

## Chapter 38

# ***Congenital Disorders: Resources for Information and Support***

### ***General***

#### ***AboutKidsHealth***

The Hospital for Sick Children  
555 University Avenue  
Toronto, Ontario  
Canada M5G 1X8  
Website:  
<http://www.aboutkidshealth.ca>

#### ***Boston Children's Hospital***

300 Longwood Avenue  
Boston, MA 02115  
Phone: 617-355-6000  
TTY: 617-730-0152  
Website:  
<http://childrenshospital.org>

#### ***American Pregnancy Association***

1425 Greenway Drive  
Suite 440  
Irving, TX 75038  
Phone: 972-550-0140  
Fax: 972-550-0800  
Website:  
<http://www.americanpregnancy.org>  
E-mail: [questions@americanpregnancy.org](mailto:questions@americanpregnancy.org)

#### ***Centers for Disease Control and Prevention***

1600 Clifton Road  
Atlanta, GA 30333  
Toll-Free: 800-CDC-INFO  
(800-232-4636)  
Toll-Free TTY: 888-232-6348  
Website: <http://www.cdc.gov>

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Resources in this chapter were compiled from several sources deemed reliable. All contact information was verified and updated in January 2013.

***Children's Hospital  
Colorado***

Anschutz Medical Campus  
13123 East 16th Avenue  
Aurora, CO 80045  
Toll Free: 800-624-6553  
Phone: 720-777-1234  
TTY: 720-777-6050  
Website:  
<http://www.childrenscolorado.org>

***Children's Hospital of  
Philadelphia***

34th St. and Civic Center Blvd.  
Philadelphia, PA 19104  
Phone: 215-590-1000  
Website:  
<http://www.chop.edu>

***Children's Memorial  
Hermann Hospital***

Texas Medical Center  
6411 Fannin Street  
Houston, TX 77030  
Phone: 713-704-KIDS  
(713-704-5437)  
Website:  
<http://childrens.memorialhermann.org>

***Cincinnati Children's  
Hospital Medical Center***

3333 Burnet Avenue  
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: <https://www.cincinnatichildrens.org>

***Fetal Hope Foundation***

9786 South Holland Street  
Littleton, CO 80127  
Toll-Free: 877-789-HOPE  
(877-789-4673)  
Phone: 303-932-0553  
Website:  
<http://www.fetalhope.org>  
E-mail:  
[info@fetalhope.org](mailto:info@fetalhope.org)

***Fetal Treatment  
Program of New  
England***

Bay Tower Medical Office  
101 Plain Street  
Providence, RI 02903  
Phone: 401-228-0559  
Website:  
<http://www.fetal-treatment.org>  
E-mail: [coordinator@fetal-treatment.org](mailto:coordinator@fetal-treatment.org)

***Johns Hopkins  
Children's Center***

1800 Orleans Street  
Baltimore, MD 21287  
Phone: 410-955-5000  
Website:  
<http://www.hopkinschildrens.org>

***Madison's Foundation***

P.O. Box 241956  
Los Angeles, CA 90024  
Phone: 310-264-0826  
Fax: 310-264-4766  
Website: <http://www.madisonsfoundation.org>  
E-mail: [getinfo@madisonsfoundation.org](mailto:getinfo@madisonsfoundation.org)

## **Congenital Disorders: Resources for Information and Support**

### ***March of Dimes***

1275 Mamaroneck Avenue  
White Plains, NY 10605  
Phone: 914-997-4488  
Website: <http://www.marchofdimes.com>

### ***Organization of Teratology Information Specialists (OTIS)***

5034A Thoroughbred Lane  
Brentwood, TN 37027  
Toll-Free: 866-626-OTIS  
(866-626-6847)  
Phone: (615) 649-3082  
Fax: (615) 523-1715  
Website:  
<http://www.otispregnancy.org>  
E-mail: [contactus@otispregnancy.org](mailto:contactus@otispregnancy.org)

### ***St. Louis Fetal Care Institute***

SSM Cardinal Glennon  
Children's Medical Center  
1465 South Grand Boulevard  
St. Louis, MO 63104-1095  
Toll-Free: 877-SSM-FETL  
(877-776-3385)  
Phone: 314-268-4037  
Website:  
<http://www.cardinalglennon.com/fetalcareinstitute>  
E-mail: [fetalcare@ssmhc.com](mailto:fetalcare@ssmhc.com)

### ***University of California San Francisco Benioff Children's Hospital***

505 Parnassus Avenue  
San Francisco, CA 94143  
Phone: 415-476-1000  
Website: <https://www.ucsfbenioffchildrens.org>

### ***University of California San Francisco Fetal Treatment Center***

400 Parnassus Avenue, A123  
San Francisco, CA 94143-0570  
Toll-Free: 800-RX-FETUS  
(800-793-3887)  
Fax: 415-502-0660  
Website: <http://fetus.ucsfmedicalcenter.org>  
E-mail: [fetus@surgery.ucsf.edu](mailto:fetus@surgery.ucsf.edu)

### ***University of Michigan Fetal Diagnosis and Treatment Center***

University of Michigan  
Health System  
1500 East Medical Center Drive  
Ann Arbor, MI 48109  
Phone: 734-936-6641  
Website: <http://www.med.umich.edu/fdtc>

### ***University of Texas Medical School at Houston-Department of Pediatric Surgery***

6410 Fannin Street  
Suite 950  
Houston, TX 77030  
Phone: 832-325-7234  
Website: <http://utsurg.uth.tmc.edu/pedisurgery>

***Birthmarks***

***Vascular Birthmarks***

***Foundation***

P.O. Box 106  
Latham, NY 12110  
Toll-Free: 877-VBF-4646  
(877-823-4646)  
Website: <http://birthmark.org>  
E-mail: [hvbf@aol.com](mailto:hvbf@aol.com)

***Brain and Spinal  
Cord Defects***

***Dandy-Walker Alliance, Inc.***

10325 Kensington Parkway  
Suite 384  
Kensington, MD 20895  
Toll-Free: 877-Dandy-Walker  
(877-326-3992)  
Website: <http://www.dandy-walker.org>  
E-mail: [comments@dandy-walker.org](mailto:comments@dandy-walker.org)

***Hydrocephalus  
Association***

4340 East West Highway  
Suite 905  
Bethesda, MD 20814  
Toll-Free: 888-598-3789  
Phone: 301-202-3811  
Fax: 301-202-3813  
Website:  
<http://www.hydroassoc.org>  
E-mail: [info@hydroassoc.org](mailto:info@hydroassoc.org)

***National  
Hydrocephalus  
Foundation***

12413 Centralia Road  
Lakewood, CA 90715-1653  
Toll-Free: 888-857-3434  
Phone: 562-924-6666  
Website:  
<http://www.nhfonline.org>

***National Institute of  
Neurological Disorders  
and Stroke***

NIH Neurological Institute  
P.O. Box 5801  
Bethesda, MD 20824  
Toll-Free: 800-352-9424  
Phone: 301-496-5751  
TTY: 301-468-5981  
Website:  
<http://www.ninds.nih.gov>  
E-mail: [me20t@nih.gov](mailto:me20t@nih.gov)

***National Organization  
for Disorders of the  
Corpus Callosum***

PMB 363  
18032-C Lemon Drive  
Yorba Linda, CA 92886  
Phone: 714-747-0063  
Fax: 714-693-0808  
Website: <http://www.nodcc.org>  
E-mail: [info@nodcc.org](mailto:info@nodcc.org)

***Pediatric Hydrocephalus Foundation***

2004 Green Hollow Drive  
Iselin, NJ 08830  
Phone: 732-634-1283  
Fax: 847-589-1250  
Website:  
<http://www.HydrocephalusKids.org/wordpress>  
E-mail:  
[info@hydrocephaluskids.org](mailto:info@hydrocephaluskids.org)

***Spina Bifida Association***

4590 MacArthur Boulevard NW  
Suite 250  
Washington, DC 20007-4226  
Toll Free: 800-621-3141  
Phone: 202-944-3285  
Fax: 202-944-3295  
Website: <http://www.spina-bifidaassociation.org>  
E-mail: [sbaa@sbaa.org](mailto:sbaa@sbaa.org)

***United Cerebral Palsy***

1825 K Street NW, Suite 600  
Washington, DC 20006  
Toll-Free: 800-872-5827  
Phone: 202-776-0406  
Fax: 202-776-0414  
Website: <http://www.ucp.org>  
E-mail: [info@ucp.org](mailto:info@ucp.org)

***Cardiovascular Defects***

***Adult Congenital Heart Association (ACHA)***

6757 Greene Street, Suite 335  
Philadelphia, PA 19119-3508  
Toll Free: 888-921-ACHA  
(888-921-2242)  
Phone: 215-849-1260  
Fax: 215-849-1261  
Website:  
<http://www.achaheart.org>  
E-mail: [info@achaheart.org](mailto:info@achaheart.org)

***American Heart Association***

7272 Greenville Avenue  
Dallas, TX 75231  
Toll-Free: 800-AHA-USA-1  
(800-242-8721)  
Phone: 214-570-5978  
Website: <http://www.heart.org>

***Congenital Heart Information Network (C. H. I. N.)***

P.O. Box 3397  
Margate City, NJ 08402-0397  
Phone: 609-822-1572  
Fax: 609-822-1574  
Website: <http://www.tchin.org>  
E-mail: [mb@tchin.org](mailto:mb@tchin.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  
Fax: 240-629-3246  
Website:  
<http://www.nhlbi.nih.gov>  
E-mail:  
[nhlbiinfo@nhlbi.nih.gov](mailto:nhlbiinfo@nhlbi.nih.gov)

***Craniofacial Defects***

***American Cleft Palate-Craniofacial Association***

1504 East Franklin Street  
Suite 102  
Chapel Hill, NC 27514-2820  
Phone: 919-933-9044  
Fax: 919-933-9604  
Website:  
<http://www.acpa-cpf.org>  
E-mail: [info@acpa-cpf.org](mailto: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:  
<http://www.ameriface.org>  
E-mail: [info@ameriface.org](mailto:info@ameriface.org)

***Children's Craniofacial Association (CCA)***

13140 Coit Road  
Suite 517  
Dallas, TX 75240  
Toll-Free: 800-535-3643  
Phone: 214-570-9099  
Fax: 214-570-8811  
Website:  
<http://www.ccakids.com>  
E-mail: [contactCCA@ccakids.com](mailto:contactCCA@ccakids.com)

***Cleft Palate Foundation***

1504 East Franklin Street  
Suite 102  
Chapel Hill, NC 27514-2820  
Toll-Free: 800-242-5338  
Phone: 919-933-9044  
Fax: 919-933-9604  
Website:  
<http://www.cleftline.org>

***FACES: The National Craniofacial Association***

P.O. Box 11082  
Chattanooga, TN 37401  
Toll-Free: 800-332-2373  
Website: <http://www.faces-cranio.org>  
E-mail: [faces@faces-cranio.org](mailto:faces@faces-cranio.org)

***National Foundation for Facial Reconstruction***

333 East 30th Street  
Lobby Unit  
New York, NY 10016  
Phone: 212-263-6656  
Fax: 212-263-7534  
Website: <http://www.nffr.org>  
E-mail: [info@nffr.org](mailto:info@nffr.org)

***National Institute of Dental  
and Craniofacial Research***

National Oral Health  
Information Clearinghouse  
Toll-Free: 866-232-4528  
Phone: 301-496-4261  
Fax: 301-480-4098  
Website:  
<http://www.nidcr.nih.gov>  
E-mail: [nidcrinfo@mail.nih.gov](mailto:nidcrinfo@mail.nih.gov)

***World Craniofacial  
Foundation***

7777 Forest Lane, Suite C-616  
Dallas, TX 75230  
Toll-Free: 800-533-3315  
Phone: 972-566-6669  
Fax: 972-566-3850  
Website: <http://www.worldcf.org>

***Digestive Tract Defects***

***American Liver Foundation***

39 Broadway, Suite 2700  
New York, NY 10006  
Toll-Free: 800-GO-LIVER  
(800-465-4837)  
Phone: 212-668-1000  
Fax: 212-483-8179  
Website:  
<http://www.liverfoundation.org>  
E-mail:  
[info@liverfoundation.org](mailto:info@liverfoundation.org)

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

3650 Rogers Road #290  
Wake Forest, NC 27587  
Phone: 919-610-0129  
Fax: 815-425-9155  
Website:  
<http://www.cherubs-cdh.org>  
E-mail: [cpab@cherubs-cdh.org](mailto:cpab@cherubs-cdh.org)

***Bowel Group for Kids Inc.***

P.O. Box 40  
Oakdale, NSW 2570  
Australia  
Website: <http://www.bgk.org.au>  
E-mail: [enquiries@bgk.org.au](mailto:enquiries@bgk.org.au)

***Canadian Liver Foundation***

3100 Steeles Avenue East  
Suite 801  
Markham, ON L3R 8T3  
Canada  
Toll-Free: 800-563-5483  
Phone: 416-491-3353  
Fax: 905-752-1540  
Website: <http://www.liver.ca>  
E-mail: [clf@liver.ca](mailto:clf@liver.ca)

***Children's Liver Association  
for Support Services***

25379 Wayne Mills Place  
Suite 143  
Valencia, CA 91355  
Toll-Free: 877-679-8256  
Phone/Fax: 661-263-9099  
Website:  
<http://www.classkids.org>  
E-mail: [info@classkids.org](mailto:info@classkids.org)

***Children's Organ  
Transplant Association***

2501 West COTA Drive  
Bloomington, IN 47403  
Toll-Free: 800-366-2682  
Fax: 812-336-8885  
Website: <http://www.cota.org>  
E-mail: [cota@cota.org](mailto:cota@cota.org)

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

P.O. Box 6  
Flourtown, PA 19031  
Phone: 215-233-0808  
Fax: 215-233-3918  
Website:  
<http://www.naspghan.org>  
E-mail: [naspghan@naspghan.org](mailto:naspghan@naspghan.org)

***National Institute of  
Diabetes, Digestive &  
Kidney Diseases***

Office of Communications &  
Public Liaison  
Building 31, Room 9A06  
31 Center Drive, MSC 2560  
Bethesda, MD 20892-2560  
Phone: 301-496-3583  
Website:  
<http://www2.niddk.nih.gov>  
E-mail:  
[NDDIC@info.niddk.nih.gov](mailto:NDDIC@info.niddk.nih.gov)

***Pull-Thru Network***

1705 Wintergreen Parkway  
Normal, IL 61761  
Phone: 309-262-0786  
Website:  
<http://www.PullthruNetwork.org>  
E-mail:  
[PullthruNetwork@gmail.com](mailto:PullthruNetwork@gmail.com)

***Kidney and Urinary Tract  
Defects***

***American Association of  
Kidney Patients***

2701 North Rocky Point Drive  
Suite 150  
Tampa, FL 33607  
Toll-Free: 800-749-AAKP  
(800-749-2257)  
Phone: 813-636-8100  
Fax: 813-636-8122  
Website: <http://www.aakp.org>  
E-mail: [info@aakp.org](mailto:info@aakp.org)

***American Kidney Fund***

11921 Rockville Pike  
Suite 300  
Rockville, MD 20852  
Toll-Free: 800-638-8299  
Phone: 301-881-3052  
Website:  
<http://www.kidneyfund.org>  
E-mail:  
[helpline@kidneyfund.org](mailto:helpline@kidneyfund.org)

## ***Congenital Disorders: Resources for Information and Support***

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### ***American Society of Pediatric Nephrology***

3400 Research Forest Drive  
Suite B-7  
The Woodlands, TX 77381  
Phone: 281-419-0052  
Fax: 281-419-0082  
Website:  
<http://www.aspneph.com>  
E-mail: [info@aspneph.com](mailto:info@aspneph.com)

### ***American Urological Association Foundation***

1000 Corporate Boulevard  
Linthicum, MD 21090  
Toll-Free: 800-828-7866  
Phone: 410-689-3700  
Fax: 410-689-3998  
Website:  
<http://www.urologyhealth.org>  
E-mail:  
[info@urologycarefoundation.org](mailto:info@urologycarefoundation.org)

### ***Association for the Bladder***

#### ***Exstrophy Community***

6737 West Washington Street  
Suite 6737  
West Allis, WI 53214  
Phone: 414-918-9002 (U.S.)  
or 519-679-8774 (Canada)  
Fax: 414-918-9001  
Website: <http://www.bladderexstrophy.com>  
E-mail: [admin@bladderexstrophy.com](mailto:admin@bladderexstrophy.com)

### ***Bladder Exstrophy Family Association***

Website:  
<http://www.bladderexstrophy.co.uk>

### ***Bladder Exstrophy Research Foundation***

P.O. Box 13083  
Newport Beach, CA 92658  
Phone: 949-922-9865  
Website:  
<http://www.exstrophyresearch.org>  
E-mail: [info@exstrophyresearch.org](mailto:info@exstrophyresearch.org)

### ***Georgia Urology***

Toll-Free: 888-788-0770  
Website:  
<http://www.gaurology.com>

### ***Hypospadias and Epispadias Association, Inc.***

235 West 102nd Street, #5E  
New York, NY 10025  
Phone: 917-861-8339  
Website: <http://www.heainfo.org>

### ***Kidney and Urology Foundation of America, Inc.***

2 West 47th Street, Suite 401  
New York, NY 10036  
Toll-Free: 800-633-6628  
Phone: 212-629-9770  
Fax: 212-629-5652  
Website:  
<http://www.kidneyurology.org>

### ***National Kidney Foundation***

30 East 33rd Street  
New York, NY 10016  
Toll-Free: 800-622-9010  
Phone: 212-889-2210  
Fax: 212-689-9261  
Website: <http://www.kidney.org>

***Limb and Joint Defects***

***American Academy of Orthopaedic Surgeons***

6300 North River Road  
Rosemont, IL 60018-4262  
Phone: 847-823-7186  
Fax: 847-823-8125  
Website: <http://www.aaos.org>

***American Society for Surgery of the Hand***

822 West Washington Boulevard  
Chicago, IL, 60607  
Phone: 312-880-1900  
Fax: 847-384-1435  
Website: <http://www.assh.org>  
E-mail: [info@assh.org](mailto:info@assh.org)

***Fibrous Dysplasia Foundation***

Website:  
<https://www.fibrousdysplasia.org>  
E-mail: [info@fibrousdysplasia.org](mailto:info@fibrousdysplasia.org)

***Helping Hands Foundation***

P.O. Box 332  
Medfield, MA 02052  
Website:  
<http://www.helpinghandsgroup.org>  
E-mail: [info@helpinghandsgroup.org](mailto:info@helpinghandsgroup.org)

***Maternal Alcohol Abuse***

***National Institute on Alcohol Abuse and Alcoholism***

5635 Fishers Lane  
Bethesda, MD 20892-9304  
Phone: 301-443-3860  
Fax: 301-480-1726  
Website:  
<http://www.niaaa.nih.gov>  
E-mail: [niaaaweb-r@exchange.nih.gov](mailto:niaaaweb-r@exchange.nih.gov)

***National Organization on Fetal Alcohol Syndrome***

1200 Eton Court NW  
Third Floor  
Washington, DC 20007  
Toll-Free: 800-66-NOFAS  
(800-666-6327)  
Phone: 202-785-4585  
Fax: 202-466-6456  
Website: <http://www.nofas.org>  
E-mail: [information@nofas.org](mailto:information@nofas.org)