISUALS:**

Media materials for young people

#### **NEWSLETTER:**

• Smooth Sailing (Quarterly)



Part Thirteen / 109

Part Fourteen
Metabolic
111



Robert S. Bolan, Ph.D., Executive Vice President

#### **CONTACT PERSON (S):**

Robert S. Bolan, Ph.D.

#### **CHAPTERS/SATELLITES:**

53 affiliates and over 1000 chapters

American
Diabetes
Association, Inc.

1660 Duke Street Alexandria Virginia 22314 (703) 549-1500

#### **PURPOSE:**

The American Diabetes Association promotes the search for a preventive and cure for diabetes and works to improve the well-being of all people with diabetes and their families.

#### **PUBLICATIONS:**

- Clinical Diabetes
- Diabetes
- Diabetes Care
- Diaberes Forecast
- Diabetes Spectrum

#### **AUDIOVISUALS:**

None

#### **NEWSLETTER:**

• Dial etes '88 (Quarterly)



## American Porphyria Foundation

P.O. Box 11163 Montgomery Alabama 36111 (205) 265-2200

#### **EXECUTIVE DIRECTOR:**

**Pesiree Dodson** 

#### **CONTACT PERSON (S):**

Desiree Dodson

#### **CHAPTERS/SATELLITES:**

Califo, nia, Florida, Georgia, Michigan, Minnesota, N.:w York, Oklahoma, Tennessee (2), and Texas

#### **PURPOSE:**

The American Porphyria Foundation has been established to enhance awareness and education about the porphyrias and to aid in advancing treatment of this group of disorders.

#### **PUBLICATIONS:**

- Acute Intermittent Porphyria (AIP): A Description for Patients and Their Relatives
- Porphyria: An Explanation
- · Questions Commonly Asked About Porphyria

#### **AUDIOVISUALS:**

• Porphyria: An Introduction

#### **NEWSLETTER:**

Quarterly



Hollie L. Arp, President

#### **CONTACT PERSON (S):**

Hollie L. Arp

#### **CHAPTERS/SATELLITES:**

None

Association for Glycogen Storage Disease

Box 896 Durant Iowa 52747 (319) 785-6038

#### **PURPOSE:**

The Association for Glycogen Storage Disease aims to protect and promote the best interests of all persons affected by glycogen storage disease, to communicate and distribute material to all members of the organization, and to promote the establishment, improvement and management of facilities for the treatment of glycogen storage disease.

#### **PUBLICATIONS:**

Catalog available upon request

#### **AUDIOVISUALS:**

None

#### **NEWSLETTER:**

• The Ray (Quarterly)



### Association of Nucro-Metabolic Disorders

5223 Brookfield Lane Sylvania Ohio 43560 (419) 885-1497

#### **EXECUTIVE DIRECTOR:**

None

#### **CONTACT PERSON (S):**

Cheryl Volk

#### CHAPTERS/SATELLITES:

None

#### **PURPOSE:**

The Association of Neuro-Metabolic Diseases serves those affected with medical conditions caused by disturbances in body chemistry. These conditions are present at birth and affect brain function. Since these disorders require prompt recognition and care, the association is dedicated to promoting education and research in order to increase awareness. Support and informational resources are offered to affected individuals and other interested parties.

#### **PUBLICATIONS:**

None

#### **AUDIOVISUALS:**

None

#### **NEWSLETTER:**

Triannually



Robert Dresing, President

#### **CONTACT PERSON (S):**

Mark Hansan, Executive Assistant to the President

#### **CHAPTERS/SATELLITES:**

65 chapters and 126 care centers located throughout the United States

#### **PURPOSE:**

The Cystic Fibrosis Foundation attempts to develop a means to control, cure, and prevent cystic fibrosis. The foundation strives to improve the quality of life for those affected by the disease. It also supports biomedical research and provides accreditation and suport of specialized care centers for CF patients throughout the United States.

#### PUBLICATIONS:

Catalog available upon request

#### **AUDIOVISUALS:**

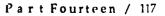
Catalog available upon request

#### **NEWSLETTER:**

• Commitment (Quarterly)

# **Cystic Fibrosis** (CF) Foundation

6931 Arlington Road Bethesda Maryland 20814 (800) FIGHT CF (301) 951-4422





# Cystinosis Foundation, Inc.

477 15th Street Suite 200 Oakland California 94612 (415) 834-7897

#### **EXECUTIVE DIRECTOR:**

Jean Hotz, President

#### **CONTACT PERSON (S):**

Jean Hotz

#### **CHAPTERS/SATELLITES:**

New Jersey

#### **PURPOSE:**

The Cystinosis Foundation acts as a support group for parents of children with cystinosis, educates the general public and medical community, and raises funds for research.

#### **PUBLICATIONS:**

- Facts about Cystinosis (pamphlet)Information Sheets

#### **AUDIOVISUALS:**

• Sessions from the annual cystinosis conference

#### **NEWSLETTER:**

• Help Us Grow (Quarterly)



Lenore F. Roseman

#### **CONTACT PERSON (S):**

Lenore F. Roseman

#### **CHAPTERS/SATELLITES:**

California, Connecticut, Florida, Illinois, Massachusetts (2). Maryland, Michigan, New Jersey, New York, Canada (2), United Kingdom. and Israel

PURPOSE:

The Dysautonomia Foundation provides a continual flow of information about familial dysautonomia (also called Riley-Day syndrome) to parents, physicians, and professionals. Through fund-raising efforts and the assistance of it's chapters, the foundation supports the Dysautonomia Treatment and Evaluation Center at New York University Medical Center.

#### **PUBLICATIONS:**

- Caring for the Child with Familial Dysautonomia (A Treatment Manual) by Felicia B. Axelrod, M.D., and Mary Ellen Sein, R.N.
- Dysautonomia: Only You Can Ensure Their Tomorrow (brochure)
- Familial Dysautonomia (brochure)

#### **AUDIOVISUALS:**

• FD - Without Tears But with Hope

#### **NEWSLETTER:**

• Dys/course (Biannually)

Dysau' nomia Foundation, Inc.

370 Lexington Avenue New York New York 10017 (212) 889-5222



## Foundation for the Study of Wilson's Disease Inc.

5447 Palisade Avenue Bronx New York 10471 (212) 430-2091

#### **EXECUTIVE DIRECTOR:**

I. Herbert Scheinberg, M.D., President

#### **CONTACT PERSON (S):**

I. Herbert Scheinberg, M.D.

#### **CHAPTERS/SATELLITES:**

None

#### **PURPOSE:**

The Foundation for the study of Wilson's Disease provides clinical and laboratory facilities for the diagnosis and management of Wilson's disease and related disorders of copper and metal metabolism. In addition, the foundation educates health professionals and the lay public to recognize undiagnosed patients with Wilson's disease and appropriately manages these patients with effective therapy.

#### **PUBLICATIONS:**

• Wilson's Disease by I.H. Schienberg, M.D. and I. Sternlieb

#### **AUDIOVISUALS:**

· Wilson's Disease

#### **NEWSLETTER:**

None



Gloria Pennington

#### **CONTACT PERSON (S):**

Mary Kelly

#### CHAPTERS/SATELLITES:

200 chapters in the United States and Canada and affiliates in Australia, Erazil, England, France, Greece, and Israel

#### **PURPOSE:**

The purpose of the Juvenile Diabetes Foundation is to support research into the cause, cure, treatment, and prevention of diabetes and its complications.

#### **PUBLICATIONS:**

- Countdown (magazine)
- Various pamphlets on dibetes care

#### **AUDIOVISUALS:**

• Video Annual Report

#### **NEWSLETTER:**

• Tie Lir.es (Quarterly)

Juvenile
Diabetes
Foundation
(JDF)
International

432 Park Avenue South 16th Floor New York New York 10010 (212) 889-7575



# Lowe's Syndrome Association, Inc.

222 Lincoln Street West Lafayette Indiana 47906 (317) 743-3634

#### **EXECUTIVE DIRECTOR:**

Kaye McSpadden, President

#### **CONTACT PERSON (S):**

Kaye McSpadden

#### **CHAPTERS/SATELLITES:**

None

#### **PURPOSE:**

The Lowe's Syndrome Association fosters communication among families, provides information, promotes a better understanding of Lowe syndrome and the potentials of individuals with this condition, and encourages and supports medical research.

#### **PUBLICATIONS:**

- Care Today, Cure Tomorrow (pamphlet)
- Focus on Lowe's Syndrome: Proceedings of the First International Conference on Lowe's Syndrome - 1986
- Living With Lowe's Syndrome (booklet)

#### **AUDIOVISUALS:**

• Care Today, Cure Tomorrow

#### **NEWSLETTER:**

• On The Beam (Triannually)



Suellen Gallamore

#### **CONTACT PERSON (S):**

Suellen Gallamore

#### **CHAPTERS/SATELLITES:**

None

# Malignant Hyperthermia Association of the United States (MHAUS)

P.O. Box 3231 Darien Connecticut 06820 (203) 655-3007

#### **PURPOSE:**

The Malignant Hyperthermia Assocation provides information and referrals to MH susceptible families and their physicians.

#### **PUBLICATIONS:**

- Malignant Hyperthermia The Anesthesiologist's Nightmare (pamphlet)
- Preventing Malignant Hyperthermia (pamphlet)
- Suggested Therapy for MH Emergency (poster)
- Understanding Malignant Hyperthermia (booklet)

#### **AUDIOVISUALS:**

None

#### **NEWSLETTER:**

• The Communicator (Quarterly)



# Maple Syrup Urine Disease (MSUD) Family Support Group

R.R. #2 Box 24-A Flemingsburg Kentucky 41041 (606) 849-4679

#### **EXECUTIVE DIRECTOR:**

Joyce Brubacher

#### **CONTACT PERSON (S):**

Peter Shaffer

#### **CHAPTERS/SATELLITES:**

None

#### **PURPOSE:**

The Maple Syrup Urine Family Support Group provides an oppurtunity for parent-to-parent contact and support; gathers and distributes information on MSUD; educates parents, professionals, and the public about MSUD; and encourages research.

#### **PUBLICATIONS:**

• MSUD Information Sheet

#### **AUDIOVISUALS:**

None

#### **NEWSLETTER:**

• Maple Syrup Urine Disease Newsletter (Triannually)



Lynn Goldblatt

#### **CONTACT PERSON (S):**

Lynn Goldblatt

#### **CHAPTERS/SATELLITES:**

None

## ML (Mucolipidosis) IV Foundation

6 Concord Drive Monsey New York 10952 (919) 425-0639

#### **PURPOSE:**

The ML IV Foundation unites parents and professionals and provides information and support to parents of affected children. In addition, the foundation works to raise funds to support reseach.

#### **PUBLICATIONS:**

• ML4 (brochure)

#### **AUDIOVISUALS:**

None

#### **NEWSLETTER:**

None



# National Gaucher Foundation, Inc. (NGF)

1424 K Street, N.W. Fourth Floor Washington, D.C. 20005 (202) 393-2777

#### **EXECUTIVE DIRECTOR:**

Karen Cohen

#### **CONTACT PERSON (S):**

Karen Cohen

#### **CHAPTERS/SATELLITES:**

Arizona, California, District of Columbia, Florida, Kentucky, Massachusetts, New Jersey, New York, Ohio, Pennsylvania, Texas, Virginia, Canada, The Netherlands, and The Republic of South Africa

#### **PURPOSE:**

The National Gaucher Foundation promotes and supports medical research and clinical programs aimed at finding a treatment and cure for Gaucher disease. Two additional priorites of the foundation are to provide information and assistance to self-help groups, as well as to individuals and families affected by Gaucher disease, and to increase public awareness of Gaucher disease through an educational campaign.

#### **PUBLICATIONS:**

Pamphlets and genetic background material

#### **AUDIOVISUALS:**

- Gaucher's Disease: Coping, Caring and Searching for a Cure
- Various public service announcements and television interview filmclips

#### **NEWSLETTER:**

• Gaucher's Disease Registry Newsletter (Bimonthly)



Marie Capobianco

#### **CONTACT PERSON (S):**

Marie Capobianco

#### **CHAPTERS/SATELLITES:**

A list of regional contact families is available

#### **PURPOSE:**

The National Mucopolysaccharidoses (MPS) Society is dedicated to serving parents through support, networking, physician referrals, professional and public education, and raising funds to further research into MPS disorders.

#### **PUBLICATIONS:**

• What is MPS?

#### **AUDIOVISUALS:**

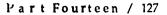
None

#### **NEWSLETTER:**

• Courage

National Mucopolysaccharidoses (MPS) Society, Inc.

17 Kraemer Street Hicksville New York 11801 (516) 931-6338



# National Organization for Albinism and Hypopigmentation (NOAH)

1500 Locust Street Suite 1811 Philadelphia Pennsylvania 19102-4316 (215) 471-2278 (215) 471-2265

#### **EXECUTIVE DIRECTOR:**

None

#### **CONTACT PERSON (S):**

Janice L. Knuth, A.C.S.W., President

#### CHAPTERS/SATELLITES:

California, Connecticut, Florida, Illinois, Massachusetts, Minnesota, New Hampshire, New Jersey, New York City, Ohio, Pennsylvania, Virginia, and Washington

#### **PURPOSE:**

The National Organization for Albinism and Hypopigmentation provides information and support to individuals and families with albinism and hypopigmentation; promotes public and professional education about albinism and hypopigmentation; and encourages research and research funding that will lead to improved diagnosis and treatment of these conditions.

#### **PUBLICATIONS:**

 Information Bulletins (handouts on topics related to albinism)

#### **AUDIOVISUALS:**

None

#### **NEWSLETTER:**

• NOAH News (Biannually)



Dale J. Carre

# CONTACT PERSON (S):

Dale I. Carre

# **CHAPTERS/SATELLITES:**

Delaware Valley, Illinois, New England, New Jersey, New York, Southern California, Texas, England, and Israel

# **PURPOSE:**

The National Tay-Sachs and Allied Diseases Association delvelops, coordinates, and implements medical, public relations, educational, and fund-raising programs related to the prevention or and research into Tay-Sachs and allied lysosomal and neurological diseases. Programs include public and professional education, prevention, services to families, quality control testing, and research fellowships.

# **PUBLICATIONS:**

- One Day at a Time
- Posters
- Prevent a Tragedy
- Services to Families
- What Every Family Should Know

# **AUDIOVISUALS:**

• For My Sister, Elusen

# **NEWSLETTER:**

• Breakthrough (Biannually)

National
Tay-Sachs and
Allied Diseases
Association, Inc.
(NTSAD)

385 Elliot Street Newton Massachusetts 02164 (617) 964-5508





# Organic Acidemia Association, Inc.

1532 South 87th Street Kansas City Kansas 66111 (913) 422-7080

# **EXECUTIVE DIRECTOR:**

Lorie Asten, Coordinator

# **CONTACT PERSON (S):**

Lorie Asten

# **CHAPTERS/SATELLITES:**

Chapters forming in Canada and the United States

# **PURPOSE:**

The Organic Acidemia Association encourages consistent communication and support among families and professionals dealing with organic acidemias and related rare metabolic disorders. The association offers referrals and a membership roster for networking purposes. A literature resource library is kept up-to-date on pertinent issues concerning organic acidemias.

# **PUBLICATIONS:**

• 1988 Membership Roster

# **AUDIOVISUALS:**

None

# **NEWSLETTER:**

Quarterly

Part Fourteen / 130



Ron and Paula Brazeai, Co-Presidents

# **CONTACT PERSON (S):**

Paula Brazeal

# **CHAPTERS/SATELLITES:**

None

United
Leukodystrophy
Foundation, Inc.
(ULF)

2304 Highland Drive Sycamore Illinois 60178 (815) 895-3211

# **PURPOSE:**

The United Leukodystrophy Foundation provides affected families with information, assists them in identifying resources, coordinates a communication network among affected families, increases public awareness, and promotes research in the leukodystrophies.

# **PUBLICATIONS:**

- Facts About Leukodystrophy
- Reprints on disease specific subjects

# **AUDIOVISUALS:**

None

# **NEWSLETTER:**

Quarterly



# Williams Syndrone Association (WSA)

P.O. Box 178373 San Diego California 92117-0910 (713) 376-7072

# **EXECUTIVE DIRECTOR:**

Gordon Biescar

# **CONTACT PERSON (S):**

Kay Biescar, Administrative Assistant

# **CHAPTERS/SATELLITES:**

10 regional directors throughout the United States and Canada

# **PURPOSE:**

The Williams Syndrome Assocation provides affected indiviuals and their families an opportunity to meet, offer support, and share knowledge about the syndrome and encourages medical, educational, and behavioral research relevant to Williams syndrome.

# **PUBLICATIONS:**

 Facts About Williams Syndrome (English, French, and Spanish)

# **AUDIOVISUALS:**

- NBC's Monitor excerpt on "Pixie Kids" (1983)
- Videotapes of national conventions, seminars, regioal meetings

# **NEWSLETTER:**

• National Newsletter (Quarterly)



Carol A. Terry, President

# **CONTACT PERSON (S):**

Carol A. Terry

# **CHAPTERS/SATELLITES:**

None

# Wilson's Disease Association

P.O. Box 75324 Washington, D.C. 20013 (703) 636-3003, 3014

# **PURPOSE:**

The Wilson's Disease Association provides aid and support to persons who have Wilson or Menkes disease and their families. It offers medical referrals, limited financial aid, and an intercommunication network of affected persons for mutual support. The association also provides current information to those affected, the general public, health care professionals, and other parties.

# **PUBLICATIONS:**

Series of three question-and answer brochures on Wilson disease

# **AUDIOVISUALS:**

None

# **NEWSLETTER:**

Quarterly



# Zain Hansen M.P.S. (Mucopolysacharridoses) Foundation

P.O. Box 4768
1200 Fernwood Drive
Arcata
California
95521
(707) 822-5421

# **EXECUTIVE DIRECTOR:**

Carl Zichella

# **CONTACT PERSON (S):**

LeAnna Carson-Hansen

# **CHAPTERS/SATELLITES:**

None

# **PURPOSE:**

The Zain Hansen M.P.S. Foundation distributes funds and other assistance to children and families affected by mucopolysaccharidoses and related disorders, supports medical treatment and research, facilitates the sharing of information between professionals and families, and operates a medical equipment exchange bank.

# **PUBLICATIONS:**

- Brochure on MPS
- Directory of Medical Professionals Experienced in MPS
- Directory of MPS Research Programs

## **AUDIOVISUALS:**

None

# **NEWSLETTER:**

Quarterly

Part Fourteen / 134



Part Fifteen
Musculoskeletal

Clifford Clarke, President

#### **CONTACT PERSON (S):**

Linda Weatherbee, Vice President for AJAO

# **CHAPTERS/SATELLITES:**

The 72 chapters of the Arthritis Foundation have varying levels of local AJAO activities.

## **PURPOSE:**

The Arthritis Foundation conducts educational programs and publishes educational materials. The American Juvenile Arthritis Organization is a membership organization within the Arthritis Foundation. The objective of the Juvenile Arthritis Organization is to serve as an advocate for children with rheumatic diseases and their families. It also serves to mobilize the energies and resources of the Arthritis Foundation to further the interests of its constituents and to promote communication among concerned parents.

### **PUBLICATIONS:**

Catalog available upon request

# **AUDIOVISUALS:**

Catalog available upon request

# **NEWSLETTER:**

Several at various intervals including AJAO Newsletter (Quarterly)

Arthritis
Foundation/
American Juvenile
Arthritis
Organization
(AJAO)

1314 Spring Street, N.W.
Atlanta
Georgia
30309
(404) 872-7100



# Freeman-Sheldon Parent Support Group

1459 East Maple Hills
Drive
Bountiful
Utah
84010
(801) 298-3149

# **EXECUTIVE DIRECTOR:**

Joyce Dolcourt

# **CONTACT PERSON (S):**

Joyce Dolcourt

# **CHAPTERS/SATELLITES:**

None

# **PURPOSE:**

The Freeman-Sheldon Parent Support Group provides emotional support to families affected by Freeman-Sheldon syndrome. The group is particularly interested in the growth and development of children with this syndrome. Members share experiences in rearing children, helpful hints to make everyday activities easier, and report on the results of various treatments to correct the numerous physical problems of the syndrome. The group mair tains a file of medical literature.

# **PUBLICATIONS:**

None

**AUDIOVISUALS:** 

None

**NEWSLETTER:** 

None



Laura B. Gowen

#### **CONTACT PERSON (S):**

Elizabeth Downie

# **CHAPTERS/SATELLITES:**

Massachusetts, Michigan, and Texas

# National Scoliosic Foundation, Inc.

93 Concord Avenue P.O. Box 547 Belmont Massachusetts 02178 (617) 489-0888, 0880

# **PURPOSE:**

The National Scoliosis Foundation alerts the public to the potentially serious health problems associated with abnormal spinal curatures and develops programs leading to early detection and treatment. This is accomplished through literature and audiovisuals, as well as direction, guidance, and material assistance for implementing or improving statewide screening programs in schools.

# **PUBLICATIONS:**

- Background Information for Volunteers and Schools
- In 30 Seconds You Can Change the Shape of Your Child's Life (brochure)
- One in Every 10 Persons Has Scoliosis (brochure in English and Spanish)
- Resources Available for Persons Involved in Health Care
- The Brace by Mary Langford & Her Brace is No Handicap by Carolyn Callison (booklet)

# **AUDIOVISUALS:**

• Growing Straighter and Srtonger

# **NEWSLETTER:**

• The Spinal Connection (Biannually)



# Osteogenesis Imperfecta Foundation, Inc. (OIF)

P.O. Box 14807 Tampa Florida 34629-4807 (813) 855-7077

# **EXECUTIVE DIRECTOR:**

Rosalind James, President

# **CONTACT PERSON (S):**

Linda K. Phillips, Staff Assistant

# **CHAPTERS/SATELLITES:**

Alabama, Arkansas, California, New York, and Pennsylania. Support groups in New York, the Illinois-Iowa area, Michigan, Ohio, and Georgia

# **PURPOSE:**

Osteogenesis Imperfecta Foundation distributes information offers moral support, and helps fund research.

# **PUBLICATIONS:**

Catalog available upon request

# **AUDIOVISUALS:**

- Kathy
- Kathy On Her Own

# **NEWSLETTER:**

• Breakthrough (Quarterly)



Margaret Cauffield

# **CONTACT PERSON (S):**

Margaret Cauffield

# **CHAPTERS/SATELLITES:**

None

Ostegenesis Imperfecta National Capital Area, Inc.

Box 941 1311 Delaware Aven S.W. Washinton, D.C. 20024 (202) 265- 1614

# **PURPOSE:**

Osteogenesis Imperfecta - National Capital Area is edicated to finding the means for detecting, preventing, treating, and ultimately curing osteogenesis imperfecta, the "brittle bone" disease. OI-NCA publishes educational materials for families, affected individuals, and the public; holds educational meetings, conferences, and seminars for health professionals; provides rehibilitation "hardware", such as braces and wheelchairs, for affected children and older individuals; and supports research.

# **PUBLICATIONS:**

- Booklet on rehabilitation of infants and young children with OI
- Organizational brochure

# **AUDIOVISUALS:**

None

#### **NEWSLETTER:**

• O. I. Edition (Quarterly)

# Paget's Disease Foundation, Inc. (PDF)

165 Cadman Plaza East Brooklyn New York 11201 (71810 596-1043

# **EXECUTIVE DIRECTOR:**

Charlene Waldman

# **CONTACT PERSON (S):**

Charlene Waldman

# **CHAPTERS/SATELLITES:**

None

# **PURPOSE:**

The Paget's Disease Foundation assists with Paget disease and similar disorders. The foundation provides free educational materials to patients and medical processionals. An advisory medical panal assists with physician referrals and consultations.

# **PUBLICATIONS:**

- Diagnostic booklet
- New Direction...New Hope
- Question and Answer Booklet
- Referral list of physicians
- Reprints of articles about Paget disease
- Understanding Paget's Disease

# **AUDIOVISUALS:**

None

# **NEWSLETTER:**

• PDF Update (Biannually)



Barbara M. Shulman, President

# **CONTACT PERSON (S):**

Barbara M. Shulman

# **CHAPTERS/SATELLITES:**

Chapters in 50 states, Australia, Canada, Malta, Sweden, and United Kingdom

# PURPOSE:

The Scoliosis Association provides support, non-medical information, and insight into the problems of scoliosis to patients, their families, and the community. The association also funds research.

# **PUBLICATIONS:**

- Reprints of articles from Backtalk
- · Scolic-is, An Annotated Bibliography
- Scoliosis Fact Sheet

# **AUDIOVISUALS:**

- Scoliosis Screening for Early Detection
- Watch That Curve

# **NEWSLETTER:**

• Backtalk (Quarterly)

Scoliosis Association, Inc.

> P.O. Box 51353 Raleigh North Carolina 27609 (919) 846-2639



Part Sixteen
Neurologic
145

Virginia Fickel, President

## **CONTACT PERSON (S):**

Virginia Fickel

# **CHAPTERS/SATELLITES:**

Chapters in 22 states, Australia, and Canada

# **PURPOSE:**

The Acoustic Neuroma Association is a patient-organized, support and information organization for persons who have experienced acoustic neuromas or other tumors affecting the cranial nerves. The association promotes and supports education and research.

# **PUBLICATIONS:**

- Acoustic Neuroma (booklet)
- Acoustic Neuroma? Inside Some Answers (brochure)

# **AUDIOVISUALS:**

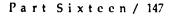
None

# **NEWSLETTER:**

• Notes (Quarterly)

# Acoustic Neuroma Association

P.O. Box 398 Carlisle Pennsylvania 17013 (717) 249-4783





Alzheimer's Disease and Related **Disorders** Association, Inc. (ADRDA)

70 East Lake Screet Chicago Illinois 60601 (800) 631-0379 (312) 853-3060

# **EXECUTIVE DIRECTOR:**

Edward Truschke, President

# **CONTACT PERSON (S):**

**Edward Truschke** 

# **CHAPTERS/SATELLITES:**

125 throughout the United States

# **PURPOSE:**

The Alzheimer's Disease and Related Disorders Association is a coalition of lay persons working to contain and conquer Alzheimer's disease. Its program goals are directed toward enhancing public awareness of this debilitating condition and informing public policy. The association responds to information requests, referring those requiring further assistance to local organizations.

# **PUBLICATIONS:**

Catalog available upon request

# **AUDIOVISUALS:**

None

# **NEWSLETTER:**



Part Sixteen/ 148

• ADRDA Newsletter (Quarterly)

William P. Baird

# **CONTACT PERSON (S):**

Jolie A. Bou

# **CHAPTERS/SATELLITES:**

Various support groups around the country

# American Narcolepsy Association (A.N.A.)

P.O Box 1187 San Carlos California 94070 (415) 591-7979

# **PURPOSE:**

The American Narcolepsy Association has as its primary purpose the improvement of the quality of life for persons with narcolepsy. The long-range goals of the association will be achieved only when effective treatments for narcolepsy are discovered.

#### **PUBLICATIONS:**

- A.N.A. Brochure
- Keep Us Awake: A Film Guide
- Narc :lepsy: A Non-Medical Presentation
- Narcolepsy: A Non-Technical Summary
- Sleep Apnea: A Non-Technical Presentation

# **AUDIOVISUALS:**

• Keep Us Awake

# **NEWSLETTER:**

• Eye Opener (Quarterly)



# American Parkinson Disease Association (APDA)

116 John Street Suite 417 New York New York 10038 (800) 223-2732 (212) 732-9550

# **EXECUTIVE DIRECTOR:**

Frank L. Williams

# **CONTACT PERSON (S):**

Frank L. Williams

# **CHAPTERS/SATELLITES:**

Alabama, Arizona, California (2), Florida (2), Georgia, Idaho (2), Illinois, Maryland, Massachusetts, Minnesota, Missouri (2), Montana, New Jersey, New York (4), Ohio, Oklahoma, Oregon, Pennsylvania (2), Rhode Island, Texas (2), Washington, and Wisconsin

#### **PURPOSE:**

The American Parkinson Disease Association funds medical research, organizes community education chapters, and provides information and referral services to patients, their families, and the public.

# **PUBLICATIONS:**

- Aids, Equipment & Suggestions to Help the Patient
- Home Exercises for Patients with Parkinson's
- Parkinson's Disease Handbook (English and Spanish)
- Speech & Swallowing Problems in Parkinson's Disease

# **AUDIOVISUALS:**

None

# **NEWSLETTER:**

Quarterly



Judith A. Grant

# **CONTACT PERSON (S):**

Judith A. Grant

# **CHAPTERS/SATELLITES:**

None

# 6707 197th Street East Spanaway Washington

98387 (206) 847-2926

Batten's Disease Support and

Research

Association

# **PURPOSE:**

The Batten's Disease Support and Research Association is committed to providing support and information to families and supporting research efforts.

# **PUBLICATIONS:**

• Batten Disease: Neuronal Ceroid Lipofuscinoses

# **AUDIOVISUALS.**

None

# **NEWSLETTER:**

Quarterly



# Epilepsy Foundation of America (EFA)

4351 Garden City Drive Landover Maryland 20785 (301) 459-3700

# **EXECUTIVE DIRECTOR:**

William M. McLin

### **CONTACT PERSON (S):**

Marie Ormsby, Director of Information and Referral

# **CHAPTERS/SATELLITES:**

85 state and local affiliates

# **PURPOSE:**

The Epilepsy Foundation is committed to the prevention and control of epilepsy and to improving the lives of people who have it. EFA works these through a broad range of programs of information and education, advocacy, support of research, and the delivery of needed services to people with epilepsy and their families. The National Epilepsy Library and Resource Center has been developed as a program service of the foundation to identify, collect, and disseminate the latest research findings, program practices, and other developments on epilepsy.

# **PUBLICATIONS:**

Catalog available upon request

# **AUDIOVISUALS:**

Catalog available upon request

# **NEWSLETTER:**

• National Spokesman (Ten issues a year)



Raymond S. McCarthy

# **CONTACT PERSON (S):**

Myrna J. Lesinsky, Administrative Assistant

# **CHAPTERS/SATELLITES:**

Alabama/Mississippi, Arizona/New Mexico, Florida, Illinois/Kentucky, Indiana, Maryland/Washington, D.C., Montana, New York/Vermont, North Carolina, Oklahoma, Pennsylvania/Delaware/New Jersey, Rhode Island, South Carolina, Tennessee, Texas, and Wisconsin. Also Australia, Canada, England, France, Germany, Ireland, Italy, The Netherlands, and New Zealand

# PURPOSE:

Friedreich's Ataxia Group in America aids pe.sons with Friedreich ataxia and their families; raises funds for research; and educates affected individuals, physicians, and the general public.

# **PUBLICATIONS:**

None

# **AUDIOVISUALS:**

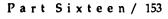
None

# **NEWSLETTER:**

• Inside...FAGA (Two to four issues a year)

# Friedreich's Ataxia Group in America, Inc. (FAGA)

P.O. Box 11116 Oakland California 94611 (415) 655-0833





# Hereditary Disease Foundation

606 Wilshire Boulevard Suite 504 Santa Monica California 90401-9990 (213) 458-4183

# **EXECUTIVE DIRECTOR:**

Allan J. Tobin, Ph.D., Scientific Advisory Board

# **CONTACT PERSON (S):**

Nancy S. Wexler, Ph.D.

# **CHAPTERS/SATELLITES:**

None

# **PURPOSE:**

The Hereditary Disease Foundation conducts basic biomedical research in hereditary disease with the primary focus on such genetic disorders as Huntington disease and other neurological illnesses. These activities are accomplished through grant programs, workshops, and post-doctoral fellowship programs and they have the support of biological specimen banks at Harvard University and UCLA.

# **PUBLICATIONS:**

Catalog available upon request

# **AUDIOVISUALS:**

Catalog available upon request

# **NEWSLETTER:**

In progress



Gary Wallach

### **CONTACT PERSON (S):**

Jeanne Farrell, Director of Patient Services

# CHAPTERS/SATELLITES:

Several throughout the United States

# Huntington's Disease Society of America, Inc. (HDSA)

140 West 22nd Street New York New York 10011-2420 (212) 242-1968

# **PURPOSE:**

The Huntington's Disease Society is dedicated to the care of patients with Huntington disease and their families and to the search for treatment and cure for HD. The society's information and referral services tap a nationwide network of physicians, scientists, social workers, and other relevant professionals. In addition, the HDSA provides fellowship grants and seed money to qualified research scientists, and it supports and coordinates a Brain Denor program which enlists the help of families in donating tissue essential to scientific research.

# **PUBLICATIONS:**

Catalog available upon request

# **AUDIOVISUALS:**

Catalog available upon request

# **NEWSLETTER:**

• The Marker (Triannually)



# International Joseph Diseases Foundation, Inc. (LJDF)

P.O. Box 2550 Livermore California 94550

# **EXECUTIVE DIRECTOR:**

Rose Marie J. Silva

# **CONTACT PERSON (S):**

Rose Marie J. Silva

# **CHAPTERS/SATELLITES:**

None

# **PURPOSE:**

The International Joseph Diseases Foundation provides information about Joseph disease; supports and conducts clinical research; and helps patients find medical, social, and genetic counseling services.

# **PUBLICATIONS:**

• Fact Sheet - Joseph Disease

# **AUDIOVISUALS:**

None

# **NEWSLETTER:**

Published when funding is available



Kathy Hunter

# **CONTACT PERSON (S):**

Kathy Hunter

# **CHAPTERS/SATELLITES:**

None

# PURPOSE:

The International Rett Syndrome Association collects and disseminates accurate and objective information regarding the cause, identification, treatment, prediction, prognosis, analysis, and prevention of Rett syndrome. The association also encourages research into Rett syndrome, assists in identifying persons with this disorder, and conducts other activities aimed at the prevention, treatment, and eradication of Rett syndrome.

# **PUBLICATIONS:**

- Rett syndrome booklet
- What is Rett Syndrome? (brochure)

# **AUDIOVISUALS:**

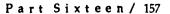
• What Is Rett Syndrome?

# **NEWSLETTER:**

• Strength Through Sharing (Quarterly)

International Rett Syndrome Association, Inc. (IRSA)

8511 Rose Mare Drive Fort Washington Maryland 20744 (301) 248-7031





# National Hydrocephalus Foundation (NHF)

Route 1 River Road Box 210 A Joliet Illinois 60436 (815) 467-6548

# **EXECUTIVE DIRECTOR:**

James A. Mazzetti

# **CONTACT PERSON (S):**

James A. Mazzetti

# **CHAPTERS/SATELLITES:**

Indiana, Kansas, Ohio, Texas, and Wisconsin

#### **PURPOSE:**

The National Hydrocephalus Foundation informs individuals with hydrocephalus and their families about relevant services. The foundation maintains a reference library for members, and it sponsors symposia and other related events which offer information to parents.

# **PUBLICATIONS:**

Various brochures on hydrocephalus

# **AUDIOVISUALS:**

Symposia videotapes

# **NEWSLETTER:**

Quarterly



Peter Bellerman

#### **CONTACT PERSON (S):**

Prissi Shapiro, Assistant Executive Director

# **CHAPTERS/SATELLITES:**

Arizona, Connecticut, District of Columbia, Florida, Illinois, Indiana, Iowa, Kansas, Massachusetts, Michigan, Missouri, New Jersey, New York, Ohio, Oregon, Pennsylvania, Texas, Utah, Virginia, Washington, Wisconsin, Rhode Island, Australia, Canada, Finland, Hungary, Israel, Italy, and Spain

#### **PURPOSE:**

The National Neurofibromatosis Foundation supports research into the cause, prevention, and treatment of neurofibromatosis. The foundation provides patients and their families with information about the disorder and helps them find medical, social and genetic counseling. It also provides information to health professionals and the general public.

# **PUBLICATIONS:**

- Neurofibromatosis: A Handbook for Parents
  Neurofibromatosis: Information for Kids
- Neurofibromatosis: Information for Patients and Families

# **AUDIOVISUALS:**

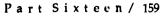
- Neurofibromatosis: A Brighter Tomorrow
- Public Service Announcement

# **NEWSLETTER:**

- neuro fibroma tosis (Quarterly)
- Research Newsletter (Quarterly)

National
Neurofibromatosis
Foundation, Inc.

141 Fifth Avenue Suite 7-S New York New York 10010 (800) 323-7983 (Outside New York) (212) 460-8980





# National Parkinson Foundation, Inc. (NPF)

1501 Northwest Ninth Avenue Bob Hope Road Miami Florida 33136-1494 (800) 327-4545 (Outside Florida) (305) 547-6666

# **EXECUTIVE DIRECTOR:**

Nathan Slewett, President

# **CONTACT PERSON (S):**

Nathan Slewett

# **CHAPTERS/SATELLITES:**

Support groups throughout the United States

# **PURPOSE:**

The National Parkinson Foundation is a major force in research, treatment, and rehabilitation programs for Parkinson syndrome. Members receive periodic written information about current research and treatment, assistance in finding proper diagnostic and treatment services, assistance in establishing local chapters and support groups, and announcements of formal education programs and seminars.

# PUBLICATIONS:

• Starting a Support Group

### **AUDIOVISUALS:**

None

# **NEWSLETTER:**

- Parkinson Report (Quarterly)
- Research Newsletter (Quarterly)



None

# CONTACT PERSON (S):

Al Shepherd and Harry Sterkel

# CHAPTERS/SATELLITES:

Michig..., New Jersey, and Wisconsin

# National Spasmodic Torticollis Association

P.O. Box 873 Royal Oak Michigan 48068-0873 (313) 775-1367 (313) 547-2189

# **PURPOSE:**

The National Spasmodic Torticollis Association serves to educate the general public and primary care physicians about spasmodic torticollis and to establish local self-help support groups of individuals with spasmodic torticollis and their families.

# **PUBLICATIONS:**

• Fact Sheer

nodic Torticollis

# **AUDIOVISUALS:**

None

# NEWSLET1 ER:

Quarterly



# National Tuberous Sclerosis Association, Inc. (NTSA)

4351 Garden City Drive Suite 660 Landover Maryland 20785 (800) CAL-NTSA (301) 459-9888

# **EXECUTIVE DIRECTOR:**

Vicky Whittemore, Ph.D., President

# **CONTACT PERSON (S):**

Vicky Whittemore, Ph.D.

# **CHAPTERS/SATELLITES:**

North Carolina

# **PURPOSE:**

The National Tuberous Sclerosis Association serves as a resource for the cure and prevention of tuberous sclerosis and for the improvement of the quality of life (medically, psychologically, and socially) of individuals and families affected by tuberous sclerosis.

# **PUBLICATIONS:**

- Parent Booklet
- Tuberous Sclerosis (brochure)
- Tuberous Sclerosis: An Illustrated Brochure for Physicians

# **AUDIOVISUALS:**

- Parents Ask About TS
- Slide presentation about the nature of Tuberous Sclerosis
- TS (prepared by T.S.A. of Great Britain)

# **NEWSLETTER:**

Quarterly



Dinah T. Orr

# **CONTACT PERSON (S):**

**Sheree Loftus** 

# **CHAPTERS/SATELLITES:**

None

Parkinson's
Disease
Foundation, Inc.
(PDF)

650 West 168th Street New York New York 10032-9982 (800) 457-6676 (212) 923-4700

# **PURPOSE:**

In addition to funding research the Parkinson's Disease Foundation offers symposia, necleal fellowships, and grants to research departments of universities and hospitals. The foundation also serves as a source of information to patients and physicians.

# **PUBLICATIONS:**

- Exercises for the Parkinson Patient
- Parkinson's Disease: Progress, Promise and Hope!
- The Parkinson Patient at Home

# **AUDIOVISUALS:**

• Management of Parkinson's Disease and Syndrome with Levodopa

# **NEWSLETTER:**

Triannually

# Parkinson's Educational Program (PEP) - USA

1800 Park Newport #302 Newport Beach California 92660 (800) 344-7872 (714) 640-0218

# EYECUTIVE DIRECTOR:

Charlotte Jayne Drake

# **CONTACT PERSON (S):**

Charlotte Jayne Drake

#### **CHAPTERS/SATELLITES:**

Local support groups throughout the United States

# **PURPOSE:**

The Parkinson's Educational Program promotes the establishment of support groups; assists the support groups in offering services; educates the public about Parkinson syndrome; encourages and supports education of the medical professions; promotes, encourages, and assists in the search for the causes and cure of Parkinson syndrome; and provides counseling services.

# **PUBLICATIONS:**

Catalog available upon request

# **AUDIOVISUALS:**

Catalog available upon request

# **NEWSLETTER:**

• Pep Exchange (Monthly)



Audrey Thomas, R.N., Co-Chairperson

# **CONTACT PERSON (S):**

Francis J. and Rosalyn M. Davis, Co-Chairpersons

# **CHAPTERS/SATELLITES:**

None

# PURPOSE:

The Reflex Sympathetic Dystrophy Syndrome Association supports research into the cause, treatment, and cure of RSDS. The association provides information on physician seminars and patient services.

# **PUBLICATIONS:**

• Reflex Sympathetic Dystrophy Syndrome: Help Us Stop the Pain

# **AUDIOVISUALS:**

None

# **NEWSLETTER:**

None

Reflex
Sympathetic
Dystrophy
Syndrome
Association
(RSDSA)

822 Wayside Lane Haddonfield New Jersey 08033 (609) 428-6510 (609) 428-6980



# Spina Bifida Association of America (SBAA)

1700 Rockville Pike Suite 540 Rockville Maryland 20852 (800) 621-3141 (301) 770-7222

# **EXECUTIVE DIRECTOR:**

Norman A. Coe

# **CONTACT PERSON (S):**

Norman A. Coe

# **CHAPTERS/SATELLITES:**

Chapters throughout the United States, Puerto Rico, and Canada

#### **PURPOSE:**

The Spina Bifida Association of America advocates for the human rights of persons with spina bifida; encourages the care, treatment, education, socialization, and vocational development of persons with spina bifida; and promotes public awareness of spina bifida.

# **PUBLICATIONS:**

Catalog available upon request

# **AUDIOVISUALS:**

Catalog available upon request

# **NEWSLETTER:**

• Insights (Bimonthly)



Karen Ball

# **CONTACT PERSON (S):**

Karen and Kirk Ball

# **CHAPTERS/SATELLITES:**

None

Sturge-Weber Foundation

P.O. Box 460931 Aurora Colorado 80015 (303) 693-2986

# **PURPOSE:**

The Sturge-Weber Foundation acts as a clearinghouse for information on all aspects of Sturge-Weber syndrome, provides a support network for families affected by the syndrome, and facilitates medical research.

# **PUBLICATIONS:**

- A pamphlet detailing each aspect of the syndrom and corrective measures needed is in progress
- Informational Brochure: The Sturge-Weber Foundation

# **AUDIOVISUALS:**

In progress

# **NEWSLETTER:**

Quarterly

## Tourette Syndrome Association, Inc. (TSA)

42-40 Bell Boulevard Bayside New York 11361 (718) 224-2999

#### **EXECUTIVE DIRECTOR:**

Dennis Herschfelder

#### **CONTACT PERSON (S):**

Jared Bernstein, C.S.W.

#### **CHAPTERS/SATELLITES:**

43 chapters throughout the United States

#### **PURPOSE:**

The Tourette Syndrome Association fosters better understanding and acceptance of Tourette syndrome among professionals and the lay public. The association disseminates information on TS, promotes scientific research, and provides counseling and advocacy services to its members.

#### **PUBLICATIONS:**

Catalog available upon request

#### **AUDIOVISUALS:**

- Stop It! I Can't
- Tourette Syndrome: The Sudden Intruder

#### **NEWSLETTER:**

• TSA Newsletter (Quarterly)



Part Sixteen / 168

Shirley L. Cort

#### **CONTACT PERSON (S):**

Raymond A. Conners

#### **CHAPTERS/SATELLITES:**

Representatives throughout the country

#### Tuberous Sclerosis Association of America, Inc. (TSAA)

P.O. Box 1305 Middleboro Massachusetts 02370 (617) 947-8893

#### **PURPOSE:**

The Tuberous Sclerosis Association of America is dedicated to supporting research on tuberous sclerosis and public and professional education on the disorder. It also serves as a contact service for patients, families, and health professionals.

#### **PUBLICATIONS:**

- A Brief Description of Tuberous Sclerosis
- TSAA Picture Brochure

#### **AUDIOVISUALS:**

None

#### **NEWSLETTER:**

• T.S.A.A. (Biannually)



- [	
	Part Seventeen
	Neuromuscular
	171

Rodney L. Houts

#### **CONTACT PERSON (S):**

Lynn M. 1 lein-Salas, Director of Patient Services

#### CHAPTERS/SATELLITES:

Arizona, California (2), Florida (4), Indiana, Kentucky, Michigan, Mississippi, Missouri, New Jersey, North Carolina, Ohio, Pennsylvania (2), Tennessee, Texas, and Wisconsin. Twer.cy-one support groups in Alabama, Arizona, California (3), Connecticut, Illinois, Iowa (2), Louisiana (2), Maryland, Minnesota, Missouri, New Mexico, New York (3), Oklahoma, Oregon, Rhode Island, Utah, and Vermont

#### **PURPOSE:**

The Amyotrophic Lateral Sclerosis Association supports research investigating ALS (also known as Lou Gehrig's disease). The association's program includes research funding, patient services, public and professional education, chapter development, and the establishment of ALS clinical service centers nationwide.

#### **PUBLICATIONS:**

- Managing Amyotrophic Lateral Sclerosis (MALS) Manuals
- What is Amyotrophic Lateral Sclerosis?

#### **AUDIOVISUALS:**

None

#### **NEWSLETTER:**

• Link (Six issues a year)

Amyotrophic Lateral Sclerosis Association, Inc. (ALSA)

15300 Ventura Boulevard Suite 315 Sherman Oaks California 91403 (818) 990-2151





# AVENUES National Support Group for Arthrogryposis Multiplex Congenita

P.O. Box 5192 Sonora California 95370 (209) 928-3689

#### **EXECUTIVE DIRECTOR:**

Mary Anne and Jim Schmidt

#### **CONTACT PERSONS:**

Mary Anne and Jim Schmidt

#### **CHAPTERS/SATELLITES:**

None

#### **PURPOSE:**

AVENUES was founded for the purposes of sharing information on arthrogryposis multiplex congenita (AMC). The group maintains a list of physicians with a special interest in the causes and treatment of AMC and promotes the exchange of information about therapy. surgeries, aids, and available services.

#### **PUBLICATIONS:**

• What is Arthrogryposis?

#### **AUDIOVISUALS:**

None

#### **NEWSLETTER:**

• Avenues (Biannually)

Part Seventeen/ 174



Sherrie Dominy

#### **CONTACT PERSON (S):**

Mattie Lou Koster, Founder and Chairman of the Board

#### **CHAPTERS/SATELLITES:**

At least one support group in every state

#### **PURPOSE:**

The Benign Essential Blepharospasm Research Foundation is an international clearinghouse for information on facial dystonia as well as a sponsor of continuing education and an annual international conference on blepharospasm and support are the main functions of the foundation, with the goal being the eradication of blepharospasm and the support of those with the disorder.

#### **PUBLICATIONS:**

• Benign Essential Blepharospasm, Meige's and Other Related Disorders

#### **AUDIOVISUALS:**

Catalog available upon request

#### **NEWSLETTER:**

**Bimonthly** 

Benign
Essential
Blepharospasm
Research
Foundation,
Inc.
(BEBRF)

P.O. Box 12468 Beaumont Texas 77706 (409) 832-0788





#### CMT (Charcot-Marie-Tooth) International, Inc.

34 Bayview Drive St. Catharines Ontario L2N 4Y6 Canada (416) 937-3851

#### **EXECUTIVE DIRECTOR:**

Linda Crabtree

#### **CONTACT PERSONS:**

Linda Crabtree

#### C!'APTERS/SATELLITES:

44 throughout the United States, Australia, Canada, Great Britain, and New Zealand

#### **PURPOSE:**

CMT International helps those with Charcot-Marie-Tooth disease (also known as peroneal muscular atrophy and here-ditary motor and sensory neuropathy) to better cope with the disease. The organization provides information, referrals, and psychological and genetic counseling.

CMT International also provides a registry for research, enabling health professionals to locz individuals for analyses. Each chapter sponsors local support meetings as the need arises.

#### **PUBLICATIONS:**

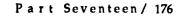
Pamphlet on Charcot-Marie-Tooth disease and CMT International

#### **AUDIOVISUALS:**

None

#### **NEWSLETTER:**

• CMT Newsletter (Bimonthly)





Lois Raphael (Canada)

#### **CONTACT PERSON (S):**

Nancy Harris (United States)

#### **CHAPTERS/SATELLITES:**

15 chapters throughout North America

#### **PURPOSE:**

The Dystonia Medical Research Foundation was created to support research directed to finding the causes of all forms of dystonia and to educate both the medical and lay communities.

#### **PUBLICATIONS:**

Various pamphlets

#### **AUDIOVISUALS:**

Documentary on dystonia Public service announcement

#### **NEWSLETTER:**

Quarterly

#### Dystonia Medical Research Foundation (DMRF)

8383 Wilshire Boulevard
Suite 800
Beverly Hills
California
90210
(213) 852-1630
77 Hornby Street
Vancouver, British
Columbia V6Z 1S4
Canada
(604) 668-5931



#### Families of S.M.A. (Spinal Muscular Atrophy)

P.O. Box 1465 Highland Park Illinois 60035 (312) 432-5551

#### **EXECUTIVE DIRECTOR:**

Audrey N. Lewis

#### **CONTACT PERSONS:**

Audrey N. Lewis

#### **CHAPTERS/SATELLITES:**

New England, New York, Missouri, Oregon, Washington, Australia, and Great Britain

#### **PURPOSE:**

Families of S.M.A. raises monies for research, provides patient support, and promotes public awareness of the diseases which are presently known as Werdnig-Hoffmann, Kugelberg-Welander, benign congenital hypotonia, and Aran-Duchenne Type (adult progressive spinal muscular atrophy).

#### **PUBLICATIONS:**

• Booklet on Werdn g-Hoffmann disease

#### **AUDIOVISUALS:**

- Living With S.M.A.
- Slide Presentation

#### **NEWSLETTER:**

• Direction (Six issue a year)

Part Seventeen / 178

ERIC

**Robert Ross** 

#### **CONTACT PERSON (S):**

Ronald J. Schenkenberger

#### CHAPTERS/SATELLITES:

240 MDA clinics throughout the United States

#### Muscular Dystrophy Association (MDA)

810 Seventh Avenue New York New York 10019 (212) 586-0808

#### **PURPOSE:**

The Muscular Dystrophy Association provides a comprehensive patient and community services program. Its clinics provide diagnostic services; therapeutic and rehabilitative follow-up care; and genetic, vocational, and social service counseling to patients and their families. Other services include repair of orthopedic appliances and transportation aid. MDA also supports an international research program to find the causes of neuromuscular disorders.

#### **PUBLICATIONS:**

Catalog available upon request

#### **AUDIOVISUALS:**

Catalog available upon request

#### **NEWSLETTER:**

• MDA News Magazine (Quarterly)



#### Myasthenia Gravis Foundation, Inc. (MGF)

7-11 South Broadway Suite 304 White Plains New York 10601 (914) 328-1717

#### **EXECUTIVE DIRECTOR:**

Valerie M. Tennent, Executive Administrator

#### **CONTACT PERSONS:**

Valerie M. Tennent

#### **CHAPTERS/SATELLITES:**

51 chapters and branches in the United States

#### **PURPOSE:**

The Myasthenia Gravis Foundation is dedicated to the detection, treatment, and cure of myasthenia gravis. Foundation programs include public and professional information and education, patient services, research grants and fellowships, annual scientific sessions, and international symposia.

#### **PUBLICATIONS:**

- A Manual for the Nurse (English and Spanish)
- A Manual for the Physician (English and Spanish)
- Facts About MG For Patients and Families
- MG and the MGF
- Myasthenia Gravis The Disease: A Case History

#### **AUDIOVISUALS:**

None

#### **NEWSLETTER:**

None

Part Seventeen/ 180



	<b></b>
EXECUTIVE DIRECTOR: Sharon Dobkin CONTACT PERSON (S):	Myoclonus Families United
Sharon Dobkin	
January Dodan	
CHAPTERS/SATELLITES: None	1564 East 34th Street Brooklyn New York 11234 (718) 252-2133
PURPOSE:  Myoclonus Families United supports affected individuals and their families. The group provides physiciar. referrals and testifies in Congress as an advocate of increased national support.	
PUBLICATIONS:  • Self-help directory	
AUDIOVISUALS: None	
NEWSLETTER:	



None

### National Ataxia Foundation

600 Twelve Oaks Center 15500 Wayzata Boulevard Wayzata Minnesota 55391 (612) 473-7666

#### **EXECUTIVE DIRECTOR:**

Donna Gruetzmacher, Patient Services Director

#### **CONTACT PERSONS:**

Donna Gruetzmacher

#### **CHAPTERS/SATELLITES:**

Arkansas, California, Iowa, Louisiana, Minnesota (2), Mississippi, Pennsylvania, South Dakota, Texas, and Virginia

#### **PURPOSE:**

The National Ataxia Foundation strives to combat all types of hereditary ataxia and closely related disorders such as hereditary spastic paraplegia, ataxia telangicctasia, and Charcot-Marie-Tooth syndrome. The foundation offers referrals and educational programs, and it supports research into the causes and early detection of ataxia.

#### **PUBLICATIONS:**

• Hereditary Ataxia(HA): The Facts

#### **AUDIOVISUALS:**

None

#### **NEWSLETTER:**

• Generations (Quarterly)

Part Seventeen/ 182



Thor Hanson, President

#### **CONTACT PERSON (S):**

Thor Hanson

#### **CHAPTERS/SATELLITES:**

5 regional groups and 140 local groups throughout the United States

#### **PURPOSE:**

The National Multiple Sclerosis Society serves affected individuals through many channels including research support. Current information and counseling are available to patients, their families, and to interested parties. The society also provides advocacy, referrals, and equipment loans.

#### **PUBLICATIONS:**

Catalog available upon request

#### **AUDIOVISUALS:**

Catalog available upon request

#### **NEWSLETTER:**

• Inside MS (Quarterly)

National Multiple Sclerosis Society

205 East 42nd Street New York New York 10017 (212) 986-3240

Part Seventeen/ 183

Part Eighteen
Short Stature

Denise Orenstein

#### **CONTACT PERSON (S):**

Denise Orenstein

#### CHAPTERS/SATELLITES:

California, District of Columbia, Illinois, Michigan, Minnesota, Missouri, New York, Texas, and Washington

#### Human Growth Foundation (HGF)

4720 Montgomery Lane Bethesda Maryland 20815 (301) 656-7540

#### **PURPOSE:**

The Human Growth Foundation disseminates information on growth (short stature), makes medical research awards in the field of growth, and sponsors educational and parent support activities.

#### **PUBLICATIONS:**

- Achondroplasia
- Growth Hormone Deficiency
- Intrauterine Growth Retardation
- Patterns of Growth
- "rurner's Syndrome

#### **AUDIOVISUALS:**

None

#### **NEWSLETTER:**

Monthly

Part Eighteen / 187



#### Little People of America, Inc. (LPA)

P.O. Box 633 San Bruno California 94066 (415) 589-0695

#### **EXECUTIVE DIRECTOR:**

None

#### **CONTACT PERSONS:**

Harriet and Al Stickney

#### **CHAPTERS/SATELLITES:**

12 districts with 43 chapters throughout the United States

#### **PURPOSE:**

Little People of America is dedicated to helping people of short stature and their families through fellowship, moral support, and the exchange of ideas and information. LPA offers publications, educational and social programs and works. ps, and discussion groups for short-statured individuals, their families, and the general public. The LPA Medical Adisory Board helps members become better informed about their particular type of short stature.

#### **PUBLICATIONS:**

- Little People in America: A Social Dimension
- Membership brochure (English and Spanish)
- My Child Is A Dwarf (English and Spanish)

#### **AUDIOVISUALS:**

• Little Peopl. (PDS documentary, 1984)

#### **NEWSLETTER:**

• LPA Today (Six issues a year)

ERIC Full float Provided by ERIC

Part Eighteen / 188

Margaret B. Badner

#### **CONTACT PERSON (S):**

Margaret and Julius Badner

#### **CHAPTERS/SATELLITES:**

None

#### **PURPOSE:**

Parents of Dwarfed Children is an organization hich parents of short-statured children help parents who have recently learned that their child has a form of dwarfism.

#### **PUBLICATIONS:**

• A Resource for Parents of Short-Statured Children (brochure)

#### **AUDIOVISUALS:**

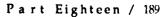
None

#### **NEWSLETTER:**

None

### Parents of Dwarfed Children

11524 Colt Terrace Silver Spring Maryland 20902 (301) 649-3275





Part Nineteen
Skin
191

Arlene Pessar, R.N.

#### **CONTACT PERSON (S):**

Arlene Pessar, R.N.

#### CHAPTERS/SATELLITES:

Regional support groups

#### **PURPOSE:**

The Dystrophic Epidermolysis Bullosa Research Association of America promotes and supports basic and clinical research in epidermolysis bullosa (EB); provides information for patients, families, health professionals, and the general public; distributes educational material on EB; and assists in finding medical care, social services, and genetic counseling for those in need.

#### **PUBLICATIONS:**

- Coping with Epidermolysis Bullosa in the Classroom: An Informed and Sensitive Home/School Partnership Makes the Difference
- Facts About D.E.B.R.A.
- Hope Through Research
- Impossible Victory of Eric Lopez
- Living with Epidermolysis Bullosa
- Researchers Scek Cause of Enigmatic Blistering Disorder

#### **AUDIOVISUALS:**

None

#### NEWSLETTER:

• E.B. Currents (Biannually)

Dystrophic Epidermolysis Bullosa Research Association of American, Inc. (D.E.B.R.A.)

Kings County Medical Center 451 Clarkson Avenue Building E-6-101 Sixth Floor Brooklyn New York 11203 (718) 774-8700



#### Foundation for Ichthyosis and Related Skin Types, Inc. (F.I.R.S.T.)

3640 Grand Avenue Suite 2 Oakland California 94610 (415) 763-9839

#### **EXECUTIVE DIRECTOR:**

Charles Eichorn

#### **CONTACT PERSON (S):**

Charles Eichorn

#### **CHAPTERS/SATELLITES:**

Alaska, Arizona, California, Colorado, Connecticut, Florida, Georgia, Idaho, Illinois, Indiana, Iowa, Kansas, Louisiana, Massachusetts, Minnesota, Mississippi, Missouri, New Jersey, New Mexico, New York, North Carolina, Ohio, Pennsylvania, South Carolina, Texas, Virginia, Washington, and Canada

#### **PURPOSE:**

The Foundation for Ichthyosis and Related Skin Types works for the benefit and education of its members and the public regarding medical, psychological, and social aspects of ichthyosis.

#### **PUBLICATIONS:**

- Ichthyosis An Overview (brochure)
- Ichthyosis The Genetics Of Its Inheritance (brochure)
- The Foundation for Ichthyosis and Related Skin Types (brochure)

#### **AUDIOVISUALS:**

None

#### **NEWSLETTER:**

• Ichthyosis Focus (Six issue a year)



Martha Woodhouse

#### **CONTACT PERSON (S):**

Martha Woodhouse

#### CHAPTERS/SATELLITES:

None

#### **PURPOSE:**

The National Congenital Port Wine Stain Foundation serves the needs of individuals with a port wine stain and their families. The organization collects and disseminates information; sponsors, designs, and conducts counseling and self-help programs; facilitates the interchange of ideas, experiences, and personal contact among persons engaged in research and treatment and families with port wine stains; and coordinates and supports research and education.

#### **PUBLICATIONS:**

• The National Foundation (brochure)

#### **AUDIOVISUALS:**

None

#### **NEWSLETTER:**

None

National
Congenital Port
Wine Stain
Foundation

125 East 63rd Street New York New York 10021 (212) 755-3820



## National Foundation for Ectodermal Dysplasias (NFED)

108 North First Street Suite 311 Mascoutah Illinois 62258 (618) 566-2020

#### **EXECUTIVE DIRECTOR:**

Mary Kaye Richter

#### **CONTACT PERSON (S):**

**Beverly Meier** 

#### CHAPTERS/SATELLITES:

None

#### **PURPOSE:**

The National Foundation for Ectodermal Dysplasias provides support and information services to families, patients, and medical professionals concerned with the needs of individuals affected by the ectodermal dysplasia syndromes. Research projects are encouraged, and cooperative efforts are undertaken. The ultimate goal is to assure all patients not only a normal life span but a normal lifestyle as well. The foundation provides information services through its monthly newsletter and other publications. Referrals for treatment are made, and a scientific advisory board is available to provide diagnostic information and assist with treatment when necessary. A treatment fund is available to assist families with the ongoing expense of dental care.

#### **PUBLICATIONS:**

- A Dental Guide to the Ectodermal Dysplasias
- A Family Guide to the Ectodermal Dysplasias
- NFED Organizational Pamphlet
- The Ectodermal Dysplasias

#### AUP OVISUALS:

• A Trip to the Dentist - A Child's First Experience with Dentures

#### **NEWSLETTER:**

• The Educator (Monthly)



Diane Williams

#### **CONTACT PERSON (S):**

Diane Williams

#### CHAPTERS/SATELLITES:

Alabama, Arizona, California (7), Florida (2), Illinois, Kentucky, Michigan, Minnesota, New Jersey, New York (2), Ohio, Oklahoma (2), Pennsylvania, South Carolina, Tennessee (2), Texas (2), and Edmonton, Canada

#### **PURPOSE:**

The United Scleroderma Foundation offers scleroderma patients and their families emotional and educational support and raises funds to finance scleroderma related programs and research.

#### **PUBLICATIONS:**

Catalog available upon request

#### **AUDIOVISUALS:**

None

#### **NEWSLETTER:**

Quarterly

United Scleroderma Foundation, Inc. (USF)

> P.O. Box 350 Watsonville California 95077-0350 (408) 728-2202

#### Xeroderma Pigmentosum Registry

UMDNJ
New Jersey Medical
School
Department of Pathology
Room C-520
Medical Science Building
100 Bergen Street
Newark
New Jersey
07103
(201) 456-6255

#### **EXECUTIVE DIRECTOR:**

W. Clark Lambert, M.D.

#### **CONTACT PERSON (S):**

W. Clark Lambert, M.D.

#### **CHAPTERS/SATELLITES:**

None

#### PURPOSE:

The Xeroderma Pigmentosum Registry provides a centralized information base concerning xeroderma pigmentosum. Statistical analyses on patient data provide insights into this disease. Professional information is also supplied

#### **PUBLICATIONS:**

None

#### **AUDIOVISUALS:**

None

#### **NEWSLETTER:**

None



Part Twenty
Visual
199

William F. Gallagher

#### **CONTACT PERSONS:**

Corinne Kirchner, Director of Social Research

#### CHAPTERS/SATELLITES:

Chapters are throughout the United States with regional offices in California, District of Columbia, Georgia, Illinois, New York, and Texas

American
Foundation for
the Blind, Inc.
(AFB)

15 West 16th Street New York New York 10011 (212) 620-2000

#### **PURPOSE:**

The American Foundation for the Blind advocates for the blind and visually impaired and develops and implements programs and services to help them achieve independence with digraty in all sectors of society.

#### **PUBLICATIONS:**

Catalog available upon request

#### **AUDIOVISUALS:**

Catalog available upon request

#### **NEWSLETTER:**

• AFB News (Quarterly)

## Association for Macular Diseases, Inc.

210 East 64th Street New York New York 10021 (212) 605-3719

#### **EXECUTIVE DIRECTOR:**

Nicholai Stevenson

#### **CONTACT PERSONS:**

Janet DeRosa

#### **CHAPTERS/SATELLITES:**

None

#### **PURPOSE:**

The Association for Macular Diseases acts as a support group for individuals and their families who are adjusting to the restrictions and changes brought about by macular disease. A forum for emotional support and counseling is provided for affected persons.

#### **PUBLICATIONS:**

None

**AUDIOVISUALS:** 

None

**NEWSLETTER:** 

Quarterly



Sherry Raynor, President

#### **CONTACT PERSONS:**

Sherry Raynor and Susan Carson, Parent Coordinator

#### CHAPTERS/SATELLITES:

Massachusetts and Michigan

#### Blind Children's Fund

230 Central Street Auburndale Massachusetts 02166-2399 (617) 332-4014

#### PURPOSE:

The Blind Children's Fund collects, develops, and disseminates information, materials, and services for (blind) infants and pre-school children, their parents, and the professionals who work with them.

#### **PUBLICATIONS:**

Catalog available upon request

#### **AUDIOVISUALS:**

Catalog available upon request

#### **NEWSLETTER:**

• VIP (Quarterly)



# National Association for Parents of the Visually Impaired, Inc. (NAPVI)

P.O. Box 180806 Austin Texas 78718 (512) 323-5710

#### **EXECUTIVE DIRECTOR:**

Keitha Robinson (Acting)

#### CONTACT PERSONS:

Keitha Robinson

#### CHAPTERS/SATELLITES:

California, Nebraska, New York, Ohio, and Pennsylvania

#### **PURPOSE:**

The membership of the National Association for Parents of the Visually Impaired includes parents, parent organizations, agencies, and other persons dedicated to supporting the parents of visually impaired children.

#### **PUBLICATIONS:**

Catalog available upon request

#### **AUDIOVISUALS:**

None

#### **NEWSLETTER:**

• Awareness (Quarterly)



Lorraine H. Marchi

#### **CONTACT PERSONS:**

Lorraine H. Marchi

#### **CHAPTERS/SATELLITES:**

None

#### **PURPOSE:**

The National Association for Visually Handicapped provides information, referrals, counseling, and guidance to the partially sighted, their families, and the professionals, paraprofessionals, and business community who work with them. Informational booklets and brochures, large-print books for pleasure-reading, textbooks, and tesing material are available for adults and children.

#### **PUBLICATIONS:**

Catalog available upon request

#### **AUDIOVISUALS:**

None

#### **NEWSLETTER:**

- In-Focus (children) (One or two issues a year)
- Seeing Clearly (adults) (One or two issues a year)

National
Association for
Visually
Handicapped

22 West 21st Street 6th Floor New York New York 10010 (212) 889-3141



#### National Society to Prevent Blindness

500 East Remington Road Schaumberg Illinois 60173 (312) 843-2020

#### **EXECUTIVE DIRECTOR:**

Michael Weamer

#### **CONTACT PERSONS:**

Linda Shaub, Director of Marketing and Communications

#### **CHAPTERS/SATELLITES:**

27 affiliates/divisions

#### **PURPOSE:**

The National Society to Prevent Blindness works to prevent blindness through community service programs, public and professional education, and research.

#### **PUBLICATIONS:**

Catalog available upon request

#### **AUDIOVISUALS:**

Catalog available upon request

#### **NEWSLETTER:**

• InSight



Julie Gerhardt

#### **CONTACT PERSONS:**

Elaine Dickenson or Geraldine Miller

#### **CHAPTERS/SATELLITES:**

Through organized networking, parents are encouraged to form cluster groups and personal/social contacts by telephone and correspondence.

#### **PURPOSE:**

Parents and Cataract Kids offers info mation and support to families with children affected by caracts by means of networking among members, informative meetings and social functions, referrals to service providers, and dissemination of information.

#### **PUBLICATIONS:**

- · Agencies to Contact For Your Visually Impaired Child
- PACK Parent Resource Library Addendum One
- PACK Parent Resource Library Bibliography
- Understanding Congenital Cataracts

#### **AUDIOVISUALS:**

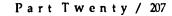
None

#### **NEWSLETTER:**

• In-Sight (Quarterly)

#### Parents and Cataract Kids (PACK)

179 Hunters Lane Devon Pennsylvania 19333 (215) 293-1917 (215) 721-9131 (215) 352-0719





#### RP Foundation Fighting Blindness

140? Mt. Royal Avenue Baltimore Maryland 21217 (800) 638-2300 (301) 225-9400

#### **EXECUTIVE DIRECTOR:**

**Robert Gray** 

#### **CONTACT PERSONS:**

Fran Ludman

#### **CHAPTERS/SATELLITES:**

Alabama (2), Alaska, California (6), Colorado, Connecticut, Delaware, the District of Columbia, Florida (5), Hawaii, Illinois, Indiana, Kansas, Kentucky, Maine, Maryland, Michigan (3), Minnesota, Missouri, Montana, Nevada, New Jersey (2), New York (4), North Carolina (2), Ohio (2), Oklahoma, Oregon (2), Pennsylvania (2), Rhode Island, South Carolina, Texas (5), Utah, Vermont, Virginia, Washington, West Virginia, Wisconsin, Wyoming, Australia, Austria, Belgium, Canada, Costa Rica, Denmark, Finland, France, India, Ireland, Italy, Mexico, The Netherlands, New Zealand, Panama, South Africa, Sweden, Switzerland, United Kingdom, and West Germany

#### **PURPOSE:**

The RP Foundation Fighting Blindness works to discover the cause, treatment, and prevention of retinitis pigmentosa, Usher syndrome, macular degeneration and other retinal degenerative conditions through research.

#### **PUBLICATIONS:**

Catalog available upon request

#### **AUDIOVISUALS:**

- Educational Slide Series
- · RP Foundation Slide Series
- Understanding the Genetics of RP

#### **NEWSLETTER**·

• Fighting Blindness News (Quarterly)



	Indexes
-	
	209



Achondroplasia, see Short Stature

Acoustic Neuroma, 147

Adrenoleukodystrophy, see Leukodystrophy

Adult Progressive Spinal Muscular Atrophy (Aran-Duchenne Type), see Spinal Muscular Atrophy, Muscular Dystrophy

Affective Disorders, see Depression

Agammaglobulinemia, see Immune Deficiency

Alagille Syndrome, see Liver Diseases

Albinism, 128

Alexander Disease, see Leukodystrophy

Alpha-1-Antitrypsin Deficiency, see Liver Diseases

Alzheimer Disease, 148

Amyotrophic Lateral Sclerosis, 173

Argininosuccinic Acidemia, see Organic Acidemia

Arthritis, 137

Arthrogryposis, 174

Ataxia, 153, 182

Ataxia Telangiectasia, see Ataxia

Auditory Disorders, 21

Autism, 67

Bardet-Biedl Syndrome. see Laurence-Moon-Biedl Syndrome

Bassen-Kornzweig Syndrome, see Retinal Degeneration

Batten Disease, 151

Benign Congenital Hypotonia, see Spinal Muscular Atrophy, Muscular Dystrophy

Best Disease, see Retinal Degeneration

Biliary Atresia, see Liver Diseases

Birth Defects, 14

Bleeding Disorders, see Hemophilia

Blepharospasm, 175

Blindness, see Visual Disorders

Canavan Disease, see Leukodystrophy, Tay-Sachs and Allied Diseases

Cancer, 25

Cardiovascular Disease, 37

Caturacts, 207

Cat Cry Syndrome, see Cri-du-Chat Syndrome

Celiac Sprue, 79, 81, 83

Cerebral Palsy, 75

Cerebrotendinous Xanthomatosis, see Leukodystrophy

Charcot-Marie-Tooth Disease, 176

Chediak-Higgshi Syndrome, see Albinism

Chronic Granulomatous Disease, see Immune Deficiency Disease

Child Syndrome, see Ichthyosis and Related Skin Types

Chondrodysplasia Punciata, see Ichthyosis and Related Skin Types

Choroidermia, see Retinal Degeneration

Chromos mal Disorders, 39

Crohn Disease, see Ileitis

#### Subject Index



# Subject Index (cont'd)

Cleft Lip/Palate, 59, 62 Cockayne Syndrome, 74 Colitis, 84 Collodion Fetus, see Ichthyosis and Related Skin Types Colorectal Cancer, 29, 30, 31 Congenital Heart Defects, see Cardiovascular Disease Congenital Ichthyosiform Erythroderma (CIE), see Ichthyosis and Related Skin Types Congenital Port Wine Stain, 195 Connective Tissue Disorders, 53 Cooley's Anemia, 87 Cornelia de Lange Syndrome, 69 Craniofacial Anomalies, 57 Crest Syndrome, see Scleroderma Cri-du-Chat Synd ome, 42 Crouron Diseas, see Craniofacial Anomalies Cystic Fibrosis, 117 Cystinosis, 118

Darier Disease, see Ichthyosis and Related Skin Types Deafness, see Auditory Disorders
Dementia, see Alzheimer Disease
Depression, 109
Dermatitis Herpetiformis, see Gluten Intolerance
Developmental Disabilities, 63
Diabetes, 113
DiGeorge Syndrome, see Immune Deficiency
Down Syndrome, 41, 45, 46, 47
Dwarfism, see Short Stature
Dysautonomia, 119
Dyslexia, 65, 71
Dystonia, 175, 177

Ectodermal Dyslasias, 196
Edwards Syndrome, see Trisomy 18/13
Ehlers Panlos Syndrome, 55
Epidermal Nevus Syndrome, see Ichthyosis and Related Skin Types
Epidermolysis Bullosa, 193
Epidermolytic Hyperkeratosis, see Ichthyosis and Related Skin Types
Epilepsy, 152
Ethylmalonic Adipic Acidemia, see Organic Acidemia

Facial Dystonia, see Blepharospasm
Facial Reconstruction, 60, 61
Familal Adenomatous Polyposis, see Familial Polyposis
Familial Dysautonomia, see Dysautonomia
Familial Polyposis, 29, 30, 31
Fanconi Anemia, 88
5p., see Cri-du-Chat Syndrome



Fragile X, 43, 44
Freeman-Sheldon Syndrome, 138
Friedreich Ataxia, 153

Galactosemia, see Liver Diseases
Gangliosidosis, see Tay-Sachs and Allied Diseases
Gardner Syndrome, see Familial Polyposis
Gastrointestinal Disorders, 77
Gastrointestinal Polyposis, see Familial Polyposis
Gaucher Disease, 126
Gilbert Syndrome, see Liver Diseases
Gluten Intolerance, 79, 81, 83
Glycogen Storage Disease, 115
Growth, 187

Harlequin Fetus, see Ichthyosis and Related Skin Types Hearing Impairments, see Auditory Disorders Heart Murmur, see Cardiovascular Disease Hematologic Disorders, 85 Hemochromatosis, 89 Hemophilia, 94 Hereditary Colon Cancer, see Familial Polyposis Hereditary Hemorrhagic Telangiectasia, 90 Hereditary Spastic Paraplegia, see Ataxia Hermansky-Pudlak Syndrome, see Albinism Histocytosis-X, 91 Homocystinuria, see Organic Acidemia Hunter Syndrome, see Mucopolysaccharidoses Huntington Disease, 154, 155 Hurler Syndrome, see Mucolysaccharidoses Hydrocephalus, 158 Hyperactivity, 68 Hypopigmentation, see Albinism

I-Cell Syndrome, see Mucolipidoses
Ichthyosis and Related Skin Types, 194
Ileitis, 84
Immune Deficiency, 100
Immunologic Disorders, 97
Inflammatory Bowel Disease (IBD), see Ilcitis
Inflammatory Myopathies, see Muscular Dystrophy
Intestinal Multiple Polyposis, see Familial Polyposis
Intrauterine Growth Retardation, see Growth
Isovaleric Acidemia, see Organic Acidemia

Joseph Diseases, 156
Juvenile Arthritis, 137
Juvenile Diabetes, 121
Juvenile Polyposis, see Familial Polyposis

# Subject Index (cont'd)



# Subject Index (cont'd)

Keratitis-Ichthyosis-Deamess (KID) Syndrome, see Ichthyosis and Related Skin Types

Kidney Diseases, 10.

Krabbe Disease, see Leukodystrophy, Tay-Sachs and Allied Diseases Kugelberg-Welander Disease, see Spinal Muscular Atrophy, Muscular Dystrophy

Kyphosis, see Scoliosis

Lamellar Ichthyosis, see Ichthyosis and Related Skin Types

Laurence-Moon-Biedl Syndrome, 70

Leber Amaurosis, see Retinal Degeneration

Learning Disabilities, 65, 71

Leukemia, 32

Leukodystrophy, 131

Liver Diseases, 80, 82

Lordosis, see Scoliosis

Lou Gehrig's Disease, see Amyotrophic Lateral Sclerosis

Lowe Syndrome, 122

Lupus, 99

Lymphomas, see Leukemia

Lysosomal Storage Diseases, see Tay-Sachs and Allied Diseases

Macular Diseases, see Retinal Degeneration

Malignant Hyperthermia, 123

Manic Depression, see Depression

Maple Syrup Urine Disease, 124

Marfan Syndrome, 56

Maroteaux-Lamy Syndrome, see Mucopolysaccharic ses

Meige Lymphedema, see Blepharospasm

Menkes Disease, see Wilson Disease

Men\* Disorders, 107

Mer al Retardation, 66

Metachromatic Leukodystrophy, see Leukodystrophy, Tay-Sachs and

Allied Diseases

Methylmalonic Acidemia, see Organic Acidemia

Monosomy 9p, 49

Morquio Syndrome, see Mucopolysaccharidoses

Motor Neuron Diseases, see Muscular Dystrophy

Mucolipidoses 125, 127

Mucolipidosis IV, 125

Mucopolysaccharidoses, 127

Multiple Myeloma, see Leukemia

Multiple Sclerosis, 183

Multiple Sulfatase Deficiency, see Ichthyosis and Related Skin Types

Muscular Dystrophy, 179

Musculoskeletal Disorders, 135

Myasthenia Gravis, 180

Myelomeningocele, see Spina Bilida

Myoclonus, 181



Myotonic Dystrophy, see Muscular Dystrophy Myotonia Congenita, see Muscular Dystrophy Myotubular Myopathy, see Muscular Dystrophy

Narcolepsy, 149
Neonatal Adrenoleukodystrophy, see Leukodystrophy
Neural Tube Defects, see Spina Bifida
Neurofibromatosis, 159
Neurologic Disorders, 145
Neuro-Metabolic Disorders, 116
Neuronal Ceroid Lipofuscinoses, see Batten Disease
Niemann-Pick Disease, see Tay-Sachs and Allied Diseases

Organic Acidemia, 130 Orphan Diseases, 18 Osler-Weber-Rendu Syndrome, see Hereditary Hemorrhagic Telangiectasia Osteogenesis Imperfecta, 140, 141

Paget Disease, 142 Parkinson Disease, 150, 160, 163 Patau Syndrome, see Trisomy 18/13 Peeling Skin Syndrome, see Ichthyosis and Related Skin Types Pelizaeus-Merzbacher Disease, see Leukodystrophy Peroneal Muscular Atrophy, see Charcot-Marie-Tooth Disease Peutz-Jeghers Syndrome, see Familial Polyposis Pierre Robin Sequence, see Cleft Lip/Palate Pityriasis Rubra Pilaris, see Ichthyosis and Related Skin Types Polycystic Kidney Disease, 106 Polymyositis, see Muscular Dystrophy Pompe Disease, see Glycogen Storage Disease Porphyria, 114 Prader-Willi Syndrome, 48 Progeria, 72 Propionic Acidemia, see Organic Acidemia

Radiation, 15
Raynaud Phenomenon, see Scleroderma
Ref. x Sympathetic Dystrophy Syndrome, 165
Refsum Disease, see Ichthyosis and Related Skin Types, Leukodystrophy, Retinal Degeneration
Retinal Degeneration, 202, 208
Retinitis Pigmentosa, 208
Rett Syndrome, 157
Rheumatic Diseases, see Arthritis
Rheumatic Fever, see Cardiovascular Disease
Riley-Day Syndrome, see Dysautonomia
Rubinstein-Taybi, Syndrome, 73



215

Subject Index

(cont'd)

## Subject Inúex (cont'd)

Sandhoff Disease, see Tay-Sachs and Allied Diseases Sanfilippo Syndrome, see Mucopolysaccharidoses Sarcoidosis, see Liver Diseases Scheie Syndrome, see Mucopolysaccharidoses Scleroderma, 197 Scoliosis, 139, 143 Short Stature, 185 Sialicosis, see Mucolipidoses Siblings, 19 Sickle Cell, 93 Siogren Syndrome, 102 Sjogren-Larsson Syndrome, see Ichthyosis and Related Skin Types Skin Disorders, 191 Sleep Apnea, see Narcolepsy Sly Syndrome, see Mucopolysaccharidoses Spasmodic Torticollis, 161 Spina Bifida, 166 Spinal Muscular Atrophy, 178, 179 Stargardt Disease, see Retinal Degeneration Sturge-Weber Syndrome, 167 Systemic Lupus Erythematosus, see Lupus

Tay-Sachs and Allied Diseases, 129
Thalassemia, see Cooley's Anemia
Thomsen Disease, see Muscular Dystrophy
Thrombocytopenia Absent Radius Syndrome, 95
Tourette Syndrome, 168
Treacher Collins Syndrome, see Craniofacial Anomalies
Trisomy 18/13, 50
Trisomy 21, see Down Syndrome
Tubercus Sclerosis, 169
Turner Syndrome, 51

Unilateral Congenital Ichthyosiforn
Erthroderma, see Ichthyosis and Related Skin Types
Usher Syndrome, see Retinal Degeneration

Visual Impairments, 199
Vitiligo, see Albinism
von Gierke Disease, see Glycogen Storage Disease
von Willebrand Disease, see Hemophilia

Waardenburg Syndrome, see Albinism Williams Syndrome, 132 Wilson Disease, 120, 133

Xeroderma Pigmentosum, 198

Zellweger Syndrome, see Leukodystrophy



Acoustic Neuroma Association, 147

Alexander Graham Bell Association for the Deaf (AGBAD), 23

Alliance of Genetic Support Groups, 13

Alzheimer's Disease and Related Disorders Associations, Inc. (ADRDA), 148

American Cancer Society, Inc., 27

American Celiac Society, 79

American Cleft Palate Association/The Cleft Palate Foundation, 59

American Diabetes Association, Inc., 113

American Foundation for the Biind, Inc. (AFB), 201

American Heart Association, see Council on Cardiovascular Disease in the Young

American Liver Foundation (ALF), 80

American Lupus Society, 99

American Narcolepsy Association (ANA), 149

American Parkinson's Disease Association (APDA), 15u

American Porphyria Foundation, 114

American Society for Deat Children (ASDC), 24

Amyotrophic Lateral Sclerosis Association, Inc. (ALSA), 173

Arthritis Foundation/American Juvenile Arhritis Organization (AJAO), 137

Association for Children and Adults with Learning Disabilities, Inc. (ACLD), 137

Association for Children with Down Syndrome, Inc. (ACDS), 41

Association for Glycogen Storage Disease, 115

Association for Macular Diseases, Inc., 202

Association for Retarded Citizens of the United States (ARC), 66

Association of Neuro-Metabolic Disorders, 116

#### Title Index



### Title Index (cont'd)

Autism Society of America (ASA), 67

AVENUES - National Support Group for Arthrogrype sis Multiplex Congenita, 174

Batten's Disease Support and Research Association, 151

Benign Essential Blepharospasm Research Foundation, Inc., (BEBRF), 175

Blind Children's Fund, 203

Candlelighters Childhood Cancer Foundation, 28

Celiac Sprue Association/United States of America, Inc. (CSA/USA), 81

Center for Hyperactive Child Information, Inc.,(CHCI), 68

Children's Liver Foundation, Inc. (CLF), 82

CMT (Charcot-Marie-Tooth) International, Inc., 176

Cooley's Anemia Foundation, Inc., 87

Cornelia de Lange Syndrome Foundation, Inc., 69

Council on Cardiovascular Disease in the Young, 37

Cystic Fibrosis (CF) Foundation, 117

Cystinosis Foundation, Inc., 118

D.E.B.R.A., see Dystrophic Epidermolysis Bullosa Research Association of America, Inc.

Depression and Related Affective Disorders Association, Inc. (DRADA), 109

Dysautonomia Foundation, Inc., 119

Dystonia Medical Research Foundation(DMRF), 177

Dystrophic Epidermolysis Bullosa Research Association of America, Inc. (D.E.B.R.A.), 193

Ehlers-Danlos National Foundation, (EDNF). 55

Epilepsy Foundation of America (EFA), 152

FACES - National Association for the Craniofacially Handicapped, 60



Familial Polyposis Registry, 29

Families of S.M.A. (Spinal Muscular Atrophy), 178

Fanconi Anemia Support Group, 88

5p-Society, 42

Foundatior for Ichthyosis and Related Skin Types, Inc. (F.I.R.S.T.), 194

Foundation for the Study of Wilson's Disease, Inc., 120

Fragile X Foundation, 43

Fragile X Support, Inc., 44

Freeman-Sheldon Parent Support Group, 138

Friedrich's Ataxia Group in America, Inc.,(FAGA), 153

G.I. Polyposis and Hereditary Colon Cancer Registry, 30

Gluten Intolerance Group of North America (GIG), 83

Hemochromatosis Research Foundation, Inc. (HRF), 89

Hereditary Disease Foundation, 154

Hereditary Hemorrhagic Telangiectasia (HHT) Foundation, Inc. 90

Histiocytosis-X Association of America, Inc., 91

Human Growth Foundation(HGF), 187

Huntington's Disease Society of America, Inc. (HDSA), 155

Immune Deficiency Foundation(IDF), 100

International Joseph Diseases Foundation, Inc. (IJDF), 156

International Parent's Organization, see Alexander Graham Bell Association for the Deaf

International Rett Syndrome Association, Inc., 157

Intestinal Multiple Polyposis and Colorectal Cancer (IMPACC), 31

Iron Overload Diseases Association, Inc. (IOD), 92

## Title Index (cont'd)



## Title Index (cont'd)

Juvenile Diabetes Foundation (JDF) International, 121

Laurence-Moon-Biedl Syndrome (LMBS) Support Network, 70

Lenkemia Society of America, Inc., 32

Little People of America, Inc.(LPA), 188

Lowe's Syndrome Association, Inc., 122

Lupus Foundation of America, Inc. (LFA), 101

Malignant Hyperthermia Association of the United States (MHAUS), 123

Maple Syrup Urine Disease (MSUD) Family Support Group, 124

March of Dimes Birth Defects Foundation, 14

ML (Mucolipidosis) IV Foundation, 125

Muscular Dystrophy Association (MDA), 179

Myasthenia Gravis Foundation, Inc. (MGF), 180

Myoclonus Families United, 181

National Association for Down Syndrome (NADS), 45

National Association for Parents of the Visually Impaired. Inc. (NAPVI), 204

National Association for Sickle Cell Disease, Inc. (NASCD), 93

National Association for Visually Handicapped, 205

National Association of Radiation Survivors (NARS), 15

National Ataxia Foundation, 182

National Cancer Care Foundation (NCCF), 33

National Congenital Port Wine Stain Foundation, 195

National Down Syndrome Congress (NDSC), 46

National Down Syndrome Society (NDSS), 47

National Easter Seal Society, 16



National Foundation for Ectodermal Dysplasias (NFED), 196

National Foundation for Facial Reconstruction, 61

National Foundation for Ileitis and Colitis, Inc. (NFIC), 84

National Foundation for Jewish Genetic Diseases, Inc., 17

National Gaucher Foundation, Inc. (NGF), 126

National Hemophilia Foundation(NHF), 94

National Hydrocephalus Foundation (NHF), 158

National Kidney Foundation, Inc., 105

National Marfan Foundation (NMF), 56

National Mucopolysaccaridosis (MPS) Society, Inc., 127

National Multiple Sclerosis Society, 183

National Neurofibromatosis Foundation, Inc, 159

National Organization for Albinism and Hypopigmentation (NOAH), 128

National Organization for Rare Disorders, Inc. (NORD), 18

National Parkinson Foundation, Inc. (NPF), 160

National Scoliosis Foundation, Inc., 139

National Society to Prevent Elindness, 206

National Spasmodic Torticollis Association, 161

National Tay-Sachs and Allied Diseases Association, Inc. (NTSAD), 129

National Tuberous Sclerosis Association, Inc. (NTSA), 162

NOAH, see National Organization for Albinism and Hypopigmentation

NORD, see National Organization for Rare Disorders, Inc.

Organic Acidemia Association, Inc., 130

Orton Dyslexia Society (ODS), 71

Osteogenesis Imperfecta Foundation, Inc., 140

Title Index (cont'd)



## Title Index (cont'd)

Osteogenesis Imperfecta-National Capital Area, Inc., 141

Paget's Disease Foundation, Inc.(PDF), 142

Parents and Cataract Kids (PACK), 207

Parents of Dwarfed Children, 189

Parkinson's Disease Foundation, Inc., 163

Parkinson's Educational Program (PEP) - USA, 164

Polycystic Kidney Research Foundation (PKR), 106

Prader-Willi Syndrome Association(PWSA), 48

Prescription Parents, Inc., 62

Progeria International Registry, 72

Reflex Sympathetic Dystrophy Syndrome Association (RSDSA), 165

RP Foundation Fighting Blindness, 208

Rubinstein-Taybi Syndrome (RTS) Parent Contact Group, 73

Scoliosis Association, Inc., 143

Share and Care, 74

Sibling Information Network, 19

Sjogren's Syndrome Foundation, Inc. (SSF), 102

Spina Bifida Association of America (SBAA), 166

Sturge-Weber Foundation, 167

Support Group for Monosomy 9P, 49

Support Organization for Trisomy 18/13 and other Related Disorders (S.O.F.T. 18/13), 50

Thrombocytopenia Absent Radius Syndrome Association (TARSA), 95

TASH: Association for Persons with Severe Handicaps, 20

Tourette Syndrome Association, Inc. (TSA), 168

Tuberous Sclerosis Association of America, Inc., (TEAA), 169



Turner's Syndrome Society, 51

United Cerebral Palsy Association (UCPA)/UCP Research and Educational Foundation, 75

United Leukodystrophy Foundation, Inc. (ULF), 131

United Scleroderma Foundation, Inc. (USF), 197

Williams Syndrome Association (WSA), 132

Wilson's Disease Association, 133

Xeroderma Pigmentosum Registry, 198

Zain Hansen M.P.S. (Mucopolysaccharidoses) Foundation, 134

Title Index (cont'd)



