

Chapter 36

Congenital Disorders: Resources for Information and Support

General

American Pregnancy Association

3007 Skyway Cir. N.
Ste. 800
Irving, TX 75038
Toll-Free: 800-672-2296
Phone: 972-550-0140
Website: www.americanpregnancy.org
E-mail: info@americanpregnancy.org

Boston Children's Hospital

300 Longwood Ave.
Boston, MA 02115
Toll-Free: 844-BCH-PEDS (844-224-7337)
Phone: 617-355-6000
TTY: 617-730-0152
Website: www.childrenshospital.org

Resources in this chapter were compiled from several sources deemed reliable; all contact information was verified and updated in December 2017.

Centers for Disease Control and Prevention (CDC)

1600 Clifton Rd.
Atlanta, GA 30329-4027
Toll-Free: 800-CDC-INFO (800-232-4636)
Toll-Free TTY: 888-232-6348
Website: www.cdc.gov

Children's Hospital Colorado

Anschutz Medical Campus
13123 E. 16th Ave.
Aurora, CO 80045
Toll Free: 800-624-6553
Phone: 720-777-0123
Website: www.childrenscolorado.org

Children's Hospital of Philadelphia

3401 Civic Center Blvd.
Philadelphia, PA 19104
Toll Free: 800-879-2467
Phone: 215-590-3800
Fax: 215-590-1415
Website: www.chop.edu

Children's Memorial Hermann Hospital

Texas Medical Center
6411 Fannin St.
Houston, TX 77030
Toll-Free: 713-222-CARE (713-222-2273)
Phone: 713-704-KIDS (713-704-5437)
Website: www.childrens.memorialhermann.org

Cincinnati Children's Hospital Medical Center

3333 Burnet Ave.
Cincinnati, OH 45229-3026
Toll-Free: 800-344-2462; Toll-Free: 877-881-8479 (outside of tri-state area)
Phone: 513-636-4200
TTY: 513-636-4900
Website: www.cincinnatichildrens.org

Congenital Disorders: Resources for Information and Support

Fetal Hope Foundation

9786 S. Holland St.
Littleton, CO 80127
Toll-Free: 877-789-HOPE (877-789-4673)
Phone: 303-932-0553
Website: www.fetalhealthfoundation.org
E-mail: info@fetalhope.org

Johns Hopkins Children's Center

The Charlotte R. Bloomberg Children's Center
1800 Orleans St.
Baltimore, MD 21287
Phone: 410-955-5000
Website: www.hopkinsmedicine.org

Lifespan

167 Pt. St.
Providence, RI 02903
Phone: 401-444-3500
Website: www.lifespan.org

March of Dimes

1275 Mamaroneck Ave.
White Plains, NY 10605
Website: www.marchofdimes.org

MotherToBaby

Organization of Teratology Information Specialists (OTIS)
5034A Thoroughbred Ln.
Brentwood, TN 37027
Phone: 615- 649-3082
Website: www.mothersbaby.org
E-mail: contactus@otispregnancy.org

SSM Health

1465 S. Grand Blvd.
St. Louis, MO 63104
Toll-Free: 877-SSM-FETL (877-776-3385)
Phone: 314-994-7800
Website: www.ssmhealth.com

University of California San Francisco (UCSF) Benioff Children's Hospital

505 Parnassus Ave.
San Francisco, CA 94143
Phone: 415-476-1000
Website: www.ucsfbenioffchildrens.org

University of California San Francisco (UCSF) Fetal Treatment Center

1855 Fourth St.
Second Fl. Rm. A-2432
San Francisco, CA 94158-2549
Toll-Free: 800-RX-FETUS (800-793-3887)
Fax: 415-502-0660
Website: www.fetus.ucsf.edu
E-mail: fetaltreatmentcenter@ucsf.edu

University of Michigan C.S. Mott Children's Hospital

1540 E. Hospital Dr.
Ann Arbor, MI 48109
Toll-Free: 877-285-7788
Phone: 734-936-4000
Website: www.mottchildren.org
E-mail: mottchildren@umich.edu

The University of Texas Health Science Center at Houston (UTHealth)

7000 Fannin St.
Ste. 1800
Houston, TX 77030
Phone: 713-500-4472
Website: www.uth.edu

Birthmarks

Vascular Birthmarks Foundation

P.O. Box 106
Latham, NY 12110
Toll-Free: 877-VBF-4646 (877-823-4646)
Website: www.birthmark.org

Brain and Spinal Cord Defects

Dandy-Walker Alliance, Inc.

10325 Kensington Pkwy
Ste. 384
Kensington, MD 20895
Toll-Free: 877-Dandy-Walker (877-326-3992)
Website: www.dandy-walker.org
E-mail: comments@dandy-walker.org

Hydrocephalus Association

4340 East West Hwy
Ste. 905
Bethesda, MD 20814-4447
Toll-Free: 888-598-3789
Phone: 301-202-3811
Fax: 301-202-3813
Website: www.hydroassoc.org
E-mail: info@hydroassoc.org

National Hydrocephalus Foundation (NHF)

12413 Centralia Rd.
Lakewood, CA 90715-1653
Toll-Free: 888-857-3434
Phone: 562-924-6666
Website: www.nhfonline.org
E-mail: info@nhfonline.org

***National Institute of Neurological Disorders and Stroke
(NINDS)***

NIH Neurological Institute
P.O. Box 5801
Bethesda, MD 20824
Toll-Free: 800-352-9424
Phone: 301-496-5751
Website: www.ninds.nih.gov
E-mail: me20t@nih.gov

***National Organization for Disorders of the Corpus Callosum
(NODCC)***

18032-C Lemon Dr.
PMB 363
Yorba Linda, CA 92886
Phone: 714-747-0063
Fax: 714-693-0808
Website: www.nodcc.org
E-mail: info@nodcc.org

Pediatric Hydrocephalus Foundation

10 Main St.
Ste. 335
Woodbridge, NJ 07095
Phone: 732-634-1283
Fax: 847-589-1250
Website: www.hydrocephaluskids.org
E-mail: info@hydrocephaluskids.org

Spina Bifida Association

1600 Wilson Blvd.
Ste. 800
Arlington, VA 22209
Toll Free: 800-621-3141
Phone: 202-944-3285
Fax: 202-944-3295
Website: www.spinabifidaassociation.org
E-mail: sbaa@sbaa.org

United Cerebral Palsy

1825 K St. N.W.
Ste. 600
Washington, DC 20006
Toll-Free: 800-872-5827
Phone: 202-776-0406
Fax: 202-776-0414
Website: www.ucp.org
E-mail: info@ucp.org

Cardiovascular Defects

Adult Congenital Heart Association (ACHA)

3300 Henry Ave.
Ste. 112
Philadelphia, PA 19119
Toll Free: 888-921-ACHA (888-921-2242)
Phone: 215-849-1260
Fax: 215-849-1261
Website: www.achaheart.org
E-mail: info@achaheart.org

American Heart Association (AHA)

7272 Greenville Ave.
Dallas, TX 75231
Toll-Free: 800-AHA-USA-1 (800-242-8721)
Phone: 214-570-5978
Website: www.heart.org
E-mail: inquiries@heart.org

National Heart, Lung, and Blood Institute (NHLBI)

NHLBI Health Information Center
P.O. Box 30105
Bethesda, MD 20824-0105
Phone: 301-592-8573
TTY: 240-629-3255
Website: www.nhlbi.nih.gov
E-mail: nhlbiinfo@nhlbi.nih.gov

Craniofacial Defects

American Cleft Palate-Craniofacial Association (ACPA)

1504 E. Franklin St.
Ste. 102
Chapel Hill, NC 27514-2820
Phone: 919-933-9044
Fax: 919-933-9604
Website: www.acpa-cpf.org
E-mail: info@acpa-cpf.org

Ameriface

P.O. Box 751112
Las Vegas, NV 89136-1112
Toll-Free: 888-486-1209
Phone: 702-769-9264
Fax: 702-341-5351
Website: www.ameriface.org
E-mail: info@ameriface.org

Children's Craniofacial Association (CCA)

13140 Coit Rd., Ste. 517
Dallas, TX 75240
Toll-Free: 800-535-3643
Phone: 214-570-9099
Fax: 214-570-8811
Website: www.ccakids.org
E-mail: contactCCA@ccakids.com

Cleft Palate Foundation

1504 E. Franklin St.
Ste. 102
Chapel Hill, NC 27514-2820
Toll-Free: 800-242-5338
Phone: 919-933-9044
Fax: 919-933-9604
Website: www.cleftline.org

FACES: The National Craniofacial Association

P.O. Box 11082
Chattanooga, TN 37401
Toll Free: 800-332-2373
Phone: 423-266-1632
Website: www.faces-cranio.org
E-mail: faces@faces-cranio.org

myFace

333 E. 30th St. Lobby Office
New York, NY 10016
Phone: 212-263-6656
Fax: 212-263-7534
Website: www.myface.org
E-mail: info@myface.org

***National Institute of Dental and Craniofacial Research
(NIDCR)***

National Institutes of Health (NIH)
31 Center Dr. MSC 2190
Bldg. 31 Rm. 5B55
Bethesda, MD 20892-2190
Toll-Free: 866-232-4528
Phone: 301-496-4261
Fax: 301-480-4098
Website: www.nidcr.nih.gov
E-mail: nidcrinfo@mail.nih.gov

World Craniofacial Foundation

7777 Forest Ln.
Ste. C-616
Dallas, TX 75230
Toll-Free: 800-533-3315
Phone: 972-566-6669
Website: www.worldcf.org
E-mail: info@worldcf.org

Digestive Tract Defects

American Liver Foundation (ALF)

39 Bdwy.
Ste. 2700
New York, NY 10006
Toll-Free: 800-GO-LIVER (800-465-4837)
Phone: 212-668-1000
Fax: 212-483-8179
Website: www.liverfoundation.org

***Association of Congenital Diaphragmatic Hernia Research
Awareness and Support (CHERUBS)***

152 S. White St.
Upstairs Ste.
Wake Forest, NC 27587
Phone: 919-610-0129
Fax: 815-425-9155
Website: www.cherubs-cdh.org
E-mail: cpab@cherubs-cdh.org

***Children's Liver Association for Support Services
(C.L.A.S.S.)***

P.O. Box 15061
Monaca, PA 15061
Phone: 724-888-2568
Website: www.classkids.org
E-mail: info@classkids.org

Children's Organ Transplant Association (COTA)

2501 W. COTA Dr.
Bloomington, IN 47403
Toll-Free: 800-366-2682
Fax: 812-336-8885
Website: www.cota.org
E-mail: cota@cota.org

***North American Society for Pediatric Gastroenterology,
Hepatology and Nutrition (NASPGHAN)***

714 N. Bethlehem Pike, Ste. 300
Ambler, PA 19002
Phone: 215-641-9800
Fax: 215-641-1995
Website: www.naspghan.org
E-mail: naspghan@naspghan.org

***National Institute of Diabetes and Digestive and Kidney
Diseases (NIDDK)***

Office of Communications & Public Liaison
31 Center Dr. MSC 2560
Bethesda, MD 20892-2560
Toll-Free: 800-860-8747
Phone: 301-435-8116
Toll-Free TTY: 866-569-1162
Website: www.niddk.nih.gov
E-mail: healthinfo@niddk.nih.gov

Pull-Thru Network

c/o Lori Parker
1705 Wintergreen Pkwy
Normal, IL 61761
Phone: 309-262-0786
Website: www.pullthrunetwork.org

Kidney and Urinary Tract Defects

American Association of Kidney Patients (AAKP)

14440 Bruce B. Downs Blvd.
Tampa, Fl 33613
Toll-Free: 800-749-AAKP (800-749-2257)
Phone: 813-636-8100
Fax: 813-636-8122
Website: www.aakp.org
E-mail: info@aakp.org

American Kidney Fund (AKF)

11921 Rockville Pike
Ste. 300
Rockville, MD 20852
Toll-Free: 800-638-8299
Phone: 301-881-3052
Website: www.kidneyfund.org
E-mail: info@kidneyfund.org

American Society of Pediatric Nephrology (ASPN)

6728 Old McLean Village Dr.
McLean, VA 22101
Phone: 703-556-9222
Website: www.aspneph.org
E-mail: info@aspneph.org

American Urological Association (AUA)

1000 Corporate Blvd.
Linthicum, MD 21090
Toll-Free: 800-828-7866
Phone: 410-689-3700
Fax: 410-689-3800
Website: www.auanet.org
E-mail: aua@AUAnet.org

Association for the Bladder Exstrophy Community (A-BE-C)

204 37th Ave. N.
Ste. 157
Saint Petersburg, FL 33704
Website: www.bladderexstrophy.com

Bladder Exstrophy Research Foundation

P.O. Box 13083

Newport Beach, CA 92658

Phone: 949-922-9865

Website: www.exstrophyresearch.org

E-mail: info@exstrophyresearch.org

Georgia Urology

1930 Brannan Rd.

McDonough, GA 30253

Toll-Free: 855-STONE11 (855-786-6311)

Phone: 678-284-4053

Website: www.gaurology.com

Hypospadias and Epispadias Association, Inc.

P.O. Box 607

Amsterdam, NY 12010

Website: www.heainfo.org

Kidney & Urology Foundation of America (KUFA)

63 W. Main St.

Ste. G

Freehold, NJ 07728

Toll-Free: 800-633-6628

Phone: 732-866-4444

Website: www.kidneyurology.org

National Kidney Foundation (NKF)

30 E. 33rd St.

New York, NY 10016

Toll-Free: 855-NKF-CARES (855-653-2273)

Phone: 800-622-9010

Fax: 212-689-9261

Website: www.kidney.org

E-mail: info@kidney.org

Limb and Joint Defects

American Academy of Orthopaedic Surgeons (AAOS)

9400 W. Higgins Rd.
Rosemont, IL 60018
Phone: 847-823-7186
Fax: 847-823-8125
Website: www.aaos.org

American Society for Surgery of the Hand (ASSH)

822 W. Washington Blvd.
Chicago, IL, 60607
Phone: 312-880-1900
Fax: 847-384-1435
Website: www.assh.org
E-mail: info@assh.org

Fibrous Dysplasia Foundation

2885 Sanford Ave. S.W. 40754
Grandville, MI 49418
Website: www.fibrousdysplasia.org
E-mail: info@fibrousdysplasia.org

Maternal Alcohol Abuse

National Institute on Alcohol Abuse and Alcoholism (NIAAA)

5635 Fishers Ln.
Bethesda, MD 20892-9304
Phone: 301-443-3860
Website: www.niaaa.nih.gov
E-mail: niaaaweb-r@exchange.nih.gov

National Organization on Fetal Alcohol Syndrome (NOFAS)

1200 Eton Ct. N.W.
Third Fl.
Washington, DC 20007
Phone: 202-785-4585
Fax: 202-466-6456
Website: www.nofas.org
E-mail: information@nofas.org