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ABSTRACT

This directory lists addresses, phone numbers, and contact persons for over 450 national organizations with a maternal and child health focus. The directory is divided into two sections. The first lists national organizations by subject area. These organizations provide a variety of services and activities, such as publication of educational materials, dissemination of general information, referrals, and assistance to health professionals and consumers in meeting their needs. Organizations listed in this section focus on: (1) pregnancy and childbirth; (2) infant health; (3) child health; (4) adolescent health; (5) school health; (6) women's health; (7) nutrition; (8) genetic services; (9) chronic illness and disability; (10) special health care needs; (11) public health programs and services; (12) health care providers. The second section lists self-help clearinghouses which collect and disseminate information about local self-help groups and assist in the formation of new groups. This section is arranged alphabetically by state. Two indexes are included; the first is a detailed subject index and the second is an alphabetical list of all organizations covered. (RJC)

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REACHING OUT:

A Directory of National Organizations Related to Maternal and Child Health



NCEMCH

National Center for Education in Maternal and Child Health

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REACHING OUT:

*A Directory of National Organizations
Related to Maternal and Child Health*

March 1989

NCEMCH

National Center for Education in Maternal and Child Health

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Maternal and Child Health
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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

Reaching Out: A Directory of National Organizations Related to Maternal and Child Health has been compiled by the National Center for Education in Maternal and Child Health (NCEMCH) to provide a reference to national organizations with a maternal and child health focus. Information for this third edition was obtained by communicating with organizations in the United States and Canada.

Part One of *Reaching Out* lists national organizations by subject area. These organizations provide a variety of services and activities, including publishing educational materials, disseminating general information, making referrals, and furnishing support to assist the health professional or the health care consumer in meeting a specific need.

Part Two lists self-help clearinghouses. These organizations collect and disseminate information about local self-help groups and assist in the formation of new groups. This section is arranged alphabetically by state.

Two indexes are included. The first is a detailed subject index. The second is an alphabetical list of all organizations.

The National Center for Education in Maternal and Child Health would like to thank all the organizations that provided information for this directory. *Reaching Out* will be updated and expanded for future editions; suggestions and changes may be directed to:

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International Association of Parents and Professionals for Safe Alternatives in Childbirth (NAPSAC, International)

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Riverside, California 92501

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Multiple Birth

National Organization of Mothers of Twins Clubs, Inc. (NOMOTC)

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Contact: Rachel Biale

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Providence, Rhode Island 02940-9487

(401) 274-TWIN
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Contact: Anne Richards, Administrative
Assistant

Perinatal Care

National Organization of Circumcision Information Resource Centers (NO-CIRC)

731 Sir Francis Drake Boulevard
San Anselmo, California 94960

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Providence, Rhode Island 02903-4908

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Positive Pregnancy and Parenting Fitness

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Pregnancy Loss

A.M.E.N.D. (Aiding a Mother and Father Experiencing Neonatal Death)

4324 Berrywick Terrace
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Association for Recognizing the Life of Stillborns (ARLS)

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Frank J. Pavlak, Executive Director

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Saratoga, California 95070

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Reach Out to the Parents of an Unknown Child, Inc.

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La Crosse-Lutheran Hospital
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LaCrosse, Wisconsin 54601

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March of Dimes Birth Defects Foundation

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Association of SIDS Program Professionals

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National Organization for Rare Disorders, Inc. (NORD)

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(416) 979-7923
Arthur M. Timms, Ph.D., Executive Director

United Cerebral Palsy Associations (UCPA) UCP Research and Educational Foundation

66 East 34th Street
New York, New York 10016

(800) USA-1UCP
(212) 481-6300
Allin Proudfoot, Executive Director

COCKAYNE SYNDROME

Share and Care

1294 "S" Street
North Valley Stream, New York 11580

(516) 825-2284
Contact: Pat Cahill

CORNELIA de LANGE SYNDROME

Cornelia de Lange Syndrome (CdLS) Foundation, Inc.

60 Dyer Avenue
Collinsville, Connecticut 06022

(800) 223-8355
(203) 693-0159
Julie A. Mairano, Executive Director

HYPERACTIVITY

Center for Hyperactive Child Information, Inc. (CHCI)

P.O. Box 66272
Washington, D.C. 20035-6272

(703) 920-7495
John C. Malloy, Executive Director

KLIPPEL-TRENAUNAY-WEBER (K-T) SYNDROME

K-T Support Group

4509 Wooddale Avenue
Edina, Minnesota 55424

(612) 925-2596
Judy Vessey, President

LAURENCE-MOON-BIEDL SYNDROME

Laurence-Moon-Biedl Syndrome (LMBS) Network

122 Rolling Road
Lexington Park, Maryland 20653

(301) 863-5658
Barbara Mielcarek, Executive Director

LEARNING DISABILITIES

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

4156 Library Road
Pittsburgh, Pennsylvania 15234

(412) 341-1515
Jean Petersen, Executive Director

Orton Dyslexia Society (ODS)

724 York Road
Baltimore, Maryland 21204

(301) 296-0232
Anne L. O'Flanagan, Executive Director

MENTAL RETARDATION

American Association on Mental Retardation (AAMR)

1719 Kalorama Road, N.W.
Washington, D.C. 20009-2684

(800) 424-3688
(202) 387-1968
Valaida S. Walker, President

Association for Retarded Citizens of the United States (ARC)

2501 Avenue J
Arlington, Texas 76006

(817) 440-0204
Alan Abeson, Ed.D., Executive Director
Contact: Sharon Davis, Ph.D., Director of
Research and Program Services

Joseph P. Kennedy, Jr. Foundation

1350 New York Avenue, N.W.
Suite 500
Washington, D.C. 20005

(202) 393-1250
George Zitnay and Herbert J. Kramer,
Directors
Contact: Eunice Kennedy Shriver

National Apostolate with Mentally Retarded Persons (NAMRP)

P.O. Box 4711
Columbia, South Carolina 29240

(803) 782-2706
Charles M. Luce, Executive Director

Mental Retardation Association of America, Inc. (MRAA)

211 East 300 South Street
Suite 212
Salt Lake City, Utah 84111

(801) 328-1575
Dr. Ernest H. Dean, President

National Association of State Mental Retardation Program Directors

113 Oronoco Street
Alexandria, Virginia 22314

(703) 683-4202
Robert M. Gettings, Executive Director
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National Association for the Dually Diagnosed (NADD)

(Mental Illness/Mental Retardation)

110 Prince Street
Kingston, New York 12401

(914) 331-4336
Robert J. Fletcher, A.C.S.W., Executive
Director

PROGERIA

Progeria International Registry

North Shore University
Division of Human Genetics
300 Community Drive
Manhasset, New York 11030

(516) 562-4610
W. Ted Brown, M.D., Ph.D., Executive
Director

RUBINSTEIN-TAYBI SYNDROME

Rubinsteir-Taybi Syndrome (RTS) Parent Group

414 East Kansas
Smith Center, Kansas 66967

(913) 282-6237
Contact: Lorrie or Garry Baxter

SMITH-LEMLI-OPITZ SYNDROME

Smith-Lemli-Opitz Syndrome Support Group

Five Hampton Court
Newark, Delaware 19703

(302) 834-4157
Contact: Carol Lolor

Eating Disorders

American Anorexia/Bulimia Association, Inc. (AABA)

133 Cedar Lane
Teaneck, New Jersey 07666

(201) 836-1800
Linda Rothenbert, M.S.W., Executive
Director

National Association of Anorexia Nervosa and Associated Disorders, Inc. (ANAD)

P.O. Box Seven
Highland Park, Illinois 60035

(312) 831-3438
Vivian Meehan, President
Contact: Christopher Athas, Vice President
or Dawn M. Ries, Administrator

Gastrointestinal Disorders

GENERAL

American Digestive Disease Society (ADDS)

7220 Wisconsin Avenue
Bethesda, Maryland 20814

(301) 223-0179
Marlin I. Hassner, Executive Director

CELIAC DISEASE

American Celiac Society

45 Gifford Avenue
Jersey City, New Jersey 07304

(201) 432-1207
Anita Garrow, Executive Director

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

2313 Rocklyn Drive
Suite One
Des Moines, Iowa 50322

(515) 270-9689
Contact: Tracey Mohns

Gluten Intolerance Group of North America (GIG)

P.O. Box 23053
Seattle, Washington 98102-0353

(206) 325-6980
Elaine I. Hartsook, Ph.D., R.D., Executive
Director

ILEITIS/COLITIS

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

444 Park Avenue South
New York, New York 10016-7374

(212) 685-3440
George Theobald, Jr., Executive Director
Contact: Terry Jennings, Director of
Communications

LIVER DISORDERS

American Liver Foundation (ALF)

998 Pompton Avenue
Cedar Grove, New Jersey 07009

(201) 857-2626
Thelma King Thiel, President
Contact: Jan Weiss, Public Relations
Director

Children's Liver Foundation, Inc. (CLF)

76 South Orange Avenue
Suite 202
South Orange, New Jersey 07079

(201) 761-1111
Maxine Turon, President

Genitourinary Disorders

Interstitial Cystitis Association, Inc.

P.O. Box 1553
Madison Square Station
New York, New York 10159

(212) 674-1454
Vicki Ratner, President

Hematologic Disorders

FANCONI ANEMIA

Fanconi Anemia Support Group

2875 Baker Boulevard
Eugene, Oregon 97403

(503) 686-0434
David B. Frohmayer, Executive Director
Contact: Lynn or David Frohmayer

**HEMOCHROMATOSIS/
IRON OVERLOAD DISEASES**

Hemochromatosis Research Foundation, Inc.

P.O. Box 8569
Albany, New York 12208

(518) 489-0972
Margaret A. Krikker, M.D., President

Iron Overload Diseases Association, Inc. (IOD)

224 Datura Street
Suite 311
West Palm Beach, Florida 33401

(305) 659-5616
(305) 659-5677
Roberta Crawford, Executive Director

HEMOPHILIA

Canadian Hemophilia Society

100 King Street West
Suite 210
Hamilton, Ontario L8P 1A2
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(416) 523-6414
Robert Shearer, Executive Director

National Hemophilia Foundation (NHF)

The Soho Building
110 Greene Street
Suite 406
New York, New York 10012

(212) 219-8180
Alan P. Brownstein, Executive Director

**HEREDITARY HEMORRHAGIC TELANGIECTASIA
(Osler-Weber-Rendu Syndrome)**

Hereditary Hemorrhagic Telangiectasia Foundation, Inc. (HHT)

Biochemistry Department
University of Massachusetts
Amherst, Massachusetts 01003

(413) 545-2048 (Massachusetts)
(415) 328-4854 (California)
Bruce Jacobson, Ph.D., Executive Director
Contact: Sharon Victor (Palo Alto,
California)

HISTIOCYTOSIS-X

Histiocytosis-X Association of America, Inc.

609 New York Road
Glassboro, New Jersey 08028

(609) 881-4911
Jeffrey M. Toughill, Executive Director

SICKLE CELL DISEASE

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

4221 Wilshire Boulevard
Suite 360
Los Angeles, California 90010-3503

(800) 321-8453
(213) 936-7205
Dorothee H. Boswell, Executive Director

THALASSEMIA

Cooley's Anemia Foundation, Inc.

105 East 22nd Street
New York, New York 10010

(212) 598-0911
Teresa G. Piropato, Executive Director

Thalassemia Action Group

105 East 22nd Street
New York, New York 10010

(212) 598-0911
Ralph Cazzetta, President

THROMBOCYTOPENIA ABSENT RADIUS SYNDROME

Thrombocytopenia Absent Radius Association (TARSA)

312 Sherwood Drive, R.D. One
Linwood, New Jersey 08221

(609) 927-0418
Edward and Sandra Purinton, Executive
Directors

Immunologic Disorders

IMMUNE DEFICIENCY

Chronic Fatigue Immune Dysfunction Society

P.O. Box 23018
Portland, Oregon 97223

(503) 684-5261
Gidget Faubion, Executive Director

Immune Deficiency Foundation

P.O. Box 586
Columbia, Maryland 21045

(301) 461-3127
Marcia Boyle, President

SJOGREN SYNDROME

Sjogren's Syndrome Foundation, Inc.

29 Gateway Drive
Great Neck, New York 11021

(516) 487-2243
Elaine K. Harris, President

SYSTEMIC LUPUS ERYTHEMATOSUS

The American Lupus Society

23751 Madison Street
Torrance, California 90505

(213) 373-1335
Milton H. Abram II, President
Contact: Charlean Wakefield

Lupus Foundation of America (LFA)

1717 Massachusetts Avenue, N.W.
Suite 203
Washington, D.C. 20036

(202) 328-4550
James E. Lewis, National President

Infectious Diseases

ACQUIRED IMMUNE DEFICIENCY SYNDROME

Foundation for Children with AIDS

77 B Warren Street
Brighton, Massachusetts 02135

(617) 783-7300
Geneva Woodruff, Executive Director

Kidney Disorders

National Kidney Foundation, Inc.

2 Park Avenue
Suite 908
New York, New York 10016

(212) 889-2210
John Davis, Executive Director
Contact: Gigi Politoski, Public Information
Director

National Association of Patients on Hemodialysis and Transplantation, Inc. (NAPHT)

211 East 43rd Street
New York, New York 10017

(212) 867-4486
Stuart Kaufer, Executive Director

PKR (Polycystic Kidney Research) Foundation

922 Walnut Street
Kansas City, Missouri 64106

(816) 421-1869
Jean G. Bacon, Executive Director
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Mental Health

American Mental Health Fund

3299 Woodburn Road
Suite 335
Annandale, Virginia 22003

(703) 573-2200
David George, Executive Director

American Orthopsychiatric Association

19 West 44th Street
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New York, New York 10036

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Contact: Faith Lamb Parker, Ph.D.

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

The Johns Hopkins Hospital
Meyer 4-181
601 North Wolfe Street
Baltimore, Maryland 21205

(301) 987-5756
(301) 955-4647, 3246
Charles Peck, President
Contact: Wendy Resnick

National Association for the Dually Diagnosed (NADD) (Mental Illness/Mental Retardation)

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Kingston, New York 12401

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Director

National Mental Health Association (NMHA)

1021 Prince Street
Alexandria, Virginia 22314

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Preston J. Garrison, Executive Director
Contact: Bonnie F. O'Neill, Manager,
Communications

Speaking for Our Selves (S4OS) (Multiple Personalities)

P.O. Box 4830
Long Beach, California 90804

(213) 438-7467
Rachel A., President

Metabolic Disorders

ALBINISM/HYPOPIGMENTATION

National Organization for Albinism and Hypopigmentation (NOAH)

1500 Locust Street, Suite 1811
Philadelphia, Pennsylvania 19102-4316

(215) 471-2278
(215) 471-2265
Janice L. Knuth, A.C.S.W., President

CYSTIC FIBROSIS

Cystic Fibrosis Foundation

6931 Arlington Road
Bethesda, Maryland 20814

(800) FIGHT CF
(301) 951-4422
Robert K. Dresing, President
Contact: Mark Hansan, Executive Assistant
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CYSTITINOSIS

Cystinosis Foundation, Inc.

477 15th Street
Suite 200
Oakland, California 94612

(415) 834-7897
Jean Hotz, President

DIABETES

American Diabetes Association, Inc.

1660 Duke Street
Alexandria, Virginia 22314

(703) 549-1500
Robert S. Bolan, Ph.D., Executive Vice
President

Juvenile Diabetes Foundation International

432 Park Avenue South
7th Floor
New York, New York 10016

(212) 889-7575
Gloria Pennington, Executive Director
Contact: Mary Kelley

DYSAUTONOMIA

Dysautonomia Foundation, Inc.

370 Lexington Avenue
New York, New York 10017

(212) 889-5222
Lenore F. Roseman, Executive Director

GALACTOSEMIA

Parents of Galactosemic Children, Inc.

One Ash Court
New City, New York 10956

(914) 638-3650
Contact: Linda Manis

GAUCHER DISEASE

National Gaucher Foundation, Inc.

1424 K Street, N.W.
Fourth Floor
Washington, D.C. 20005

(202) 393-2777
Karen Cohen, Executive Director

GLYCOGEN STORAGE DISEASE

Association for Glycogen Storage Disease

Box 896
Durant, Iowa 52747

(319) 785-6038
Hollie Arp, President

LEUKODYSTROPHY

United Leukodystrophy Foundation, Inc. (ULF)

2304 Highland Drive
Sycamore, Illinois 60178

(815) 895-3211
Ron and Paula Brazeal, Co-Presidents

LOWE SYNDROME

Lowe's Syndrome Association, Inc.

222 Lincoln Street
West Lafayette, Indiana 47906

(317) 743-3634
Kaye McSpadden, President

MALIGNANT HYPERTHERMIA

Malignant Hyperthermia Association of the United States (MHAUS)

P.O. Box 3231

Darien, Connecticut 06820

(203) 655-3007

Suellen Gallamore, Executive Director

MAPLE SYRUP URINE DISEASE

Maple Syrup Urine Disease (MSUD) Family Support Group

RR #2, Box 24-A

Flemingsburg, Kentucky 41041

(606) 849-4679

Joyce Brubacher, Executive Director

Contact: Peter Shaffer

MUCOLIPIDOSES/MUCOPOLYSACCHARIDOSES

ML (Mucopolipidosis) IV Foundation

Six Concord Drive

Monsey, New York 10952

(914) 425-0639

Lynn Goldblatt, Executive Director

National MPS Society

(Mucopolysaccharidoses and Mucopolipidoses)

17 Kraemer Street

Hicksville, New York 11801

(516) 931-6338

Marie Capobianco, President

Zain Hansen M.P.S. Foundation

(Mucopolysaccharidoses)

1200 Fernwood Drive

P.O. Box 4768

Arcata, California 95521

(707) 822-5421

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NEURO-METABOLIC DISORDERS

Association of Neuro-Metabolic Disorders

5223 Brookfield Lane

Sylvania, Ohio 43560

(419) 885-1497

Contact: Cheryl Volk

ORGANIC ACIDEMIA

Organic Acidemia Association, Inc.

1532 South 87th Street
Kansas City, Kansas 66111

(913) 422-7080
Lorie Asten, Coordinator

PORPHYRIA

American Porphyria Foundation

P.O. Box 11163
Montgomery, Alabama 36111

(205) 265-2200
Desiree Dodson, Executive Director

TAY-SACHS DISEASE

National Tay-Sachs and Allied Diseases Association (NTSAD)

(Allied Diseases: Gaucher Disease, Krabbe Disease, Niemann-Pick Disease, Sandhoff Disease)

385 Elliot Street
Newton, Massachusetts 02164

(617) 964-5508
Dale I. Carre, Executive Director

WILLIAMS SYNDROME

Canadian Association for Williams Syndrome (CAWS)

3806 Garden Grove Drive
Burnaby, British Columbia V5G 4A7
Canada

(604) 433-8979
Contact: Patrice Pratt

Williams Syndrome Association (WSA)

P.O. Box 178373
San Diego, California 92117-0910

(713) 376-7072
Gordon Biescar, Executive Director
Contact: Kay Biescar, Administrative
Assistant

WILSON DISEASE

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

5447 Palisade Avenue
Bronx, New York 10471

(212) 430-2091
Contact: I. Herbert Scheinbert, M.D.

Wilson's Disease Association (Also Menkes Disease)

P.O. Box 75324
Washington, D.C. 20013

(703) 636-3014
(703) 636-3003
Carol A. Terry, Executive Director

Musculoskeletal Disorders

GENERAL

American Academy of Orthopaedic Surgeons

222 South Prospect Avenue
Park Ridge, Illinois 60068

(312) 823-7186
Thomas C. Nelson, Executive Director
Contact: Cindy Thomas

ARTHRITIS

Arthritis Foundation

American Juvenile Arthritis Organization (AJAO)

1314 Spring Street, N.W.
Atlanta, Georgia 30309

(404) 872-7100
Clifford Clarke, President
Contact: Linda Weatherbee, Vice
President for AJAO and Special Projects

ARTHROGRYPOSIS MULTIPLEX CONGENITA

AVENUES (National Support Group for Arthrogryposis Multiplex Congenita)

P.O. Box 5192
Sonora, California 95379

(209) 928-3688
Mary Anne and Jim Schmidt, Executive
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FREEMAN-SHELDON SYNDROME

Freeman-Sheldon Parent Support Group

1459 East Maple Hills Drive
Bountiful, Utah 84010

(801) 298-3149
Joyce Dolcourt, Executive Director

OSTEOGENESIS IMPERFECTA

Osteogenesis Imperfecta Foundation, Inc. (OIF)

P.O. Box 14807
Tampa, Florida 34629-4807

(813) 855-7077
Rosalind James, President
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Osteogenesis Imperfecta—National Capital Area (OI-NCA)

Box 941
1311 Delaware Avenue, S.W.
Washington, D.C. 20024

(202) 265-1614
Margaret Cauffield, Executive Director

PAGET DISEASE

Paget's Disease Foundation, Inc. (PDF)

165 Cadman Plaza East
Brooklyn, New York 11201

(718) 596-1043
Charlene Waldman, Executive Director

SCOLIOSIS

National Scoliosis Foundation, Inc.

93 Concord Avenue
P.O. Box 547
Belmont, Massachusetts 02178

(617) 489-0880
(617) 489-0888
Laura B. Gowen, Executive Director
Contact: Elizabeth Downie

Scoliosis Association, Inc.

P.O. Box 51353
Raleigh, North Carolina 27609

(919) 846-2639
Barbara M. Shulman, President

Neurologic Disorders

GENERAL

American Academy of Neurology

2221 University Avenue, S.E.
Suite 335
Minneapolis, Minnesota 55414

(612) 623-8115
Jan Kolehmainen, Executive Director
Contact: Richard P. Hames

ACOUSTIC NEUROMA

Acoustic Neuroma Association

P.O. Box 398
Carlisle, Pennsylvania 17013

(717) 249-4783
Virginia Fickel, President

ALZHEIMER DISEASE

Alzheimer's Disease and Related Disorders Association (ADRDA)

70 East Lake Street
Chicago, Illinois 60601

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(312) 853-3060
Edward Truschke, President

ANGELMAN SYNDROME

Angelman Research Group

Box J-296, JHMHC
Division of Genetics/Department of Pediatrics
University of Florida
Gainesville, Florida 32610-0296

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ATAXIA

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

P.O. Box 11116
Oakland, California 94611

(415) 655-0833
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National Ataxia Foundation

600 Twelve Oaks Center
15500 Wayzata Boulevard
Wayzata, Minnesota 55391

(612) 473-7666
Donna Gruetzmacher, Patient Services Director

BATTEN DISEASE

Batten's Disease Support and Research Association

6707 197th Street East
Spanaway, Washington 98387

(206) 847-2926
Judith A. Grant, President

Children's Brain Diseases Foundation

350 Pamassus Avenue
Suite 900
San Francisco, California 94117

(415) 566-5402
J. Alfred Rider, M.D., Ph.D., Executive
Director

EPILEPSY

Epilepsy Foundation of America (EFA)

4351 Garden City Drive
Landover, Maryland 20785

(301) 459-3700
William McLin, Executive Director
Contact: Marie Ormsby, Director of
Information and Referral

GUILLAIN-BARRÉ SYNDROME

Guillain-Barré Syndrome Support Group International

P.O. Box 262
Wynnewood, Pennsylvania 19096

(215) 896-6855
Estelle and Robert Benson, Executive
Directors
Contact: Estelle Benson

HEAD INJURY

National Head Injury Foundation, Inc.

333 Turnpike Road
Scutthboro, Massachusetts 01772

(617) 485-9950
Marilyn Price Spivack, Executive Director,
Contact: Janet Williams, M.S.W., Director of
Clearinghouse

HUNTINGTON DISEASE

Hereditary Disease Foundation

606 Wilshire Boulevard
Suite 504
Santa Monica, California 90401-9990

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Scientific Advisory Board
Contact: Nancy S. Wexler, Ph.D.

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

140 West 22nd Street
New York, New York 10011-2420

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Gary Wallach, Executive Director

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13 Water Street
Suite Three
Box 333
Cambridge, Ontario N1R 5T8
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(519) 622-1002
Ralah Walker, Director, Research and
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HYDROCEPHALUS

National Hydrocephalus Foundation (NHF)

Route One River Road
Box 210 A
Joliet, Illinois 60436

(815) 467-6548
James A. Mazzetti, Executive Director

JOSEPH DISEASES

International Joseph Diseases Foundation, Inc. (IJDF)

P.O. Box 2550
Livermore, California 94550

Rose Marie J. Silva, Executive Director

NARCOLEPSY

American Narcolepsy Association

P.O. Box 1187
San Carlos, California 94070

(415) 591-7979
William P. Baird, Executive Director
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NEUROFIBROMATOSIS

National Neurofibromatosis Foundation, Inc.

141 Fifth Avenue
Suite 7-S
New York, New York 10010

(800) 323-7938
(212) 460-8980
Peter Beilerman, Executive Director
Contact: Prissi Shapiro, Assistant Executive
Director

PARKINSON DISEASE

American Parkinson Disease Association (APDA)

116 John Street
Suite 417
New York, New York 10038-9982

(800) 223-2732
(212) 732-9550
Frank L. Williams, Executive Director

National Parkinson Foundation, Inc. (NPF)

1501 Northwest Ninth Avenue-Bob Hope Road
Miami, Florida 33136-1494

(800) 327-4545
(305) 547-6666
Nathan Stewett, President

Parkinson's Disease Foundation, Inc. (PDF)

650 West 168th Street
New York, New York 10032

(800) 456-6676
(212) 923-4700
Dinah T. Orr, Executive Director
Contact: Sheree Loftus

PEP (Parkinson's Educational Program) USA

1800 Park Newport, #302
Newport Beach, California 92660

(800) 344-7872
(714) 640-0218
Contact: Charlotte Jayne Drake

REFLEX SYMPATHETIC DYSTROPHY SYNDROME

Reflex Sympathetic Dystrophy Syndrome Association (RSDSA)

822 Wayside Lane
Haddonfield, New Jersey 08033

(609) 428-6510
(609) 428-6980
Audrey Thomas, R.N., Francis J. Davis, and
Rosalyn M. Davis, Co-chairpersons

RETT SYNDROME

International Rett Syndrome Association, Inc. (IRSA)

8511 Rose Marie Drive
Fort Washington, Maryland 20744

(301) 248-7031
Kathy Hunter, President

SPASMODIC TORTICOLLIS

National Spasmodic Torticollis Association

P.O. Box 873
Royal Oak, Michigan 48068-0873

(313) 775-1367
(313) 547-2189
Contact: Al Shepherd or Harry Sterkel

SPINA BIFIDA

Spina Bifida Association of America (SBAA)

1700 Rockville Pike
Suite 540
Rockville, Maryland 20852

(800) 621-3141
(301) 770-7222
Norman A. Coe, Executive Director

STURGE WEBER SYNDROME

Sturge-Weber Foundation

P.O. Box 460931
Aurora, Colorado 80013

(303) 693-2986
Karen Ball, Executive Director
Contact: Karen or Kirk Bull

TOURETTE SYNDROME

Tourette Syndrome Association, Inc. (TSA)

42-40 Bell Boulevard
Bayside, New York 11361

(718) 224-2999
Dennis Herschfelder, Executive Director
Contact: Jared Bernstein, C.F.W.

TUBEROUS SCLEROSIS

National Tuberos Sclerosis Association (NTSA)

4351 Garden City Drive
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(301) 459-9888
Vicky Whittemore, Ph.D., President

Tuberous Sclerosis Association of America, Inc. (TSAA)

P.O. Box 1305
Middleboro, Massachusetts 02370

(617) 947-8893
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Neuromuscular Disorders

AMYOTROPHIC LATERAL SCLEROSIS (LOU GEHRIG'S DISEASE)

Amyotrophic Lateral Sclerosis Association (ALSA)

21021 Ventura Boulevard
Suite 321
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(818) 340-7500
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CHARCOT-MARIE-TOOTH DISEASE/ PERONEAL MUSCULAR TROPHY

CMT International, Inc.

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Linda Crabtree, President

National Foundation for Peroneal Muscular Atrophy

University City Science Center
3624 Market Street
Philadelphia, Pennsylvania 19104

(215) 664-6010
Contact: Karol B. Hitt

DYSTONIA

Benign Essential Blepharospasm Research Foundation, Inc.

P.O. Box 12468
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(409) 832-0788
Sherrie Dominy, Executive Director
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Chairman of the Board

Dystonia Medical Research Foundation (DMRF)

8213 Wilshire Boulevard
Suite 800
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(213) 852-1630 (California)
Contact: Nancy Harris (California)

777 Hornby Street
Vancouver, British Columbia V6Z 1S4
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Lois Raphael, Executive Director (Canada)

MULTIPLE SCLEROSIS

National Multiple Sclerosis Society

205 East 42nd Street
New York, New York 10017

(212) 986-3240
Thor Hanson, President

MUSCULAR DYSTROPHY

Muscular Dystrophy Association (MDA)

810 Seventh Avenue
New York, New York 10019

(212) 586-0808
Contact: Robert Ross, Vice President

MYASTHENIA GRAVIS

Myasthenia Gravis Foundation

7-11 South Broadway
Suite 304
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(914) 328-1717
Valerie M. Tennent, Executive Administrator

MYOCLONUS

Myoclonus Families United

1564 East 34th Street
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(718) 252-2133
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National Myoclonus Foundation

845 Third Avenue
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SPINAL MUSCULAR ATROPHY

Families of S.M.A.

(Adult Progressive Spinal Muscular Atrophy, (Aran-Duchenne Type) Benign Congenital Hypotonia, Kugelberg-Wander Disease, Werdnig-Hoffmann Disease)

P.O. Box 1460
Highland Park, Illinois 60035

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Respiratory Disorders

GENERAL

American Association for Respiratory Care

1720 Regal Row
Dallas, Texas 75235

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Contact: Gary L. Peschka, M.Ed., R.R.T.,
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American Lung Association

1740 Broadway
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ALLERGY/ASTHMA

American Academy of Allergy and Immunology (AAAAI)

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American Allergy Association (AAA)

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Asthma and Allergy Foundation of America (AAFA)

1717 Massachusetts Avenue
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Mothers of Asthmatics, Inc.

5316 Summit Drive
Fairfax, Virginia 22030

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Short Stature

Human Growth Foundation (HGF)

4720 Montgomery Lane
Bethesda, Maryland 20815

(301) 656-7540
Denise Orenstein, Executive Director

Little People of America, Inc. (LPA)

P.O. Box 633
San Bruno, California 94066

(415) 589-0695
Contact: Harriet or Al Stickney

Skin Disorders

ALOPECIA AREATA

National Alopecia Areata Foundation (NAAF)

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CONGENITAL PORT WINE STAIN

National Congenital Port Wine Stain Foundation

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ECTODERMAL DYSPLASIAS

National Foundation for Ectodermal Dysplasias (NFED)

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EPIDERMOLYSIS BULLOSA

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

c/o Kings County Medical Center
451 Clarkson Avenue
Building E-6-101
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ICHTHYOSIS

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

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SCLERODERMA

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Soivent Abuse Foundation for Education (SAFE)

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Stop Teenage Addiction to Tobacco (STAT)

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Visual Disorders

BLINDNESS/VISUAL IMPAIRMENT

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Vision Foundation, Inc.

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CATARACTS

Parents and Cataract Kids (PACK)

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RETINAL DEGENERATION

Association for Macular Diseases, Inc.

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RP Foundation Fighting Blindness

(Retinitis Pigmentosa, Usher Syndrome, Macular Degeneration)

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Part II

Self-Help Clearinghouses

Self-help groups offer people who face a common problem the opportunity to meet with others and share experiences, knowledge, strengths, and hopes. Self-help clearinghouses collect and disseminate information about local self-help groups and assist people in forming new groups. Self-help clearinghouses differ in their ability to provide information and referrals. This list of self-help clearinghouses is organized by state. If you are unable to locate a service to meet your needs, we suggest you contact your state mental health association. In addition, the National Self-Help Clearinghouse, the New Jersey Self-Help Clearinghouse, or the National Center for Education in Maternal and Child Health may be able to provide a referral.

UNITED STATES

National

National Self-Help Clearinghouse

Graduate School and University Center
of the City University of New York
33 West 42nd Street
Room 1227
New York, New York 10036

(212) 840-1258/9
Frank Riessman, Director

California

Bay Area Self-Help Clearinghouse

Mental Health Association
2398 Pine Street
San Francisco, California 94115

(415) 921-4401
Mara Weiss, Coordinator

California Self-Help Center

University of California - Los Angeles
2349 Franz Hall
405 Hilgard Avenue
Los Angeles, California 90024

(800) 222-LINK
(213) 825-1799
Mark Mayeda, Bonnie Burstein,
Co-Directors

Merced County Self-Help Clearinghouse

Mental Health Association
P.O. Box 343
Merced, California 95341

(209) 723-8861
Geri Steward, Coordinator

Mental Health Association of Contra Costa

604 Ferry Street
Martinez, California 94553

(415) 229-0444

Sacramento Self-Help Clearinghouse

Mental Health Association
5370 Elvas Avenue
Suite B
Sacramento, California 95819

(916) 456-2070
Pat Camper, Coordinator

Tri-County Clearinghouse (Placer, Yolo, Sacramento)

Mental Health Association
P.O. Box 447
Davis, California 95617

(916) 756-8181
Elaine Talley, Coordinator

Connecticut

Connecticut Self-Help/Mutual Support Network

Consultation Center
19 Howe Street
Haven, Connecticut 06511

(203) 789-7645
Marvin Steinberg, Sophie Tworkowski,
Co-Directors
Contact: Vicki Spiro Smith, Coordinator

Illinois

Self-Help Center

1600 Dodge Avenue, Suite S-122
Evanston, Illinois 60201

(312) 328-0473
Daryl Isenberg, Ph.D. Director

Kansas

Self-Help Network

Campus Box 34
Wichita State University
Wichita, Kansas 67208-1595

(316) 686-1205
Evelyn Middelstadt, Executive Director
David F. Gleason, Director

Massachusetts

Boston Self Help Center

18 Williston Road
Brookline, Massachusetts 02146

(617) 277-0080
Concetta Panzarino, Executive Director

Massachusetts Clearinghouse of Mutual Support Groups

Massachusetts Cooperative Extension
113 Skinner Hall
University of Massachusetts
Amherst, Massachusetts 01003

(413) 545-2313
Warren Schumacher, Director
Thomas Zink, Coordinator

Michigan

Michigan Self-Help Clearinghouse

Michigan Protection and Advocacy Service
109 West Michigan Avenue
Suite 900
Lansing, Michigan 48933

(800) 752-5858
(517) 484-7373
Toni Young, Coordinator

Michigan Protection and Advocacy Service

109 West Michigan Avenue, Suite 900
Lansing, Michigan 48933

(616) 983-0343
Toni Young, Coordinator
Center for Self-Help

Riverwood Community Mental Health Center

512 Ship Street
St. Joseph, Michigan 49085

Contact: Rob Hess or Linda Hellenga

Minnesota

Minnesota Mutual Help Resource Center

Wilder Foundation Community Care Unit
919 Lafond Avenue
St. Paul, Minnesota 55104

(612) 642-4060
Thomas Duke, CCU Director
Ron Brand, Clearinghouse Coordinator

Missouri

Support Group Clearinghouse

Kansas City Association for Mental Health
1020 East 63rd Street
Kansas City, Missouri 64110

(816) 361-5007
Sandy Sanders, Coordinator

Nebraska

Self-Help Information Services

1601 Euclid Avenue
Lincoln, Nebraska 68502

(402) 476-9668
Barbara Fox, Director
Joyce Burgess, Information Specialist

New Jersey

New Jersey Self-Help Clearinghouse

St. Clares-Riverside Medical Center
Pocono Road
Denville, New Jersey 07834

(800) FOR-MASH
(201) 625-7101
Edward J. Madara, Director

New York

Brooklyn Self-Help Clearinghouse

30 Third Avenue
Brooklyn, New York 11217

(718) 834-7341
Contact: Carol Berkvist

CAPC Self-Help Clearinghouse

Community Action Planning Council of
Jefferson County
28 The Arcade Balcony
P.O. Box 899
Watertown, New York 13601

(315) 782-4900
Carman Boccioloff, Coordinator

Cattaraugus County Self-Help Clearinghouse

Crossties
American Red Cross - Olean Branch
130 South Union Street
Olean, New York 14760

(716) 372-5800
Linore Lipka, Coordinator

Dutchess County Self-Help Clearinghouse

United Way of Dutchess County, Inc.
P.O. Box 832
75 Market Street
Poughkeepsie, New York 12601

(914) 473-1500
Evelyn Stevenson, Coordinator

Erie County Self-Help Clearinghouse

Mental Health Association of Erie County
1237 Delaware Avenue
Buffalo, New York 14209

(716) 886-1242
Linda and Joe Maggio, Coordinators

Franklin County Self-Help Clearinghouse

CEF (Clinton, Essex, Franklin) Crisis/Hotline
36 Brinkerhoff Street
Plattsburgh, New York 12901

(800) DIAL-SOS
David Rotman, Coordinator

Fulton County Self-Help Clearinghouse

Family Counseling Center
113 Bleecker Street
Gloversville, New York 12078

(518) 725-4310

Greene County Self-Help Clearinghouse

Greene County Community Action Agency
One Bridge Street
Catskill, New York 12414

(518) 943-9205
Diane McElroy, Executive Director

Haitian Self-Help Group Program

Haitian Centers Council, Inc.
50 Court Street
Suite 605
Brooklyn, New York 11201

(718) 855-7275
Joseph Etienna, Executive Director

Herkimer County Self-Help Clearinghouse

Herkimer County Help Line
104 North Washington Street
Herkimer, New York 13350

(315) 866-1310
Donna Durant, Executive Director

Long Island Self-Help Clearinghouse

New York Institute of Technology
Student Activities Center
Cottage B
Central Islip, New York 11722

(516) 348-3030
Audrey Lief Muller, Director
Pat Verdino, Coordinator

Monroe County Self-Help Clearinghouse

Mental Health Chapter of Rochester/Monroe
One Mount Hope Avenue
Rochester, New York 14620

(716) 423-9490
Pat Woods, Coordinator

Montgomery County Enablers Advocating for New Support (MEANS)

Saint Mary's Hospital
427 Guy Park Avenue
Amsterdam, New York 12010

(518) 842-1900
Sr. Rita Jean Dubrey, C.S.J., Coordinator

New York City Self-Help Clearinghouse, Inc.

P.O. Box 022812
Brooklyn, New York 11202

(718) 596-6000
Fran Dory, Director

New York State Self-Help Clearinghouse

New York State Council on Children and Families
Mayor Erastus Corning Second Tower
Empire State Plaza
Albany, New York 12223

(518) 474-6293
Mary Huber, Coordinator

Niagara County Self-Help Clearinghouse

Mental Health Association in
Niagara County, Inc.
151 East Avenue
Lockport, New York 14094

(716) 433-3780
Carol Gettings, Coordinator

Oneida County Self-Help Clearinghouse

Rome Voluntary Action Center
Voluntary Action Center of Greater Utica
City Hall on the Mall
Rome, New York 13440

(315) 336-5638
Lois Portman, Coordinator

Onondaga County Self-Help Clearinghouse

The Volunteer Center, Inc.
115 East Jefferson Street
Suite 300
Syracuse, New York 13202

(315) 474-7011
Sally Starr, Coordinator

Oswego County Self-Help Clearinghouse

Catholic Charities in Oswego County
365 West First Street
Fulton, New York 13069

(315) 598-3980
Andrea McCabe, Coordinator

Rensselaer County Self-Help Clearinghouse

Commission on Economic Opportunity
for the Rensselaer
County Area
2331 Fifth Avenue
Troy, New York 12180

(518) 272-6012
Contact: Karen E. Gordon

Rockland County Self-Help Clearinghouse and Information Center

Mental Health Association of Rockland
Sanatorium Road
Building J
Pomona, New York 10970

(914) 354-0200, Ext. 3609
Sidney Paul, Executive Director

Saint Lawrence County Self-Help Clearinghouse, Inc.

Reachout of Saint Lawrence County, Inc.
Potsdam College
203 Sisson Hall
Potsdam, New York 13676

(315) 265-2422
Karen Butler Easter, Coordinator

Schenectady County Self-Help Clearinghouse

Human Services Planning Council of
Schenectady County, Inc.
432 State Street
Room 220
Schenectady, New York 12305

(518) 372-3395
Catherine Raycroft, Coordinator

Schuyler/Chemung Self-Help Clearinghouse

Economic Opportunity Program, Inc.
207 South Catherine Street
Montour Falls, New York 14865

(800) 348-0448
Kathy Lewis, Coordinator

Tomkins County Support Group Clearinghouse

Tomkins County Mental Health Association
313 North Aurora Street
Ithaca, New York 14850

(607) 273-9250
Arlene Richardson, Coordinator

Westchester Self-Help Clearinghouse

Westchester Community College
Academic Arts Building
75 Grasslands Road
Valhalla, New York 10595

(914) 347-3620
Leslie Brock, Director
Lenore Rosenbaum, Coordinator

Oregon

Northwest Regional Self-Help Clearinghouse

718 West Burnside Street
Portland, Oregon 97209

(503) 222-5555
Doreen Akkerman, Coordinator

Pennsylvania

Self-Help Group Network of the Pittsburgh Area

710 1/2 South Avenue
Wilkesburg, Pennsylvania 15221

(412) 247-5400
Betsy Hepner, Coordinator

S.H.I.N.E. (Self-Help Information Network Exchange)

c/o Voluntary Action Center
225 North Washington Avenue
Park Plaza, Lower Level
Scranton, Pennsylvania 18503

(717) 961-1234
Arlene S. Hopkins, Director
Dolly Michalczyk, Consultant

South Carolina

Midland Area Support Group Network

Lexington County Hospital
2720 Sunset Boulevard
West Columbia, South Carolina 29169

(803) 791-2426
Becky Stone, Coordinator
Lindy Watson, Assistant Coordinator

Tennessee

Cverlook Mental Health Center

3001 Lake Brook Boulevard
Knoxville, Tennessee 37909

(615) 588-9747
Contact: Diana Nelson

Texas

Dallas Self-Help Clearinghouse

Mental Health Association of Dallas County
2500 Maple Avenue
Dallas, Texas 75201-1998

(214) 871-2420
Carol Madison, Director

Tarrant County Self-Help Clearinghouse

Mental Health Association of Tarrant County
3136 West Fourth Street
Fort Worth, Texas 76107-2113

(817) 335-5405
Christine B. Siegfried, Executive Director

Vermont

Vermont Self-Help Clearinghouse

c/o Parents Assistance Line
103 South Main Street
Waterbury, Vermont 05676

(800) 442-5356
(802) 241-2249
Donna Carpenter, Coordinator

Washington, D.C.

Self-Help Clearinghouse of Greater Washington

(Washington, D.C.; Northern Virginia; and Southern Maryland)

Mental Health Association of Northern Virginia
100 North Washington Street
Suite 232
Falls Church, Virginia 22046

(703) 536-4100
Elizabeth Lee McManus, Director
Contact: Information and Education
Assistant

Wisconsin

Health and Human Services Outreach

University of Wisconsin - Madison
610 Langdon Street
Madison, Wisconsin 53706

(608) 263-4432
Contact: Roger Williams

Mutual Aid Self-Help Association (MASHA)

P.O. Box 09304
Milwaukee, Wisconsin 53211

Deborah Mosley, President

CANADA

Family Life Education Council of Calgary

223 12th Avenue, S.W.
Calgary, Alberta T2R 0G9
Canada

(403) 262-1117
Contact: Sonia Eisler

Camac, Inc.

14 Aberdeen
Montreal, Quebec J4P 1R3
Canada

(514) 484-7406
Contact: Irene Ranti

Saskatchewan Self-Help Development Unit

410 Cumberland Avenue North
Saskatoon, Saskatchewan S7N 1M6
Canada

(306) 652-7817
Contact: Sharon Miller

Self-Help Clearinghouse for Metropolitan Toronto

40 Orchard View Boulevard
Suite 215
Toronto, Ontario M4R 1B9
Canada

(416) 487-4355
Lori Kociol, Executive Director

Winnipeg Self-Help Resource Center

103-61 Tyndall Avenue
Winnipeg, Manitoba R2X 2T4
Canada

(204) 633-5955
Contact: Bernice Marmel

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