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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)

A Guide to Selected
NATIONAL GENETIC VOLUNTARY ORGANIZATIONS

EC 220546

NCEMCH
National Center for Education in Maternal and Child Health

A GUIDE TO SELECTED NATIONAL 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

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

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FOREWORD

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.

Part One

General

Alliance of Genetic Support Groups

38th and R Streets, N.W.
Washington, D.C.
20057
(202) 625-7853

EXECUTIVE DIRECTOR:

Jayne Mackta, President

CONTACT PERSON (S):

Brett Emmerson

CHAPTERS/SATELLITES:

None

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 availablility 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:

Complete catalog available upon request

AUDIOVISUALS:

Complete catalog available upon request

NEWSLETTER:

- *Genetics in Practice* (Quarterly)

National Association of Radiation Survivors (NARS)

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

EXECUTIVE DIRECTOR:

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 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)

National Foundation for Jewish Genetic Diseases, Inc.

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

EXECUTIVE DIRECTOR:

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 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)

Sibling Information Network

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

EXECUTIVE DIRECTOR:

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

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
Two

Auditory

Alexander Graham Bell Association for the Deaf (AGBAD)

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

EXECUTIVE DIRECTOR:

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*

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)

Part Three

Cancer

American Cancer Society, Inc.

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

EXECUTIVE DIRECTOR:

William Tipping

CONTACT PERSON (S):

Ruth Donnelly Corcoran

CHAPTERS/SATELLITES:

58 divisons

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/SATELLITES:

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)

Familial Polyposis Registry

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

EXECUTIVE DIRECTOR:

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)

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 or several 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)

Intestinal Multiple Polyposis and Colorectal Cancer (IMPACC)

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

EXECUTIVE DIRECTOR:

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)

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)

National Cancer Care Foundation (NCCF)

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

EXECUTIVE DIRECTOR:
Harvey Newman

CONTACT PERSON (S):
Diane Blum

CHAPTERS/SATELLITES:
Satellite offices in New Jersey and New York

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

Council on Cardiovascular Disease in the Young

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

EXECUTIVE DIRECTOR:

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

Part
Five

Chromosomal

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

2616 Martin Avenue
Bellmore
Long Island
New York
11710
(516) 221-4700

EXECUTIVE DIRECTOR:
Fredda Stimell

CONTACT PERSON (S):
Fredda Stimell

CHAPTERS/SATELLITES:
None

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)

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)

Fragile X Foundation

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

EXECUTIVE DIRECTOR:

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 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

National Association for Down Syndrome (NADS)

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

EXECUTIVE DIRECTOR:

Sheila Hebein

CONTACT PERSON (S):

Sheila Hebein

CHAPTERS/SATELLITES:

Encourages the formation of community support groups

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 clearinghouse 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)

National Down Syndrome Society (NDSS)

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

EXECUTIVE DIRECTOR:

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)

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.

PUBLICATIONS:

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:

- *The Gathered View* (Bimonthly)

Support Group for Monosomy 9P

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

EXECUTIVE DIRECTOR:
Jonathan C. Storr

CONTACT 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 [illegible]en 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 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)

Turner's Syndrome Society

York University
Administrative Studies
Building #006
4700 Keele Street
Downsview
Ontario M3J 1P3
Canada
(416) 736-5020

EXECUTIVE DIRECTOR:

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 their 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

Part Six

Connective Tissue

Ehlers-Danlos National Foundation (EDNF)

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

EXECUTIVE DIRECTOR:

Nancy A. Rogowski

CONTACT PERSON (S):

Nancy A. Rogowski

CHAPTERS/SATELLITES:

Arkansas, California, Illinois, Indiana, and Virginia

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)

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:

- *Connective Issues* (Quarterly)

Part Seven

Craniofacial

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

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

EXECUTIVE DIRECTOR:

Nancy C. Smythe

CONTACT PERSON (S):

Nancy C. Smythe

CHAPTERS/SATELLITES:

None

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)

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*
- *Craniofacial Surgery*

AUDIOVISUALS:

- *MASK* videotape
- Slide presentation for fund raising

NEWSLETTER:

Biannually

National Foundation for Facial Reconstruction

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

EXECUTIVE DIRECTOR:

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*

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

Part Eight

Developmental Disabilities

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

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

EXECUTIVE DIRECTOR:

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 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

CHAPTERS/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 welfare 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 with 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)

Autism Society of America (ASA)

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

EXECUTIVE DIRECTOR:

David Lorms

CONTACT PERSON (S):

Ken Laureys, Director of Information and Referral

CHAPTERS/SATELLITES:

200 local chapters throughout the United States

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:

None

NEWSLETTER:

- *Advocate* (Quarterly)

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 Child* (National Institute of Mental Health)
- CHCI brochure

AUDIOVISUALS:

None

NEWSLETTER:

None

Cornelia de Lange Syndrome (CdLS) Foundation, Inc.

60 Dyer Avenue
Collinsville
Connecticut
06022
(800) 223-8355
(Outside Connecticut)
(203) 693-0159

EXECUTIVE DIRECTOR:

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)

Laurence-Moon-Biedl Syndrome (LMBS) Support Network

122 Rolling Road
Lexington Park
Maryland
20653
(301) 863-5658

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)

Orton Dyslexia Society (ODS)

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

EXECUTIVE DIRECTOR:

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)

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

Rubinstein-Taybi Syndrome (RTS) Parent Group

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

EXECUTIVE DIRECTOR:

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.

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

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

EXECUTIVE DIRECTOR:

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

Part Nine

Gastrointestinal

American Celiac Society

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

EXECUTIVE DIRECTOR:

Anita Garrow

CONTACT PERSON (S):

Anita Garrow

CHAPTERS/SATELLITES:

None

PURPOSE:

The American Celiac Society provides educational 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

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)

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

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

EXECUTIVE DIRECTOR:

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)

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 available upon request

NEWSLETTER:

- *CLF Lifeline* (Quarterly)

Gluten Intolerance Group of North America (GIG)

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

EXECUTIVE DIRECTOR:

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

CONTACT PERSON (S):

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

CHAPTERS/SATELLITES:

Support groups and affiliates throughout the United States

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 Ileitis and Colitis is committed to a nationwide coordinated research and education program aimed at conquering ileitis and colitis.

PUBLICATIONS:

Catalog available upon request

AUDIOVISUALS:

Catalog available upon request

NEWSLETTER:

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

Part Ten

Hematologic

Cooley's Anemia Foundation, Inc.

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

EXECUTIVE DIRECTOR:

Teresa G. Piropato

CONTACT PERSON (S):

Teresa G. Piropato

CHAPTERS/SATELLITES:

California, Florida, Illinois, Massachusetts, New Jersey (2), New York (9), Pennsylvania, and Tennessee

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 Anemia - 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):
Lynn 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)

Hemochromatosis Research Foundation, Inc. (HRF)

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

EXECUTIVE DIRECTOR:

Margaret A. Krikker, M.D., President

CONTACT PERSON (S):

Margaret A. Krikker, M.D.

CHAPTERS/SATELLITES:

Now being formed

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) Hermochromatosis - 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)

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

Histiocytosis-X Association of America, Inc.

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

EXECUTIVE DIRECTOR:

Jeffrey M. Toughill

CONTACT PERSON (S):

Jeffrey M. Toughill

CHAPTERS/SATELLITES:

None

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

Iron Overload Diseases Association, Inc. (IOD)

224 Datura Street
Suite 311
West Palm 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)

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

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

EXECUTIVE DIRECTOR:

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 available upon request

AUDIOVISUALS:

Catalog available upon request

NEWSLETTER:

- *Sickle Cell News* (Quarterly)

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, Illinois, 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:

- *Joey*

NEWSLETTER:

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

Thrombocytopenia Absent Radius Syndrome Association (TARSA)

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

EXECUTIVE DIRECTOR:

Edward and Sandra Purinton

CONTACT PERSON (S):

Edward and Sandra Purinton

CHAPTERS/SATELLITES:

None

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 Eleven

Immunologic

American Lupus Society

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

EXECUTIVE DIRECTOR:

Milton H. Abram, II, President

CONTACT PERSON (S):

Charlean Wakefield

CHAPTERS/SATELLITES:

25 chapters throughout the United States

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

AUDIOVISUALS:

None

NEWSLETTER:

- *The Quarterly*

Immune Deficiency Foundation (IDF)

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

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 deficiency 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 fellowship for the study of immune deficiency diseases.

PUBLICATIONS:

- *Immune Deficiency Diseases: 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)

Lupus Foundation of America, Inc. (LFA)

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

EXECUTIVE DIRECTOR:

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)

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 Twelve

Kidney

National Kidney Foundation, Inc.

Two Park Avenue
New York
New York
10016
(212) 889-2210

EXECUTIVE DIRECTOR:

John Davis

CONTACT PERSON (S):

Gigi Politoski, Public Information Director

CHAPTERS/SATELLITES:

50 affiliates throughout the United States

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:

- *Kidney '88* (Five issues a year)

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 Thirteen

Mental

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

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

EXECUTIVE DIRECTOR:

Charles Peck, President

CONTACT PERSON (S):

Wendy Resnick

CHAPTERS/SATELLITES:

None

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 Fourteen

Metabolic

American Diabetes Association, Inc.

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

EXECUTIVE DIRECTOR:

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

CONTACT PERSON (S):

Robert S. Bolan, Ph.D.

CHAPTERS/SATELLITES:

53 affiliates and over 1000 chapters

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*
- *Diabetes Forecast*
- *Diabetes Spectrum*

AUDIOVISUALS:

None

NEWSLETTER:

- *Diabetes '88* (Quarterly)

American Porphyria Foundation

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

EXECUTIVE DIRECTOR:

Desiree Dodson

CONTACT PERSON (S):

Desiree Dodson

CHAPTERS/SATELLITES:

California, Florida, Georgia, Michigan, Minnesota, New 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

Association for Glycogen Storage Disease

Box 896
Durant
Iowa
52747
(319) 785-6038

EXECUTIVE DIRECTOR:

Hollie L. Arp, President

CONTACT PERSON (S):

Hollie L. Arp

CHAPTERS/SATELLITES:

None

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 Nuero-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

Cystic Fibrosis (CF) Foundation

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

EXECUTIVE DIRECTOR:

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)

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)

Dysautonomia Foundation, Inc.

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

EXECUTIVE DIRECTOR:

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)

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

Juvenile Diabetes Foundation (JDF) International

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

EXECUTIVE DIRECTOR:

Gloria Pennington

CONTACT PERSON (S):

Mary Kelly

CHAPTERS/SATELLITES:

200 chapters in the United States and Canada and affiliates in Australia, Brazil, 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 Lines* (Quarterly)

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)

Malignant Hyperthermia Association of the United States (MHAUS)

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

EXECUTIVE DIRECTOR:
Suellen Gallamore

CONTACT PERSON (S):
Suellen Gallamore

CHAPTERS/SATELLITES:
None

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)

ML (Mucolipidosis) IV Foundation

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

EXECUTIVE DIRECTOR:

Lynn Goldblatt

CONTACT PERSON (S):

Lynn Goldblatt

CHAPTERS/SATELLITES:

None

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)

National Mucopolysaccharidoses (MPS) Society, Inc.

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

EXECUTIVE DIRECTOR:

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 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)

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

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

EXECUTIVE DIRECTOR:

Dale I. 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, Elyssa*

NEWSLETTER:

- *Breakthrough* (Biannually)

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

United Leukodystrophy Foundation, Inc. (ULF)

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

EXECUTIVE DIRECTOR:

Ron and Paula Brazeal, Co-Presidents

CONTACT PERSON (S):

Paula Brazeal

CHAPTERS/SATELLITES:

None

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)

Wilson's Disease Association

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

EXECUTIVE DIRECTOR:

Carol A. Terry, President

CONTACT PERSON (S):

Carol A. Terry

CHAPTERS/SATELLITES:

None

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 professsionals, 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 Fifteen

Musculoskeletal

Arthritis Foundation/ American Juvenile Arthritis Organization (AJAO)

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

EXECUTIVE DIRECTOR:

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)

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 maintains a file of medical literature.

PUBLICATIONS:

None

AUDIOVISUALS:

None

NEWSLETTER:

None

National Scoliosis Foundation, Inc.

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

EXECUTIVE DIRECTOR:

Laura B. Gowen

CONTACT PERSON (S):

Elizabeth Downie

CHAPTERS/SATELLITES:

Massachusetts, Michigan, and Texas

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)

Ostegenesis Imperfecta National Capital Area, Inc.

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

EXECUTIVE DIRECTOR:

Margaret Cauffield

CONTACT PERSON (S):

Margaret Cauffield

CHAPTERS/SATELLITES:

None

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 similiar disorders. The foundation provides free educational materials to patients and medical professionals. 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)

EXECUTIVE DIRECTOR:

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*
- *Scoliosis, 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

Acoustic Neuroma Association

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

EXECUTIVE DIRECTOR:

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)

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

70 East Lake Street
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:

- *ADRDA Newsletter* (Quarterly)

American Narcolepsy Association (A.N.A.)

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

EXECUTIVE DIRECTOR:

William P. Baird

CONTACT PERSON (S):

Jolie A. Bou

CHAPTERS/SATELLITES:

Various support groups around the country

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*
- *Narcolepsy: 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

Batten's Disease Support and Research Association

6707 197th Street East
Spanaway
Washington
98387
(206) 847-2926

EXECUTIVE DIRECTOR:

Judith A. Grant

CONTACT PERSON (S):

Judith A. Grant

CHAPTERS/SATELLITES:

None

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)

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

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

EXECUTIVE DIRECTOR:

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 persons 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)

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

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

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

EXECUTIVE DIRECTOR:

Gary Wallach

CONTACT PERSON (S):

Jeanne Farrell, Director of Patient Services

CHAPTERS/SATELLITES:

Several throughout the United States

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 Donor 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. (IJDF)

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

International Rett Syndrome Association, Inc. (IRSA)

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

EXECUTIVE DIRECTOR:

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)

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

National Neurofibromatosis Foundation, Inc.

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

EXECUTIVE DIRECTOR:

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 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)

National Spasmodic Torticollis Association

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

EXECUTIVE DIRECTOR:

None

CONTACT PERSON (S):

Al Shepherd and Harry Sterkel

CHAPTERS/SATELLITES:

Michigan, New Jersey, and Wisconsin

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 Sheet* [illegible] *odic Torticollis*

AUDIOVISUALS:

None

NEWSLETTER:

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

Parkinson's Disease Foundation, Inc. (PDF)

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

EXECUTIVE DIRECTOR:

Dinah T. Orr

CONTACT PERSON (S):

Sheree Loftus

CHAPTERS/SATELLITES:

None

PURPOSE:

In addition to funding research the Parkinson's Disease Foundation offers symposia, medical 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

EXECUTIVE 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)

Reflex Sympathetic Dystrophy Syndrome Association (RSDSA)

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

EXECUTIVE DIRECTOR:

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

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)

Sturge-Weber Foundation

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

EXECUTIVE DIRECTOR:

Karen Ball

CONTACT PERSON (S):

Karen and Kirk Ball

CHAPTERS/SATELLITES:

None

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 syndrome 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)

Tuberous Sclerosis Association of America, Inc. (TSAA)

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

EXECUTIVE DIRECTOR:

Shirley L. Cort

CONTACT PERSON (S):

Raymond A. Conners

CHAPTERS/SATELLITES:

Representatives throughout the country

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

Amyotrophic Lateral Sclerosis Association, Inc. (ALSA)

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

EXECUTIVE DIRECTOR:

Rodney L. Houts

CONTACT PERSON (S):

Lynn M. Klein-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. Twenty-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)

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)

Benign Essential Blepharospasm Research Foundation, Inc. (BEBRF)

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

EXECUTIVE DIRECTOR:

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

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

CHAPTERS/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 hereditary 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 locate 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)

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

EXECUTIVE DIRECTOR:

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

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 Werdnig-Hoffmann disease

AUDIOVISUALS:

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

NEWSLETTER:

- *Direction* (Six issue a year)

Muscular Dystrophy Association (MDA)

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

EXECUTIVE DIRECTOR:
Robert Ross

CONTACT PERSON (S):
Ronald J. Schenkenberger

CHAPTERS/SATELLITES:
240 MDA clinics throughout the United States

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

Myoclonus Families United

1564 East 34th Street
Brooklyn
New York
11234
(718) 252-2133

EXECUTIVE DIRECTOR:
Sharon Dobkin

CONTACT PERSON (S):
Sharon Dobkin

CHAPTERS/SATELLITES:
None

PURPOSE:

Myoclonus Families United supports affected individuals and their families. The group provides physician 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 telangiectasia, 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)

National Multiple Sclerosis Society

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

EXECUTIVE DIRECTOR:

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)

Part Eighteen

Short Stature

Human Growth Foundation (HGF)

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

EXECUTIVE DIRECTOR:

Denise Orenstein

CONTACT PERSON (S):

Denise Orenstein

CHAPTERS/SATELLITES:

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

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*
- *Turner's Syndrome*

AUDIOVISUALS:

None

NEWSLETTER:

Monthly

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 workshops, 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 People* (PBS documentary, 1984)

NEWSLETTER:

- *LPA Today* (Six issues a year)

Parents of Dwarfed Children

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

EXECUTIVE DIRECTOR:

Margaret B. Badner

CONTACT PERSON (S):

Margaret and Julius Badner

CHAPTERS/SATELLITES:

None

PURPOSE:

Parents of Dwarfed Children is an organization which 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

Part Nineteen

Skin

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

EXECUTIVE DIRECTOR:

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 Seek Cause of Enigmatic Blistering Disorder*

AUDIOVISUALS:

None

NEWSLETTER:

- *E.B. Currents* (Biannually)

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)

National Congenital Port Wine Stain Foundation

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

EXECUTIVE DIRECTOR:
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 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*

AUDIOVISUALS:

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

NEWSLETTER:

- *The Educator* (Monthly)

United Scleroderma Foundation, Inc. (USF)

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

EXECUTIVE DIRECTOR:

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

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

American Foundation for the Blind, Inc. (AFB)

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

EXECUTIVE DIRECTOR:

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

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 dignity 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

Blind Children's Fund

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

EXECUTIVE DIRECTOR:

Sherry Raynor, President

CONTACT PERSONS:

Sherry Raynor and Susan Carson, Parent Coordinator

CHAPTERS/SATELLITES:

Massachusetts and Michigan

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)

National Association for Visually Handicapped

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

EXECUTIVE DIRECTOR:

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 testing 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 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*

Parents and Cataract Kids (PACK)

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

EXECUTIVE DIRECTOR:

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 information and support to families with children affected by cataracts 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)

RP Foundation Fighting Blindness

1401 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)

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