

# ***RESOURCES for SPECIFIC CONDITIONS and DISABILITIES***

*Agencies, programs and organized groups that provide information and support regarding specific conditions and disabilities.*

## **ACOUSTIC NEUROMA**

### **Acoustic Neuroma Association**

*Provides information and support to patients diagnosed with acoustic neuroma and other benign tumors of the cranial nerves.*

600 Peachtree Parkway, Suite 108  
Cumming, GA 30041

**Phone:** (770) 205-8211

**Fax:** (770) 205-0239

**Email:** info@anausa.org

**Website:** www.anausa.org

**Serving:** National

## **ADD/ADHD**

### **Attention Deficit Information Network of Plymouth (AD-IN OF PLYMOUTH)**

*Provides info about ADD, conferences and support groups.*

42 Talia Way  
Plymouth, MA 02360

**Serving:** Southeast

### **Children and Adults with Attention Deficit Disorder: Metrowest (CHADD)**

*Works to improve the lives of people with Attention-Deficit/Hyperactivity Disorder through education, advocacy and support. Offers regional groups throughout the state that meets regularly for support, information and sharing.*

31 Speen St.  
Natick, MA 01080

**Phone:** (508) 655-2590

**Website:** www.chadd.org

**Serving:** Metrowest

### **National Resource Center on ADHD**

*The National Resource Center can answer questions on a broad range of topics: educational rights, treatment options, diagnostic procedures, and how to locate support and services.*

8181 Professional Place  
Landover, MD 20785

**Phone:** (800) 233-4050

**Website:** www.help4adhd.org

**Serving:** National

## **AIDS AND INFECTIOUS BLOOD DISORDERS**

### **AIDS Action Committee**

*Provides support services to men, women and children living with HIV/AIDS; also educates the public about HIV, as well as advocates for fair and effective AIDS policy.*

294 Washington St.  
Boston, MA 02108

**Phone:** (617) 437-6200, (800) 235-2331  
(617) 450-1312 (TTY)

**Fax:** (617) 437-6445

**Website:** www.aac.org

**Serving:** Statewide

### **AIDS Project Worcester**

*Helps people living with HIV/AIDS in Worcester County make future permanency plans for their children. Provides a variety of services for families or individuals living with HIV or AIDS, including: case management, alternative therapies, food bank, mental health services, family services and counseling.*

85 Green St.  
Worcester, MA 01604

**Phone:** (508) 755-3773, (800) 756-4148,  
(800) 756-4148 (TTY)

**Fax:** (508) 795-1665

**Email:** aidsworc@aol.com

**Website:** www.aidsprojectworchester.org

**Serving:** Central

### **Boston Pediatric and Family AIDS Project**

*Community-based, culturally competent, comprehensive care for women, children, adolescents and families infected, affected or at risk of HIV/AIDS. Provides funding for a friend or relative to care for children of HIV positive parents on a short-term basis.*

55 Dimock Street  
Roxbury, MA 02119

**Phone:** (617) 442-8800

**Fax:** (617) 442-1702

**Email:** ngallowa@dimock.org

**Website:** www.dimock.org

**Serving:** Boston

### Child and Family Services

Assists parents affected by HIV/AIDS to prepare and develop plans for their children's future. Offers family counseling; advocacy; parent mentor; legal consultation; creating a living legacy by recording videos, tapes, journals. Provides family outings, groups. Services are free, confidential and voluntary.

800 Purchase St. 4th Floor  
New Bedford, MA 02740

**Phone:** (508) 990-0894, (800) 722-5567

**Fax:** (508) 990-0289

**Email:** dlanagan@cfservices.org

**Website:** www.child-family-services.org

**Serving:** Southeast

### Children's AIDS Program (CAP)

Specialized day care, afterschool and summer programs for children with HIV/AIDS.

253 River St.  
Mattapan, MA 02126

**Phone:** (617) 5342050

**Email:** Pediaids@aol.com

**Website:** www.bostonchildhealth.org/  
childrensaidsproject/index.html

**Serving:** Boston

### Community Servings

Provides hot meals to individuals and families with AIDS and other acute life-threatening illnesses

125 Magazine St.  
Roxbury, MA 02119

**Phone:** (617) 445-7777

**Fax:** (617) 445-2444

**Email:** csmith@servings.org

**Website:** www.servings.org

**Serving:** Boston

### HIV/AIDS Law Consortium of Western Massachusetts

Provides referrals to volunteer attorneys for persons with HIV & AIDS, as well as some direct legal representation and advocacy. Also offers programs about estate planning, guardianship, confidentiality, discrimination, and benefits.

425 Union St.  
Box 118  
West Springfield, MA 01089

**Phone:** (413) 732-0011, (800) 633-1890

**Fax:** (413) 732-3331

**Email:** hivaidslawinfo@chd.org

**Website:** www.hivaidslawconsortium.org

**Serving:** Western

**Additional Languages Served:** Spanish

### Home for Little Wanderers

Provides a trained person to give hourly or overnight care for children who are HIV infected or affected.

271 Huntington Ave.  
Boston, MA 02115

**Phone:** (617) 267-3700, (888) 466-3321  
(617)927-0699 (TTY)

**Fax:** (617) 267-8142

**Website:** www.thehome.org

**Serving:** Boston

### Living Legacy

Project designed to help people living with HIV/AIDS plan and prepare for their children's future.

55 Dimock Street  
Roxbury, MA 02119

**Phone:** (617) 442-8800

**Fax:** (617) 442-1702

**Serving:** Boston

**Additional Languages Served:** Spanish

### Massachusetts Community Aids Resource Enhancement (MASSCARE)

MassCARE is a statewide program that serves women, children, youth and families living with HIV and their families. Medical, case management, and family support services are available at seven sites statewide.

250 Washington St., 4th Floor  
Boston, MA 02108

**Phone:** (617) 624-5070, (617) 994-9819,  
(617) 624-5992 (TTY)

**Fax:** (617) 624-5990

**Serving:** Statewide

**Additional Languages Served:** Spanish

### Parents of Kids with Infectious Diseases (PKIDS)

PKIDS assists the families of children living with hepatitis, HIV/AIDS, or other chronic viral diseases by offering emotional, financial and informational support. PKIDS also provides a moderated kids and teen listserve.

P.O. Box 5666  
Vancouver, WA 98668

**Phone:** (360) 695-0293, (877) 557-5437

**Fax:** (360) 695-6941

**Email:** pkids@pkids.org

**Website:** www.pkids.org

**Serving:** National

## **ALLERGY AND ASTHMA**

### **Allergy and Asthma Network/Mothers of Asthmatics**

AANMA provides patient education, and advocates for people with asthma and allergies. A monthly newsletter provides members with information on medical research, new products, how-to-tips, updates on legislation, product recalls, prevention and coping techniques. AANMA offers many books, pamphlets, and videos.

2751 Prosperity Ave. Suite 150  
Fairfax, VA 22031

**Phone:** (703) 641-9595, (800) 878-4403

**Fax:** (703) 573-7794

**Email:** info@aanma.org

**Website:** www.breatherville.org

**Serving:** National

### **American Academy of Allergy, Asthma & Immunology**

AAAAI promotes the early detection and treatment of asthma and other allergic diseases. An informational guide about diagnosis, treatment and resources, as well as problem foods and additives is provided. AAAAI has many brochures on the various types of allergies and short videos on topics related to allergies and asthma. A quarterly newsletter is published; for printed materials or a referral to a physician, call the toll-free number.

611 E. Wells St.  
Milwaukee, WI 53202

**Phone:** (414) 272-6071, (800) 822-2762

**Fax:** 414) 276-3349

**Website:** www.aaaai.org

**Serving:** National

### **American Latex Allergy Association (ALAA)**

ALAA is a national nonprofit organization that provides information on educational materials, support groups, publications and product information to assist with the understanding of natural rubber latex allergy.

3791 Sherman Road  
Slinger, WI 53086

**Phone:** (888) 972-5378

**Fax:** (262) 677-0324

**Email:** alert@latexallergyresources.org

**Website:** www.latexallergyresources.org

**Serving:** National

### **Asthma and Allergy Foundation of America**

AAFA is a nonprofit organization that provides practical information, community-based services and supports; organizes state and national advocacy efforts; and funds research to find better treatments and cures.

1233 20th Street NW, Suite 402  
Washington, DC 20036

**Phone:** (202) 466-7643, (800) 727-8462

**Fax:** (202) 466-8940

**Email:** info@aafa.org

**Website:** www.aafa.org

**Serving:** National

### **Allergy and Asthma Foundation of America, New England Chapter**

The New England Chapter provides a number of services including, but not limited to: a telephone information line, support groups, speakers, and training for childcare providers.

220 Boylston Street  
Chestnut Hill, MA 02467

**Phone:** (617) 965-7771, (877) 227-8462

**Fax:** (617) 965-8886

**Email:** aafane@aol.com

**Website:** www.asthmaandallergies.org

**Serving:** Statewide

### **Food Allergy and Anaphylaxis (FAAN)**

Provides education, emotional support, and coping strategies to individuals with food allergies. FAAN works with families, doctors, nurses, dieticians, and the food industry and publishes a bi-monthly newsletter that is included in membership. A bibliography of books and articles is available to members, as well as books and videos for distribution. Assistance is provided to individuals who wish to start a support group in their locality. FAAN also provides information on physicians and researchers who treat/ study allergy and anaphylaxis.

11781 Lee Jackson Hwy. Suite 160  
Fairfax, VA 22033

**Phone:** (703) 691-3179, (800) 929-4040

**Fax:** (703) 691-2713

**Email:** faan@foodallergy.org

**Website:** www.foodallergy.org

**Serving:** National

### **Healthy Kids: The Key to Basics**

*HEALTHY KIDS: THE KEY TO BASICS is dedicated to promoting a better understanding of the health and educational needs of students with asthma and other chronic health conditions. Healthy Kids is designed to help educators, health professionals, community officials, organizations, policy makers, advocates and parents work together to improve educational and environmental health policies and practices so that schools are safe for children's healthy development.*

79 Elmore St.  
Newton, MA 02459

**Phone:** (617) 965-9637  
**Email:** erg\_hk@juno.com  
**Website:** www.healthy-kids.info  
**Serving:** National

### **Parents of Allergic Children**

*Provides support and information to parents whose children suffer from allergies to foods, chemicals and the environment.*

P.O. Box 1808  
Midlothian, VA 23113

**Phone:** (804) 739-1495  
**Email:** queries@parentsofallergicchildren.org  
**Website:** www.parentsofallergicchildren.org  
**Serving:** National

### **ARTHRITIS**

#### **Arthritis Foundation**

*Supports research, provides information and referral, as well as service programs and support groups for individuals with arthritis, including children with Juvenile Rheumatoid Arthritis.*

29 Crafts St., Suite 450  
Newton, MA 02458

**Phone:** (617) 244-1800, (800) 766-9449  
**Fax:** (617) 558-7686  
**Email:** info.ma@arthritis.org  
**Website:** www.arthritis.org  
**Serving:** Statewide

### **ASPERGER'S SYNDROME**

#### **Asperger's Association of New England (AANE)**

*Provides information, referrals and support for individuals with Asperger's Syndrome and their families.*

182 Main St.  
Watertown, MA 02472

**Phone:** 617) 393-3824  
**Fax:** (617) 393-3827  
**Email:** info@aane.org  
**Website:** www.aane.org  
**Serving:** Statewide

### **AUTISM**

#### **Autism Alliance of Metrowest**

*The Autism Alliance of Metrowest provides families affected by autism with information, education and support.*

14 East Central Street  
Natick, MA 01760

**Phone:** (508) 652-9900  
**Website:** www.autismalliance.org  
**Serving:** Metrowest

#### **Autism Center of South Shore**

*Provides information and referral services, promotes social and recreational opportunities, facilitates support groups for families affected by ASD, provides parent and educator training, and provides a library of resources.*

210 Winter St., Suite 101  
Weymouth, MA 02188

**Phone:** (800) 482-5788  
**Email:** info@autismsouthshore.org  
**Website:** www.autismsouthshore.org  
**Serving:** Southeast

#### **Autism Resource Center of Central Massachusetts**

*Provides information and referral, family support groups, resource library, software preview and equipment loan, as well as a newsletter.*

360 W. Boylston St., Suite 204  
W. Boylston, MA 01583

**Phone:** (508) 595-9101  
**Fax:** (508) 854-8148  
**Email:** autism@hmea.org  
**Website:** www.arccm.org  
**Serving:** Central

#### **Autism Society of America, Massachusetts Chapter**

*Provides information and referral, a newsletter, and three open meetings yearly, featuring guest speakers. Serving people with autism and their families.*

789 Clapboardtree St.  
Westwood, MA 02090

**Phone:** (781) 237-0272  
**Fax:** (781) 237-5020  
**Email:** asamasschapter@hotmail.com  
**Website:** www.geocities.com/asamasschapter/  
**Serving:** Metrowest

### Autism Support Center

Information and support for families of people with autism; supports a parent/professional network, facilitates a parent support group.

6 Southside Rd  
Danvers, MA 01923

**Phone:** (978) 777-9135, (800) 728-8576

**Fax:** (978) 762-3980

**Email:** asc@nsarc.org

**Website:** www2.shore.net/~nsarc

**Serving:** Northeast

### Boston Families for Autism, Inc.

A parent organization that provides local support services in the community including: support groups, mentorships, recreational activities, trainings, and information about other local services.

P.O. Box 365437  
Hyde Park, MA 02136

**Phone:** (617) 327-9486

**Fax:** (617) 469-4922

**Serving:** Boston

### Community Autism Resources Inc. (CAR)

Information on Autism Spectrum disorders, newsletter, courses and clinics. Support to parent networks.

2315 Grand Army Hwy.  
Swansea, MA 02777

**Phone:** (508) 379-0371, (800) 588-9239

**Fax:** (508) 379-0371

**Email:** car@community-autism-resources.org

**Website:** www.community-autism-resources.org

**Serving:** Southeast

### Community Resources for People with Autism (CRPA)

Assists families, individuals, schools, and agencies in Western Mass. with information and support for children with autism. English and Spanish speaking advocates.

116 Pleasant St., Suite 3315  
Easthampton, MA 01027

**Phone:** (413) 529-2428, (800) 892-7003

**Fax:** (413) 529-2567

**Email:** crautism@crocker.com

**Website:** www.crocker.com/~crautism

**Serving:** Western

### Educational Consultants of New England, Inc., The School for Accelerated Learning

The School for Accelerated Learning is a year-round day school in Waltham, MA for students ages 3-22; focusing on social skills, executive functioning skills, coping skills, and self-esteem in conjunction with academics. Serves students who have a diagnosis of Asperger's Syndrome, non-verbal learning disabilities, high functioning PDD, anxiety disorders, OCD, Tourette's, and other related disorders. There is a low student-to-teacher ratio, concentrated learning in the child's area, family participation programs, and use of the latest technology.

460 Totten Pond Road Suite 300  
Waltham, MA 02451

**Phone:** (781) 895-3200

**Fax:** (781) 895-3226

**Email:** info@stopthatbehavior.com

**Website:** www.stopthatbehavior.com

**Serving:** Statewide

### Family Autism Center

Privately funded and DMR supported organization to assist families, individuals, schools, and agencies with information and support for children with autism.

789 Clapboardtree Rd  
Westwood, MA 02090

**Phone:** (781) 762-4001

**Website:** www.snarc.org

**Serving:** Metrowest

### TILL's Autism Services

Provides and locates services for families with children with autism. Holds parent trainings and social skills groups. Offers in-home services, family activities, recreational opportunities, and lending library available as well.

20 Eastbrook Rd.  
Dedham, MA 02026

**Phone:** (781) 302-4600

**Fax:** (781) 329-4254

**Email:** info@tillinc.org

**Website:** www.TILLinc.org

**Serving:** Statewide

## **BECKWITH-WEIDEMANN SYNDROME**

### **Beckwith-Weidemann Syndrome Foundation (BWSF), Massachusetts Chapter**

*BWSF is a non-profit organization dedicated to increasing the quality of life for those affected by this birth disorder.*

433 Court Street  
New Bedford, MA 02740

**Phone:** (508) 994-4839

**Fax:** (774) 202-1824

**Email:** KathyK@beckwith-wiedemannsyndrome.org

**Website:** www.beckwith-wiedemannsyndrome.org

**Serving:** Statewide

## **BLIND AND VISUALLY IMPAIRED**

### **National Association for Parents of Visual Impairments, Inc. (NAPVI)**

*Self-help organization specific to the needs of families of children with visual impairments. Hosts annual conference for parents and professionals and offers informative website.*

P.O. Box 317  
Watertown, MA 02471

**Phone:** (617) 972-7441, (800) 562-6265

**Fax:** (617) 972-7444

**Email:** NAPVI@perkins.pvt.k12.ma.us

**Website:** www.spedex.com/NAPVI

**Serving:** National

### **Massachusetts Association for Parents of Visual Impairments (MAPVI)**

*Provides parent support to families of children with visual impairments. Information is shared through speaker meetings, internet resources, quarterly newsletters. Also offer periodic social events and legislative advocacy opportunities.*

Groton, MA

**Phone:** (978) 897-3005

**Email:** westgatene@aol.com

**Website:** www.viguide.com/mapvi

**Serving:** Statewide

### **Massachusetts Commission for the Blind (MCB)**

*Provides specialized social and rehabilitative services as well as medical and financial assistance to blind individuals. Translation services are available.*

**Boston**

48 Boylston St.  
Boston, MA 02116

**Phone:** (617) 727-5550, (800) 392-6450  
(800) 392-6556 (TTY)

**Fax:** (617) 626-7685

**Website:** www.state.ma.us/mcb

**Serving:** Statewide

**Worcester**

390 Main St, Suite 620  
Worcester, MA 01608

**Phone:** (508) 754-1148, (800) 263-6944  
(508) 754-1148 (TTY)

**Fax:** (508) 752-7832

**Serving:** Central

**New Bedford**

800 Purchase St., Suite 290  
New Bedford, MA 02740

**Phone:** (508) 993-6140, (800) 989-4411  
(800) 392-6556 (TTY)

**Fax:** (508) 992-4147

**Serving:** Southeast

### **Massachusetts Commission for the Blind (MCB)**

**Springfield**

436 Dwight St., Room 109  
Springfield, MA 01103

**Phone:** (413) 781-1290, (800) 332-2772  
(800) 332-2772 (TTY)

**Fax:** (413) 746-8570

**Serving:** Western

### **Perkins School for the Blind**

*Programs provide educational training opportunities for students from birth to 22 years of age and services for adults in residential, day and community-based programs. All of the programs and services strive to enable each student to develop his or her greatest potential and maximum independence.*

175 North Beacon St.  
Watertown, MA 02472

**Phone:** (617) 972-7334, (617) 924-5525 (TTY)

**Fax:** (617) 972-7234

**Email:** preschoolservices@perkins.org

**Website:** www.perkins.org

**Serving:** Statewide

## **BRAIN INJURY**

### **Massachusetts Brain Injury Association (MBIA)**

*Offering information, hope, and support to persons with brain injuries, their families, and the professionals who care for them.*

484 Main St., #325  
Worcester, MA 01608

**Phone:** (508) 475-0032, (800) 242-0030  
(508) 797-0101 (TTY)

**Fax:** (508) 475-0400

**Email:** MBIA@MBIA.net

**Website:** www.MBIA.net

**Serving:** Statewide

## **CANCER**

### **American Cancer Society (ACS)**

A national organization with offices in many Massachusetts communities. Provides information regarding specific diagnosis and referral to services and supports, including parent groups.

1599 Clifton Rd. NE  
Atlanta, GA 30329

**Phone:** (404) 320-3333, (800) 227-2345  
(866) 228-4327 (TTY)

**Website:** [www.cancer.org](http://www.cancer.org)

**Serving:** National

### **Candlelighters Childhood Cancer Foundation (CCCF)**

CCCF was founded by parents of children with cancer. CCCF has a network of parent support groups in all states. Services include: meetings, speakers, parent-to-parent visitation, summer camps, transportation, emergency funding, and publications. To be referred to your nearest group, contact the toll free number of CCCF.

PO Box 498  
Kensington, MD 20895

**Phone:** (301) 962-3520, (800) 366-2223

**Fax:** (301) 962-3521

**Email:** [info@candlelighters.org](mailto:info@candlelighters.org)

**Serving:** National

## **CARDIAC CONDITIONS**

### **Little Hearts, Inc.**

A nonprofit organization that offers support, networking, resources and hope to families of children affected by a congenital heart defect.

P.O. Box 171  
Cromwell, CT 06416

**Phone:** (860) 635-0006, (866) 435-4673

**Fax:** (860) 635-0006

**Email:** [info@littlehearts.org](mailto:info@littlehearts.org)

**Website:** [www.littlehearts.org](http://www.littlehearts.org)

**Serving:** National

## **CEREBRAL PALSY**

### **United Cerebral Palsy (UCP)**

Offers an information and referral service, legislative advocacy, technology initiatives and research programs to consumers and families of children with Cerebral Palsy.

1600 L St. NW, Suite 700  
Washington, DC 20036

**Phone:** (202) 776-0406, (800) 872-5827,  
(202) 973-7197 (TTY)

**Fax:** (202) 973-7197

**Email:** [webmaster@ucp.org](mailto:webmaster@ucp.org)

**Website:** [www.ucpa.org](http://www.ucpa.org)

**Serving:** National

### **Cerebral Palsy of Massachusetts**

Provides recreation and rehabilitation programs which include physical therapy, occupational therapy and speech therapy. Offers early intervention, day care and Personal Care Attendants.

43 Old Colony Ave  
Quincy, MA 02170

**Phone:** (617) 479-7443, (800) 924-7570

**Fax:** (617) 786-9820

**Website:** [www.masscp.org](http://www.masscp.org)

**Serving:** Statewide

### **United Cerebral Palsy (UCP)**

Offers an information and referral service, legislative advocacy, technology initiatives and research programs to consumers and families of children with cerebral palsy.

1600 L. St., NW, Suite 700  
Washington, DC 20036

**Phone:** (202) 776-0406, (800) 872-5827

**Fax:** (202) 776-0414

**Email:** [national@ucp.org](mailto:national@ucp.org)

**Website:** [www.ucpa.org](http://www.ucpa.org)

**Serving:** National

### **United Cerebral Palsy of MetroBoston, Inc.**

Agency services to families with special needs, including information and referral, financial assistance, PCAs, support groups, residential and day supports for adults.

71 Arsenal St.  
Watertown, MA 02472

**Phone:** (617) 926-5480, (617) 926-8051 (TTY)

**Fax:** (617) 926-3059

**Email:** [ucpboston@ucpboston.org](mailto:ucpboston@ucpboston.org)

**Website:** [www.ucpboston.org](http://www.ucpboston.org)

**Serving:** Boston, Metro

**Additional Languages Served:** Spanish

### **United Cerebral Palsy of Berkshire County**

UCP assists any individual with a disability in Berkshire County. Our programs include: assistance with general and educational advocacy, assistive technology, which includes computer training, augmentative communication devices and devices to make work, school and home easier to access; a mobility repair clinic; loaner program of durable medical equipment; Berkshire Family Toy Library; and Verizon special telephone equipment program.

208 West St.  
Pittsfield, MA 01201

**Phone:** (413) 442-1562

**Fax:** (413) 499-4077

**Email:** [info@ucpberkshire.org](mailto:info@ucpberkshire.org)

**Serving:** Western

**Additional Languages Served:** Spanish

## **CHROMOSOME ABNORMALITIES**

(See also Down Syndrome and Genetics)

### **Chromosome 18 Registry & Research Society**

*Locates persons with chromosome 18 anomalies; educates families and the public about the prognoses and treatments of these disorders; encourage, conduct and publish research in areas that impact our families; and link affected families and physicians to research community.*

7155 Oakridge Dr.  
San Antonio, TX 78229

**Phone:** (210) 657-4968

**Fax:** (210) 657-4968

**Email:** office@chromosome18.org

**Website:** www.chromosome18.org

**Serving:** National

### **Chromosome Deletion Outreach (CDO)**

*CDO is a nonprofit organization founded, supported and run by parents. CDO provides support and information through an extensive library of articles, detailed registry, newsletter and listserv.*

P.O. Box 724  
Boca Raton, FL 33429

**Phone:** (561) 395-4292

**Email:** info@chromodisorder.org

**Website:** www.chromodisorder.org

**Serving:** National

## **IDEAS**

*IDEAS is a nonprofit organization that provides information, education and support to families affected by isodicentric 15 and other related disorders.*

18 Kings Rd.  
Canton, MA 02021

**Phone:** (781) 575-0847

**Website:** www.idic15.org

**Serving:** Statewide

**Additional Languages Served:** Spanish

## **S.O.F.T. USA**

*Support organization for Trisomy 18, 13, and related disorders offers support for parents who have children with chromosome disorder, and education to families and professionals interested in the care of these children.*

Barbara Vanherreweghe  
2981 South Union St.  
Rochester, NY 14624

**Phone:** (800) 716-7638

**E-mail:** barbsoft@rochester.rr.com

**Website:** www.trisomy.org

**Serving:** National

## **S.O.F.T. USA, Massachusetts Chapter**

Pamela Healey  
18 Richard Road  
Lexington, MA 02473

**Phone:** (781) 862-8273

**Email:** Healeylex@aol.com

**Serving:** Statewide

## **CYSTIC FIBROSIS**

### **Cystic Fibrosis Foundation, Massachusetts Chapter (CFF)**

*The mission of the Cystic Fibrosis Foundation is to assure the development of the means to cure and control cystic fibrosis and to improve the quality of life for those with the disease.*

220 North Main St., Suite 104  
Natick, MA 01760

**Phone:** (508) 655-6000, (800) 966-0444

**Fax:** (508) 653-6942

**Email:** mass-ri@cff.org

**Website:** www.cff.org

**Serving:** Statewide

## **CHRONIC FATIGUE**

### **Chronic Fatigue Immune Dysfunction Syndrome**

*Volunteer self-help education and support organization.*

P.O. Box 690305  
Quincy, MA 02269

**Phone:** (617) 471-5559

**Fax:** (617) 472-5157

**Email:** webmaster@masscfids.org

**Website:** www.masscfids.org

**Serving:** Statewide

## **DEAF AND HARD OF HEARING**

### **American Society for Deaf Children (ASDC)**

*ASDC is a national, independent nonprofit organization whose purpose is providing support, encouragement and information to families raising children who are deaf or hard of hearing.*

3820 Hartzdale Dr.  
Camp Hill, PA 17011

**Phone:** (717) 703-0073 (V/TTY), (800) 942-2732

**Fax:** (717) 909-5599

**Email:** asdu4u@aol.com

**Website:** www.deafchildren.org

**Serving:** National

### **Central Massachusetts Parent Association for the Deaf and Hearing Impaired (CMPA)**

*Supports activities to provide informational, emotional, social and/or financial supports to families of deaf or hard of hearing children in Central Massachusetts.*

RR #2 Box 1601  
Holland, MA 01521

**Phone:** (413) 245-6036 (V/TTY)  
**Email:** cmpadeaf@aol.com  
**Website:** www.members.aol.com/cmpadeaf  
**Serving:** Central, Western

### **Developmental Evaluation and Adjustment Facilities, Inc. (DEAF, INC.)**

*DEAF, Inc's mission is to encourage and empower each deaf individual to lead an independent and productive life. We provide comprehensive supports in a fully communication-accessible, deaf-affirmative environment.*

215 Brighton Ave.  
Allston, MA 02134

**Phone:** (617) 254-4041 (V/TTY)  
**Fax:** (617) 254-7091  
**Email:** info@deafonline.org  
**Website:** www.deafinonline.org  
**Serving:** Boston, Northeast, Southeast

### **Massachusetts Commission for the Deaf and Hard of Hearing (MCDHH)**

*Provides services for individuals who are deaf or hard of hearing; including interpreters, case management and technology services.*

150 Mt. Vernon St., Suite 550  
Dorchester, MA 02125

**Phone:** (617) 740-1600, (800) 882-1155  
(617) 530-7570 (TTY)  
**Fax:** (617) 740-1800  
**Email:** mcdhh.office@state.us.ma  
**Website:** www.state.ma.us/mcdhh  
**Serving:** Statewide

### **Massachusetts State Association of the Deaf Family Sign Language Program**

*Agency contracted to provide American Sign Language instruction to EI families with children who are deaf or hard of hearing.*

220 Main St.  
Malden, MA 02148

**Phone:** (781) 388-9114, (781) 388-9115 (TTY)  
**Fax:** (781) 388-9015  
**Email:** mafamsign@aol.com  
**Website:** www.msad.org  
**Serving:** Statewide

### **DEAF-BLIND**

#### **DB-LINK: The National Information Clearinghouse on Children who are Deaf-Blind**

*National information clearinghouse for children birth-22 who are deaf and blind. Catalog and resource database, listings of specialists and consultants. Services are free.*

345 N. Monmouth Ave.  
Monmouth, OR 97361

**Phone:** (800) 438-9376, (800) 438-9376,  
(800) 854-7013 (TTY)  
**Fax:** (503) 838-8150  
**Email:** dblink@tr.wou.edu  
**Website:** www.dblink.org  
**Serving:** National

#### **National Family Association for Deaf-Blind (NFADB)**

*NFADB is a non-profit, volunteer-based family association. Our philosophy is that individuals who are deaf-blind are valued members of society and are entitled to the same opportunities and choices as other members of the community. NFADB is the largest national network of families focusing on issues surrounding deaf blindness.*

111 Middle Neck Rd.  
Sands Point, NY 11050

**Phone:** (800) 255-0411  
**Fax:** (516) 883-9060  
**Email:** nfadb@aol.com  
**Website:** www.nfadb.org  
**Serving:** National

#### **National Technical Assistance Consortium**

*NTAC assists states to improve results for approximately 10,500 children and youth who are deaf-blind. Our goal is to see these children and young adults meet challenging educational standards and prepare for employment and living arrangements of their choice. Funded by US DOE.*

141 Middle Neck Rd.  
Sands Point, NY 11050

**Phone:** (516) 994-8900, (516) 883-9059 (TTY)  
**Fax:** (516) 993-9060  
**Email:** ntac4a@attglobal.net  
**Website:** www.tr.wou.edu/ntac/index.htm  
**Serving:** National

### **New England Center Deaf-Blind Project (NECDBP)**

NECDBP provides technical assistance and consultation relative to "effective practices" in deaf-blind education. Consultation available specific to family issues, particularly in the area of advocacy training and self-determination, community resources, and evaluation referral. Serving families in Massachusetts, New Hampshire, Maine, and Connecticut.

175 North Beacon St.  
Watertown, MA 02472

**Phone:** (617) 972-7515, (617) 924-5525 (TTY)

**Fax:** (617) 972-7354

**Email:** NEC@perkins.org

**Website:** www.necdbp.org

**Serving:** Statewide

### **DEVELOPMENTAL DELAY**

#### **Developmental Delay Resources**

Nonprofit organization dedicated to meeting the needs of parents and professionals working with children with sensory, motor, language, social, and emotional delays.

580 Beacon Street  
Pittsburgh, PA 15217

**Phone:** (800) 497-0944

**Fax:** (412) 422-1734

**Email:** devdelay@mindspring.com

**Website:** www.devdelay.org

**Serving:** National

### **Pathways Awareness Foundation**

Pathways Awareness Foundation is a national nonprofit organization dedicated to raising awareness about the benefit of early detection and early therapy for children with physical movement differences. Supports include a parent answered toll free line providing help and information.

150 N. Michigan Avenue Suite 2100  
Chicago, IL 60601

**Phone:** (800) 955-2445

**Email:** friends@pathwaysawareness.org

**Website:** www.pathwaysawareness.org

**Serving:** National

### **DIABETES**

#### **American Diabetes Association**

Provides educational and management information about diabetes, as well as referrals. Provides information about programs for individuals with diabetes.

1701 N. Beauregard St.  
Alexandria, VA 22311

**Phone:** (703) 549-1500 (V/TTY), (800) 342-2383

**Fax:** (703) 549-6995

**Email:** askadad@diabetes.org

**Website:** www.diabetes.org

**Serving:** National

### **Juvenile Diabetes Research Foundation (JDRF)**

JDRF web team provides one to one support and some practical suggestions to individuals and families affected by juvenile diabetes.

120 Wall St.  
New York, NY 10005

**Phone:** (800) 533-2873

**Fax:** (212) 785-9595

**Email:** info@jdrf.org

**Website:** www.jdrf.org

**Serving:** National

### **Juvenile Diabetes Research Foundation: New England Chapter, Bay State Branch (JDRF)**

Networking Coffee Program- Parents of children with Type 1 diabetes open their homes to other parents dealing with this disease.

20 Walnut St.  
Wellesley, MA 02481

**Phone:** (781) 431-0700

**Fax:** (781) 431-8836

**Email:** baystate@jarf.org

**Website:** www.jdrf.org/baystate

**Serving:** Statewide

### **Pediatric Diabetes Center**

UMass Memorial Medical Center-Pediatric Endocrinology

55 Lake Ave.  
Worcester, MA 01655

**Phone:** (508) 856-3862

**Fax:** (508) 856-3123

**Serving:** Statewide

### **DOWN SYNDROME**

#### **International Mosaic Down Syndrome Association (IMDSA)**

A nonprofit organization to help and support parents of children with mosaic Down Syndrome in research and meeting new people. Includes research, education and contact details.

P.O. Box 1052  
Franklin, TX 77856

**Phone:** (978) 828-4177, (888) 637-5465

**Fax:** (775) 295-9373

**Email:** mosaicdownsyndrome@yahoo.com

**Website:** www.imdsa.com

### Massachusetts Down Syndrome Congress (MDSC)

Statewide parent organization. Holds yearly conference, picnic, and workshops throughout the year. Publishes a newsletter for parents. Maintains a list of parent support groups that meet throughout the state, either run independently, through local ARC's, Early Intervention Programs or private agencies.

P.O. Box 866  
Melrose, MA 02176

**Phone:** (800) 664-6372  
**Email:** welcome@mdsc.org  
**Website:** www.mdsc.org  
**Serving:** Statewide

### National Down Syndrome Congress (NDSC)

The mission of the NDSC is to provide information, advocacy and support concerning all aspects of life for individuals with Down Syndrome. It is the purpose of the National Down Syndrome Congress to create a climate in which all people will recognize and embrace the value of people with Down Syndrome.

National Down Syndrome Congress  
1370 Center Drive, Suite 102  
Atlanta, GA 30338

**Phone:** (770) 604-9500, (800) 232-6372  
**Fax:** (770) 604-9898  
**Email:** info@ndscenter.org  
**Website:** www.ndscenter.org  
**Serving:** National

### National Down Syndrome Society (NDSS)

The mission of the NDSS is to benefit people with Down syndrome and their families through national leadership in education, research and advocacy.

666 Broadway  
New York, NY 10012  
**Phone:** (212) 460-9330, (800) 221-4602  
**Fax:** (212) 979-2873  
**Email:** info@ndss.org  
**Website:** www.ndss.org  
**Serving:** National

### Parents' First Call (MDSC)

A parent to parent outreach program for new parents of babies born with Down Syndrome. Contact parents are located throughout the state.

P.O. Box 866  
Melrose, MA 02176

**Phone:** (800) 664-6372  
**Email:** mdsc@mdsc.org  
**Website:** www.mdsc.org/first.htm  
**Serving:** Statewide

### Down Syndrome Resource Group of Western Massachusetts

The mission of the Down Syndrome Resource Group of Western Massachusetts is to discover, encourage, and embrace the potential of ALL individuals with Down syndrome. We will accomplish this by supporting the individual, their families, caregivers, and communities through outreach, unity, resources, community involvement, and education.

243 King Street Suite 109  
Northampton MA 01060

**Phone:** (413) 586-8196, (800) 337-7791  
**Fax:** (413) 582-9098  
**Email:** info@dsresource.org  
**Website:** www.dsresource.org  
**Serving:** Western

### DYSLEXIA

#### International Dyslexia Association (IDA)

The IDA is a non-profit organization dedicated to helping individuals with dyslexia, their families and the communities that support them. Provides information and referrals to local resources for testing and tutoring.

Chester Building  
8600 LaSalle Road, Suite 382  
Baltimore, MD 21286

**Phone:** (410) 296-0232 (V/TTY), (800) 222-3123  
**Fax:** (410) 321-5069  
**Email:** info@interdys.org  
**Website:** www.interdys.org  
**Serving:** National

#### International Dyslexia Association, Massachusetts Chapter (MABIDA)

P.O. Box 662  
Lincoln, MA 01773

**Phone:** (508) 646-0011, (866) 906-0011  
**Email:** mabida@comcast.net  
**Serving:** Statewide

### EATING DISORDERS

#### Anorexia Nervosa and Related Eating Disorders, Inc. (ANRED)

ANRED is a nonprofit organization that has a website providing information about anorexia nervosa, bulimia nervosa, binge eating disorder, and other less well-known food and weight disorders. Website includes self-help tips, as well as information about recovery and prevention.

**Email:** jarinor@rio.com  
**Website:** www.anred.com  
**Serving:** National

### **National Association of Anorexia Nervosa and Associated Disorders (ANAD)**

*The National Association of Anorexia and Associated Disorders is a nonprofit organization which seeks to alleviate the problems of eating disorders, especially anorexia nervosa and bulimia nervosa. ANAD gathers and provides information about eating disorders, including sources and facilities for treatment.*

P.O. Box 7  
Highland Park, IL 60035

**Phone:** (847) 831-3438  
**Email:** anad20@aol.com  
**Website:** www.anad.org  
**Serving:** National

### **National Eating Disorders Association**

*NEDA is dedicated to expanding public understanding and prevention of eating disorders and promoting access to quality treatment for those affected along with support for their families through education, advocacy and research. Provides treatment information, research studies, support groups, parent/family network and on-line newsletter.*

603 Stewart St., Suite 803  
Seattle, WA 98101

**Phone:** (206) 382-3587, (800) 931-2237  
**Email:** info@NationalEatingDisorders.org  
**Website:** www.nationaleatingdisorders.org  
**Serving:** National

### **ECTODERMAL DYSPLASIA**

#### **National Foundation for Ectodermal Dysplasia (NFED)**

*Provides help to families around the world who are dealing with Ectodermal Dysplasia. Offers regional and national educational publications and newsletter. Provides financial assistance to qualified families for medical and dental related items.*

410 East Main St. P.O. Box 114  
Mascoutah, IL 62258

**Phone:** (618) 566-2020  
**Fax:** (618) 566-4718  
**Email:** info@nfed.org  
**Website:** www.nfed.org  
**Serving:** National

### **EPILEPSY**

#### **Epilepsy Foundation of America (EFA)**

*The Epilepsy Foundation (formerly the Epilepsy Foundation of America)® is the national organization that works for people affected by seizures through research, education, advocacy and service. We are an organization of volunteers committed to the prevention and cure of epilepsy and a positive quality of life for everyone who lives with seizure disorders. Our current strategic goals include broadening and strengthening of research, providing individuals and families with easy access to reliable information, and assuring access to appropriate medical care for those affected by seizures.*

4351 Garden City Dr.  
Landover, MD 20785

**Phone:** (301) 459-3700, (800) 332-1000  
**Fax:** (301) 577-4941  
**Website:** www.efa.org  
**Serving:** National

#### **Epilepsy Foundation of Massachusetts and Rhode Island**

*Provides information and referral, employment placement, support, information groups throughout Massachusetts and Rhode Island.*

540 Gallivan Blvd. 2nd Floor  
Boston, MA 02124

**Phone:** (617) 506-6041, (888) 576-9996  
**Fax:** (617) 542-7312  
**Email:** epilepsymassri@aol.com  
**Website:** www.epilepsyfoundation.org  
**Serving:** Statewide

### **FETAL ALCOHOL SYNDROME (FAS)**

#### **National Organization on Fetal Alcohol Syndrome (NOFAS)**

*NOFAS is dedicated to eliminating birth defects caused by alcohol consumption during pregnancy and improving the quality of life for those affected individuals and families.*

900 17th Street NW  
Washington, DC

**Phone:** (800) 666-6327  
**Fax:** (202) 466-6456  
**Email:** information@nofas.org  
**Website:** www.nofas.org  
**Serving:** National

## **FG SYNDROME**

### **FG Syndrome Family Alliance, Inc.**

*The FG Syndrome Family Alliance, Inc. is a voluntary, non profit organization dedicated to enhance the quality of life for those individuals and families affected by FG Syndrome or related disorders, through education, peer support, referral, advocacy and research. Activities include newsletter, listserv, on-line family album and educational materials.*

946 NW Circle Blvd. #290  
Corvallis, OR 97330

**Phone:** (617) 577-9050  
**Email:** info@fg-syndrome.org  
**Website:** www.fg-syndrome.org/  
**Serving:** National

## **FRAGILE X**

### **Fragile X Research Foundation (FRAXA)**

*FRAXA directly funds research projects aimed at treatment. The foundation promotes awareness of Fragile X, publishes a newsletter & informational booklets, sponsors website and listserv, organizes parent advocacy groups, and holds fundraising events around the country.*

45 Pleasant St.  
Newburyport, MA 01950

**Phone:** (978) 462-1866  
**Fax:** (978) 463-9985  
**Email:** info@fraxa.org  
**Website:** www.fraxa.org  
**Serving:** National

### **National Fragile X Foundation (NFXF)**

*Education awareness, resources and research regarding Fragile X syndrome.*

P.O. Box 190488  
San Francisco, CA 94119

**Phone:** (925) 938-9300, (800) 688-8765  
**Fax:** (925) 938-9315  
**Email:** natlfx@fragilex.org  
**Website:** www.fragilex.org  
**Serving:** National

## **GASTROINTESTINAL DISORDERS**

### **Crohn's and Colitis Foundation of America (CCFA)**

*The Crohn's & Colitis Foundation of America is a nonprofit volunteer-driven organization dedicated to finding the cure for Crohn's Disease and ulcerative colitis.*

386 Park Avenue South, 17th Floor  
New York, NY 10016

**Phone:** (508) 646-0011 (V/TTY), (866) 906-0011  
**Email:** info@ccfa.org  
**Website:** www.ccfa.org  
**Serving:** National

### **Crohn's and Colitis Foundation of America, New England Chapter (CCFA)**

280 Hillside Avenue  
Needham, MA 02494

**Phone:** (781) 449-0324, (800) 314-3459  
**Fax:** (781) 449-0325  
**Email:** ne@ccfa.org  
**Website:** www.ccfa.org/chapters/ne  
**Serving:** National

### **International Foundation for Functional Gastrointestinal Disorders (IFFGO)**

*Provides information, care and support for families of children with gastrointestinal motility and functional GI disorders. Promotes public awareness.*

PO Box 170864  
Milwaukee, WI 53217

**Phone:** (800) 964-2001  
**Website:** www.aboutkidsgi.org  
**Serving:** National

### **Kids with Tubes**

*Information and support for families and caregivers of tube-fed children, including quarterly educational seminars.*

59 Sweetwater Ave  
Bedford, MA 01730  
Phone: (617) 825-6364  
Email: info@kidswithtubes.org  
Website: www.kidswithtubes.org

### **Oley Foundation**

*Information, education and outreach for families with children and adults dependent on home parental (IV) and/or enteral (tube-fed) nutrition.*

214 Hun Memorial A-28  
Albany, NY 12208

**Phone:** (518) 262-5079, (800) 776-6539  
**Fax:** (518) 262-5528  
**Email:** bishopj@mail.amc.edu  
**Website:** www.oley.org  
**Serving:** National

## **GENETICS**

### **Baystate Medical Center**

*Provides information about genetics and genetic counseling.*

759 Chestnut St.  
Springfield, MA 01199

**Phone:** (413) 794-0000  
**Fax:** (413) 794-3623  
**Website:** www.baystate.com  
**Serving:** Statewide

### **Genetic Alliance (GA)**

*The Genetic Alliance is an international coalition representing more than 600 consumer and health professional organizations working together to improve the quality of life for everyone impacted by genetics. The Genetic Alliance supports individuals with genetic conditions and their families, educates the public, and advocates for consumer-informed public policy.*

4301 Connecticut Ave. NW, Suite 404  
Washington, DC 20008

**Phone:** (202) 966-5557, (800) 336-4363

**Fax:** (202) 966-8553

**Email:** info@geneticalliance.org

**Website:** www.geneticalliance.org

**Serving:** National

### **Massachusetts Genetics Program**

*Information and referral about genetic-related conditions and health services. Provides technical assistance to parents and professionals regarding availability of medical, genetic and support services. Provides genetics education and training programs. Can make referrals to genetic counseling centers throughout the state.*

250 Washington St., 4th Floor  
Boston, MA 02108

**Phone:** (617) 624-5070, (617) 624-5992 (TTY)

**Fax:** (617) 624-5990

**Serving:** Statewide

### **National Organization for Rare Disorders (NORD)**

*Database and index of rare diseases, with subscriptions for libraries and medical facilities and summary reports for public.*

55 Kenosia Avenue, P.O. Box 1968  
Danbury, CT 06813

**Phone:** (203) 744-0100, (800) 999-6673,  
(203) 797-9590 (TTY)

**Fax:** (203) 798-2291

**Email:** orphan@rarediseases.org

**Website:** www.rarediseases.org

**Serving:** National

### **National Society of Genetic Counselors (NSGC)**

*Genetic counselors work as members of a health care team, providing information and support to families who have members with birth defects or genetic disorders and to families who may be at risk for a variety of inherited conditions. A feature of the website is ResourceLink, developed to assist consumers in locating genetic counseling services and for students curious about the profession. Genetic Counselors can be searched by State, City, Counselor's Name, Institution or Areas of Practice or Specialization.*

401 N. Michigan Avenue  
Chicago, IL 60611

**Phone:** (312) 321-6834

**Fax:** (312) 673-6972

**Email:** FYI@nsgc.org

**Website:** www.nsgc.org

**Serving:** National

### **New England Newborn Screening Program of UMass Medical School**

*All newborns undergo mandatory screening for genetic disorders. If you have not received information about newborn screening from your obstetrician or pediatrician, or do not have a pediatrician, you may call this number for a booklet and more information about this process and about specific genetic disorders. Clinicians and scientists will provide more information and direct you to a specific genetics clinic.*

305 South St.  
Jamaica Plain, MA 02130

**Phone:** (617) 983-6300

**Fax:** (617) 522-2846

**Email:** nbs@massmed.edu

**Website:** www.umassmed.edu/NBS

**Serving:** Statewide

### **New England Regional Genetics (NERGG)**

*NERGG is a consortium of genetic service providers, representatives of the public health community, and consumers of genetic services. Its mission is to promote the health of both children and adults by increasing the awareness of genetic concerns, the understanding of the role of genetics in health care, and the availability of appropriate services. The A. Merrill Henderson Scholarship Fund offers support to consumers for national conferences relating to genetic disorders.*

P. O Box 920288  
Needham, MA 02492

**Phone:** (781) 444-0126

**Fax:** (781) 444-0127

**Email:** admin@nergg.org

**Website:** www.nergg.org

**Serving:** Statewide

## **GROWTH DISORDERS**

### **The Magic Foundation (MAGIC)**

The MAGIC Foundation is a national nonprofit organization created to provide education and support services for adults and families of children afflicted with a wide variety of chronic and/or critical disorders, syndromes and diseases that affect a child's growth. Supports include a comprehensive website, newsletters, chatrooms, (English and Spanish), scholarships, a website for kids, as well as an annual conference.

6645 West North Avenue  
Oak Park, IL 60302

**Phone:** (708) 383-0808, (800) 362-4423

**Fax:** (708) 383-0899

**Email:** info@magicfoundation.org

**Website:** www.magicfoundation.org

**Serving:** National

**Additional Languages Served:** Spanish

## **HEMOPHILIA**

### **New England Hemophilia**

Education, support, and advocacy programs for individuals and families with hemophilia and von Willebrand disease in New England.

347 Washington St. #402  
Dedham, MA 02026

**Phone:** (781) 326-7645

**Fax:** (781) 329-5122

**Email:** info@newenglandhemophilia.org

**Website:** www.newenglandhemophilia.org

**Serving:** Statewide

## **HUNTINGTON'S DISEASE**

### **Huntington's Disease Society of America, Massachusetts Chapter (HDSA)**

HDSA is dedicated to finding a cure for Huntington's Disease and providing support and services for those living with HD and their families. HDSA promotes and supports clinical and basic HD research, aids families in coping with the multi-faceted problems presented by HD and educates the families, the public and healthcare professionals about Huntington's Disease.

1253 Worcester Rd., Suite 202  
Framingham, MA 01701

**Phone:** (508) 872-8102, (888) 872-8102

**Fax:** (508) 872-8103

**Email:** kimberly@hdsa-ne.org

**Website:** www.hdsa-ne.org

**Serving:** Statewide

## **KIDNEY**

### **National Kidney Foundation (NKF)**

NKF serves kidney patients and families, transplant recipients of all types, and donors and donor families. NKF provides a wealth of educational and supportive programs. There are 51 local chapters throughout the country.

30 East 33rd St. Suite 1100  
New York, NY 10016

**Phone:** (212) 889-2210, (800) 662-9010

**Fax:** (212) 689-9261

**Email:** info@kidney.org

**Website:** www.kidney.org

**Serving:** National

### **National Kidney Foundation of Mass./ Rhode Island/ New Hampshire and Vermont, Inc.**

The mission of the NKF-MA/RI/NH/VT is to prevent kidney and urinary tract diseases, improve the health and well being of individuals and families affected by these diseases and increase availability of all organs for transportation. They provide patient education, medical bracelets, holiday parties, field trips and support groups for families with children who have Nephrotic Syndrome. Student scholarships, Summer Science Research Awards, camp sponsorships, and financial assistance is available.

11 Vanderbilt Ave. Suite 105  
Norwood, MA 02062

**Phone:** (781) 278-0222, (800) 542-4001

**Fax:** (781) 278-0333

**Email:** information@kidneyhealth.org

**Website:** www.kidneyhealth.org

**Serving:** Statewide

## **LEARNING DISABILITIES**

### **Learning Disabilities Association of America (LDA)**

LDA is a volunteer organization dedicated to enhancing the quality of life for all individuals with learning disabilities and their families, alleviating the restricting effects of learning disabilities, and supporting endeavors to determine the causes of learning disabilities. LDA seeks to accomplish this through advocacy, education, research and service, and through collaborative efforts.

4156 Library Rd.  
Pittsburgh, PA 15234

**Phone:** (412) 341-1515

**Fax:** (412) 344-0224

**Email:** ldanatl@usaor.net

**Website:** www.ldanatl.org/

**Serving:** National

### **Learning Disabilities Worldwide (LDW)**

*Advances the education and general welfare of children with perceptual, conceptual or coordinative learning disabilities. Newsletter, calendar of events.*

PO Box 142  
Weston, MA 02493

**Phone:** (781) 890-5399  
**Fax:** (781) 890-0555  
**Website:** [www.ldworldwide.org](http://www.ldworldwide.org)  
**Serving:** National

## **MENTAL HEALTH**

### **Anxiety Disorders Association of America (ADAA)**

*ADAA promotes prevention, treatment and cure of anxiety disorders, and works to improve the lives of all people who suffer from them.*

8730 Georgia Avenue  
Silver Spring, MD 20910

**Phone:** (240) 485-1001  
**Fax:** (240) 485-1035  
**Website:** [www.adaa.org](http://www.adaa.org)  
**Serving:** National

### **Child and Adolescent Bipolar Foundation (CABF)**

*CABF's on-line community includes parents, researchers, medical doctors, neuroscientists, social workers, therapists, civic leaders, teachers and others. CABF educates the public about early-onset bipolar disorders. CABF provides online information and support groups, a message board, chat rooms, and lists of doctors.*

1000 Skokie Blvd.  
Wilmette, IL 60091

**Phone:** (847) 256-8525  
**Fax:** (847) 920-9498  
**Email:** [cabf@bpkids.org](mailto:cabf@bpkids.org)  
**Website:** [www.bpkids.org](http://www.bpkids.org)  
**Serving:** National

### **Depression and Bipolar Support Alliance (DBSA)**

*DBSA's mission is to improve the lives of people living with mood disorders. DBSA educates the public, healthcare professionals, and legislators about the diagnosis and treatment of bipolar disorder and depression.*

730 North Franklin Street  
Chicago, IL 60610

**Phone:** (800) 826-3632  
**Fax:** (312) 642-7243  
**Email:** [questions@dbsalliance.org](mailto:questions@dbsalliance.org)  
**Website:** [www.dbsalliance.org](http://www.dbsalliance.org)  
**Serving:** National

### **Families for Depression Awareness**

*Families for Depression Awareness is a national nonprofit organization helping families recognize and cope with depressive disorders. The organization provides education, outreach and advocacy to support families.*

300 Fifth Avenue  
Waltham, MA 02451

**Phone:** (781) 890-0220  
**Fax:** (781) 487-0009  
**Email:** [info@familyaware.org](mailto:info@familyaware.org)  
**Website:** [www.familyaware.org](http://www.familyaware.org)  
**Serving:** National

### **Federation of Families for Children's Mental Health (FFCMH)**

*Provides information, support and referrals through federation chapters throughout the country. The national parent run organization focuses on the needs of children with broad mental health problems.*

110 King St. Suite 420  
Alexandria, VA 22314

**Phone:** (703) 684-7710  
**Fax:** (703) 836-1040  
**Website:** [www.ffcmh.org](http://www.ffcmh.org)  
**Serving:** National

### **Freedom From Fear (FFF)**

*Freedom From Fear is a national nonprofit mental health advocacy association. The mission of FFF is to impact, in a positive way, the lives of all those affected by anxiety, depressive and related disorders through advocacy, education, research and community support.*

308 Seaview Avenue  
Staten Island, NY 10305

**Phone:** (888) 442-2022  
**Fax:** (718) 667-8893  
**Email:** [contactfff@aol.com](mailto:contactfff@aol.com)  
**Website:** [www.freedomfromfear.org](http://www.freedomfromfear.org)  
**Serving:** National

### **Juvenile Bipolar Research (JBRF)**

*JBRF is an organization dedicated to the support of research for the study of early onset bipolar disorder.*

550 Ridgewood Rd.  
Maplewood, NJ 07040

**Phone:** (866) 333-5273  
**Fax:** (973) 275-0420  
**Email:** [info@jbrf.org](mailto:info@jbrf.org)  
**Website:** [www.jbrf.org](http://www.jbrf.org)  
**Serving:** National

### **Manic-Depressive and Depressive Association of Boston (MDDA)**

*MDDA Boston is a nonprofit, self-help organization run by and for people with affective disorders such as depression and manic-depression (or Bipolar). MDDA members come together to share support and information with others in similar situations. MDDA sponsors a book store, informative newsletters, lectures, support groups, the Cole Mental Health Regional Resource Center and numerous other activities. Regional support groups are available for both people with these disorders and their families.*

P.O. Box 102, 115 Mill St.  
Belmont, MA 02478

**Phone:** (617) 855-2795  
**Fax:** (617) 855-3666  
**Website:** [www.mddaboston.org](http://www.mddaboston.org)  
**Serving:** Statewide

### **Mental Help Net**

*Comprehensive guide to on-line mental health, featuring over 7500 individual resources.*

**Website:** [www.mentalhelp.net](http://www.mentalhelp.net)  
**Serving:** National

### **National Alliance on Mental Illness (NAMI)**

*Information about specific disorders, medications and support group listings.*

Colonial Place Three  
2107 Wilson Blvd., Suite 300  
Arlington, VA 22201

**Phone:** (703) 524-9094, (800) 950-6264,  
(703) 516-7227 (TTY)  
**Fax:** (703) 524-9094  
**Website:** [www.nami.org](http://www.nami.org)  
**Serving:** National

### **National Alliance for the Mentally Ill of Western Massachusetts (NAMI-WM)**

*NAMI is a grassroots family and consumer self-help, support, education, and advocacy organization dedicated to improving the lives of people with severe mental illnesses.*

717 ½ Main St.  
Agawam, MA 01001

**Phone:** (413) 786-9139, (800) 295-2121  
**Fax:** (413) 789-1137  
**Email:** [AMIWMA@aol.com](mailto:AMIWMA@aol.com)  
**Website:** [www.members.aol.com/amiwma](http://www.members.aol.com/amiwma)  
**Serving:** Western

### **National Mental Health Association (NMHA)**

*National nonprofit mental health advocacy organization concerned with all aspects of mental health and mental illness. The Association's Resource Center serves the general public by providing literature about mental illness and referrals to mental health services. In addition, the Resource Center provides technical assistance to mental health consumer and consumer supporter organizations, advocacy organizations, and NMHA's nationwide network of 340 affiliate offices.*

2001 N. Beauregard St., 12th Floor  
Alexandria, VA 22311

**Phone:** (703) 684-7722, (800) 969-6642  
(800) 433-5959 (TTY)  
**Fax:** (703) 684-5968  
**Email:** [info@nmha.org](mailto:info@nmha.org)  
**Website:** [www.NMHA.org](http://www.NMHA.org)  
**Serving:** National

### **National Substance Abuse and Mental Health Information Center (SAMHSA)**

*This national center, a component of the U.S. Public Health Service, provides a range of information on mental health, treatment and support services.*

P.O. Box 42557  
Washington, DC 20015

**Phone:** (800) 789-2647, (866) 889-2647 (TTY)  
**Fax:** (240) 747-5470  
**Website:** [www.mentalhealth.org](http://www.mentalhealth.org)  
**Serving:** National

### **Parent Professional Advocacy League (PAL)**

*A statewide network of families, local family support groups, and professionals who advocate on behalf of children and adolescents with mental, emotional or behavioral special needs, and their families.*

#### **Boston**

59 Temple Pl., Suite: 664  
Boston, MA 02111

**Phone:** (617) 542-7860, (866) 815-8122  
**Fax:** (617) 542-7832  
**Email:** [info@ppal.net](mailto:info@ppal.net)  
**Website:** [www.ppal.net](http://www.ppal.net)  
**Serving:** Statewide

#### **Worcester**

21 Cedar Street  
Worcester, MA 01609

**Phone:** (508) 767-9725  
**Fax:** (508) 767-9727  
**Website:** [www.ppal.net](http://www.ppal.net)  
**Serving:** Central

**Western MA  
Support Network for Families of Western MA,  
Parent/Professional Advocacy League (PAL)**

187 High St. Suite 202  
Holyoke, MA 01040

**Phone:** (413) 536-2401  
**Fax:** (413) 536-4166  
**Email:** supportnetwork@wmtcinfo.org  
**Website:** <http://www.wmtcinfo.org>  
**Serving:** Western

**Project Connect (MSPCC)**

*Support services for families of children with mental health issues.*

63 Fountain St., Suite 402  
Framingham, MA 01701

**Phone:** (800) 884-8827  
**Fax:** (508) 820-3121  
**Website:** [www.msppcc.org/programs/projectconnect.cfm](http://www.msppcc.org/programs/projectconnect.cfm)  
**Serving:** Metrowest

**S.T.E.P. UP 4 KIDS**

*An organization developed for parents, families, mental health professionals, clinicians and teachers aimed at providing necessary education, support and tools that will create a better understanding and more enriching life for children and adolescents affected with early onset bipolar spectrum disorder.*

P.O. Box 65  
North Scituate, MA 02066

**Phone:** (781) 545-9909, (866) 922-5427  
**Email:** [info@stepup4kids.com](mailto:info@stepup4kids.com)  
**Website:** [www.stepup4bpkids.com](http://www.stepup4bpkids.com)  
**Serving:** National

**Suicide Prevention Resource Center**

*The SPRC provides prevention support, training, and resources to assist organizations and individuals to develop suicide prevention programs, interventions and policies, and to advance the national strategy for suicide prevention.*

55 Chapel Street  
Newton, MA 02458

**Phone:** (617) 969-9186, (888) 438-7772  
(617) 964-5448 (TTY)  
**Email:** [info@sprc.org](mailto:info@sprc.org)  
**Website:** [www.sprc.org](http://www.sprc.org)  
**Serving:** National

**Worcester Communities of Cares:  
Coordinated Family Focused Care (WCC)**

*Works with families with children ages 3-21 who have serious emotional and/or behavior problems who also live in Worcester and meet criteria. Families must have MASSHEALTH MBHP (Mental Health Services).*

275A Belmont St.  
Worcester, MA 01604

**Phone:** (508) 856-5242  
**Fax:** (508) 856-1378  
**Email:** [matilde.rodriguez@umassmed.edu](mailto:matilde.rodriguez@umassmed.edu)  
**Website:** [www.worcestercommunitiesofcare.com](http://www.worcestercommunitiesofcare.com)  
**Serving:** Central

**MULTIPLE BIRTHS**

**Arlington Mothers of Multiples (AMOM)**

*A clearinghouse of information related to parenting twins, triplets and more.*

P.O. Box 151142  
Arlington, TX 76015  
**Phone:** (608) 263-5776  
**Fax:** (608) 263-0529  
**Website:** <http://www.amoms.org/>  
**Serving:** National

**National Organization of Mothers of Twins Clubs, Inc.**

*Our goal is to improve public awareness of the needs of multiple birth children by fostering development of local support groups, enhancing the quality of educational materials available to parents, educators and others and by cooperating with and participating in research projects which involve twins and/or their families.*

PO BOX 700860  
Plymouth, Michigan 48170-0955  
**Email:** [Info@NOMOTC.ORG](mailto:Info@NOMOTC.ORG)  
**Website:** [www.nomotc.org/](http://www.nomotc.org/)  
**Serving:** National  
**Additional Languages Served:** Spanish

**Triplets, Moms, and More Inc.**

*Triplets, Moms, and More. (TMM) is a Massachusetts-based support group for families and families-to-be of triplets, quads and more. TMM provides opportunities for these families to address the unique aspects of parenting higher order multiples (HOMs).*

22 Mt. Pleasant St.  
Saugus, MA 01906  
**Phone:** (339) 927-2365  
**Email:** [info@tripletsmomsandmore.org](mailto:info@tripletsmomsandmore.org)  
**Website:** [www.tripletsmomsandmore.org/](http://www.tripletsmomsandmore.org/)  
**Serving:** Statewide

## **MULTIPLE SCLEROSIS**

### **National Multiple Sclerosis Society, Central New England Chapter Office (NMSS)**

*Information and support services for individuals and families with multiple sclerosis.*

101A First Avenue, Suite 6  
Waltham, MA 02451

**Phone:** (781) 890-4990, (800) 493-9255  
**Fax:** (781) 890-2089  
**Website:** [www.msnewengland.org](http://www.msnewengland.org)  
**Serving:** Statewide

## **MUSCULAR DYSTROPHY**

### **Muscular Dystrophy Association (MDA)**

*Provides medical and psycho-social supports, services and referrals to families who are affected by the 43 diseases under Muscular Dystrophy.*

275 Turnpike St., Suite 201  
Canton, MA 02021

**Phone:** (781) 575-1881, (800) 730-0318  
**Fax:** (781) 575-1886  
**Email:** [nfma2000@aol.com](mailto:nfma2000@aol.com)  
**Website:** [www.mdausa.org](http://www.mdausa.org)  
**Serving:** National

## **NEUROFIBROMATOSIS**

### **Children's Tumor Foundation**

*National organization providing support, informational material on the National Neurofibromatosis Foundation's MA chapter and Neurofibromatosis.*

75 McNeil Way Suite 310  
Dedham, MA 02026

**Phone:** (508) 879-5638, (888) 585-5316  
**Fax:** (781) 326-4940  
**Email:** [mbraden@ctf.org](mailto:mbraden@ctf.org)  
**Website:** [www.ctf.org](http://www.ctf.org)  
**Serving:** National

### **Children's Tumor Foundation**

*National organization providing support, informational material on the National Neurofibromatosis Foundation's MA chapter and Neurofibromatosis.*

75 McNeil Way, Suite 310  
Dedham, MA 02026

**Phone:** (508) 879-5638, (888) 585-5316  
**Fax:** (781) 326-4940  
**Email:** [mbraden@ctf.org](mailto:mbraden@ctf.org)  
**Website:** [www.ctf.org](http://www.ctf.org)  
**Serving:** Statewide

## **NEUROLOGICAL DISORDERS**

### **Batten Disease Support and Research Association**

*BDSRA's mission is to be an international support and research networking organization for families of children and young adults with an inherited neurological degenerative disorder known as Batten Disease.*

120 Humphries Drive, Suite 2  
Reynoldsburg, OH 43068

**Phone:** (800) 448-4570  
**Email:** [bdsra1@bdsra.org](mailto:bdsra1@bdsra.org)  
**Website:** [www.bdsra.org](http://www.bdsra.org)  
**Serving:** National

### **Family Circle**

*A support, mentoring, and resource program for families who have children, all ages, with a severe neurological disorder.*

198 Vanderbilt Ave.  
Norwood, MA 02062

**Phone:** (781) 551-0405  
**Fax:** (781) 551-9901  
**Email:** [preardon@jfcsboston.org](mailto:preardon@jfcsboston.org)  
**Website:** [www.jfcsboston.org](http://www.jfcsboston.org)  
(click on family and children)  
**Serving:** Statewide

### **National Ataxia Foundation (NAF)**

*The NAF is a nonprofit organization dedicated to improving the lives of those affected by ataxia through support, education and research.*

2600 Fernbrook Lane, Suite 119  
Minneapolis, MN 55447

**Phone:** (763) 553-0020  
**Fax:** (763) 553-0167  
**Email:** [naf@ataxia.org](mailto:naf@ataxia.org)  
**Website:** [www.ataxia.org](http://www.ataxia.org)  
**Serving:** National

## **OBSESSIVE-COMPULSIVE**

### **The Obsessive-Compulsive Foundation (OCF)**

*Support, information and referral services for individuals with obsessive-compulsive disorder and their family and friends. Local support groups, clinician referral listing, reference materials, newsletter and annual conference.*

676 State St.  
New Haven, CT 06511

**Phone:** (203) 401-2070  
**Email:** [info@ocfoundation.org](mailto:info@ocfoundation.org)  
**Website:** [www.ocfoundation.org](http://www.ocfoundation.org)  
**Serving:** National

### **The Obsessive-Compulsive Foundation of Greater Boston**

Support, information and referral services for individuals with obsessive-compulsive disorder and their family and friends. Local support groups, clinician referral listing, reference materials and newsletter.

115 Mill St.  
Belmont, MA 02478

**Phone:** (617) 855-2252  
**Email:** [egan-stack@ocd.mclean.org](mailto:egan-stack@ocd.mclean.org)  
**Website:** [www.ocfboston.org](http://www.ocfboston.org)  
**Serving:** Boston

### **PKU**

#### **New England Connection for PKU and Allied Disorders**

To provide better support and necessary services to all families affected with PKU and allied disorders, including Homocystinuria, Maple Syrup Urine Disease, Organic Acidemias, Tyrosinemia, and Urea Cycle Disorders; and to encourage research and to increase public awareness of the diseases. Support network available for parents.

**Website:** [www.necpad.org](http://www.necpad.org)  
**Serving:** Statewide

### **PRADER WILLI**

#### **Prader-Willi Syndrome Association of New England**

Provides information and support, quarterly parent support groups, family recreation events, conference every other year, list of parents who can be contacted for support, and newsletter.

18 Claridge Circle  
Milford, MA 01757

**Phone:** (508) 478-2065  
**Email:** [pwsane@aol.com](mailto:pwsane@aol.com)  
**Website:** [www.members.aol.com/pwsane](http://www.members.aol.com/pwsane)  
**Serving:** Statewide

### **PREMATURITY**

#### **Birth Defect Research for Children**

Offers on-line support and resources.

930 Woodcock Rd. Suite 255  
Orlando, FL 32803

**Phone:** (608) 263-5776  
**Fax:** (608) 263-0529  
**Email:** [staff@birthdefects.org](mailto:staff@birthdefects.org)  
**Website:** [www.birthdefects.org](http://www.birthdefects.org)  
**Serving:** National

### **Premature Baby-Premature Child**

Offers on-line support and resources, including suggested reading, developmental milestones and support network.

**Website:** [www.prematurity.org](http://www.prematurity.org)  
**Serving:** National

### **RETT SYNDROME**

#### **Rett Syndrome Association of Massachusetts**

Agency has parent volunteers who will call and provide information and support to families.

217 South St.  
Waltham, MA 02154

**Phone:** (781) 444-8164  
**Website:** [www.orgsites.com/ma/rsam](http://www.orgsites.com/ma/rsam)  
**Serving:** Statewide

### **SENSORY PROCESSING DISORDERS**

#### **Sensory Integration International (SII)**

SII is a nonprofit corporation concerned with the impact of sensory integrative problems on people's lives. Its goal is to improve the quality of life for person's with sensory processing disorders.

P.O. Box 5339  
Torrance, CA 90510

**Phone:** (310) 787-8805  
**Fax:** 310) 787-8130  
**Email:** [info@sensoryint.com](mailto:info@sensoryint.com)  
**Website:** [www.sensoryint.com](http://www.sensoryint.com)  
**Serving:** National

### **Spiral Foundation (SF)**

SF is committed to improving the quality of life for children with sensory processing disorder in the home, classroom and community. Through education, research and support, SF provides families, educators and healthcare professionals with information about symptoms, effective treatment, community resources and the impact sensory processing disorder has on other disorders.

124 Watertown Street  
Watertown, MA 02472

**Phone:** (617) 923-4410  
**Email:** [info@thespiralfoundation.org](mailto:info@thespiralfoundation.org)  
**Website:** [www.thespiralfoundation.org](http://www.thespiralfoundation.org)  
**Serving:** Statewide

## **SIDS**

### **Sudden Infant Death Syndrome Outreach Foundation, Inc., Massachusetts Center**

*Coordinates services to families who are affected by SIDS or other causes of infant mortality. Services include 24-hr. counseling provided by nurses and physicians; bereavement counseling, home visits; parent support groups and parent-to-parent contacts. There are support groups in Boston, Worcester, and Springfield.*

One Boston Medical Center Pl.  
The MA Center for SIDS  
Boston, MA 02118

**Phone:** (617) 414-7437, (800) 641-7437

**Fax:** (617) 414-5555

**Email:** mary.mcclain@bmc.org

**Website:** www.bmc.org/pediatrics/special/sids

**Serving:** Statewide

## **SPEECH-LANGUAGE-HEARING**

### **Apraxia Kids Support**

*Information about apraxia of speech or developmental verbal dyspraxia.*

123 Eisele Road  
Cheswick, PA 15024

**Phone:** (412) 343-7102

**Fax:** (412) 767-0534

**Email:** helpdesk@apraxia-kids.org

**Website:** www.apraxia-kids.org

**Serving:** National

### **Childhood Apraxia of Speech Association (CASANA)**

*CASANA is a non profit organization whose mission is to strengthen the support systems in the lives of children with apraxia so that each child is afforded their best opportunity to develop speech.*

P.O. Box 130909  
Carlsbad, CA 92013

**Phone:** (760) 632-5020

**Fax:** (760) 632-8992

**Email:** info@hendrixfoundation.org

**Website:** www.apraxia-kids.org

**Serving:** National

### **Speech, Hearing and Language**

*Outpatient services, information and education.*

2007 Bay St., Suite B100  
Taunton, MA 02780

**Phone:** (508) 823-3050, (508) 821-4470 (TTY)

**Fax:** (508) 828-5858

**Email:** shl@mortonhospital.org

**Website:** www.mortonhospital.com

**Serving:** Southeast

## **SPINA BIFIDA**

### **Massachusetts Spina Bifida Association**

*Provides information related to spina bifida including progress in the areas of medicine, education, legislation and financial support. Helps fund research into the causes, effects and treatment of spina bifida and encourages the training of professionals involved in treatment.*

733 Turnpike St. #282  
North Andover, MA 01845

**Phone:** (978) 549-8725, (888) 479-1900

**Email:** apbcon@mindspring.com

**Website:** www.msbaweb.org

**Serving:** Statewide

## **SPINAL INJURY**

### **National Spinal Cord Injury (NSCIA)**

*Information and support for individuals with spinal cord injury and their families.*

6701 Democracy Blvd. Suite 300  
Bethesda, MD 20817

**Phone:** (301) 214-4006, (800) 962-9629

**Fax:** (301) 963-1265

**Email:** info@spinalcord.org

**Website:** www.spinalcord.org

**Serving:** National

### **Spinal Cord Injury Association (NSCIA)**

*Information and support for individuals with spinal cord injury and their families.*

2 Rehabilitation Way  
Woburn, MA 01801

**Phone:** (781) 933-8666

**Fax:** (781) 933-0043

**Email:** sciboston@aol.com

**Website:** www.sciboston.com

**Serving:** Boston

## **TOURETTE SYNDROME**

### **Tourette Syndrome Association, Inc.**

*Provides information and referral, adult and parent support groups, kids group, lending library, advocacy services, newsletter, and physician referral service. Regional parents contacts are available to provide local support group information or one-on-one support.*

P.O. Box 653  
Marstons Mills, MA 02648

**Phone:** (617) 277-7589

**Website:** www.tsamass.org

**Serving:** Statewide

## **TRACHEOSTOMIES**

### **TrachCare, Inc.**

*The mission of TrachCare is to provide a means for families who share similar experiences of caring for children with trachs to connect with each other, share relevant resources and information, and promote an advocacy-focused network.*

P.O. Box 550075  
Waltham, MA 02455

**Phone:** (617) 787-1990

**Email:** [info@trachcare.org](mailto:info@trachcare.org)

**Website:** [www.trachcare.org](http://www.trachcare.org)

**Serving:** Statewide

### **Tracheostomy.com**

*On-line support with a mission to help assure the highest quality home care for children with tracheostomies; provide needed tracheostomy information in order to ease some of the anxiety related to caring for a child with a trach. A well-informed family will usually experience less anxiety; and facilitate parent-to-parent networking and support.*

**Website:** [www.tracheostomy.com](http://www.tracheostomy.com)

**Serving:** National

## **TURNER SYNDROME**

### **Turner Syndrome Society of the United States (TSSUS)**

*TSSUS is a nonprofit organization whose mission is to increase public awareness and understanding of Turner Syndrome, provide a forum where those affected by Turner Syndrome can become acquainted with others in similar situations, and work together with medical professionals to better understand the condition through research and communication of ideas.*

14450 TC Jester, Suite 260  
Houston, TX 77014

**Phone:** (832) 249-9988, (800) 365-9944

**Fax:** (832) 249-9987

**Email:** [tssus@turner-syndrome-us.org](mailto:tssus@turner-syndrome-us.org)

**Website:** [www.turner-syndrome-us.org](http://www.turner-syndrome-us.org)

**Serving:** National

### **Turner Syndrome Society, Southeastern New England Chapter**

*Regional chapter of the Turner Syndrome Society, provides information and referral, quarterly support group meetings.*

1034 Maple Street  
Mansfield, MA

**Phone:** (508) 339-3022

**Email:** [beth\\_wheeler@comcast.net](mailto:beth_wheeler@comcast.net)

**Serving:** Statewide