



PARENT SUPPORT GROUPS AND RESOURCES FOR SELECTED BIRTH DEFECTS

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CENTRAL NERVOUS SYSTEM

Anencephalus

- Anencephaly Support Foundation
(www.familyvillage.wisc.edu/lib_anen.htm)
- Anencephaly Net
(www.anencephaly.net/)
- Yahoo Support Group
(<http://health.groups.yahoo.com/group/anencephaly/>)
- Anencephaly Information
(www.anencephalie-info.org/e/index.htm)

Spina bifida

- Spina Bifida Association of America (SBA)
(www.sbaa.org/)
- SB-Parents
(<http://health.groups.yahoo.com/group/SB-Parents/>)
- Children with Spina Bifida: A Resource Page for Parents
(www.waisman.wisc.edu/~rowley/sb-kids/)
- Spina Bifida Association of America (SBA)
(www.spinabifidaassociation.org/site/c.evKRI7OXIoJ8H/b.8028963/k.BE67/Home.htm)
- Spina Bifida Association - St. Louis
(www.sbstl.com/)

Hydrocephalus

- Hydrocephalus Association
(www.hydroassoc.org/)
- Hydrocephalus Groups
(<http://health.groups.yahoo.com/group/lifewithhydrocephalus/>)
- Hydrocephalus Groups (<http://health.groups.yahoo.com/group/HydroParents/>)
- Hydrocephalus Groups (<http://health.groups.yahoo.com/group/hydrocephalus/>)

Encephalocele

- Children's Craniofacial Association
(www.ccakids.com/)
- FACES The National Craniofacial Association
(www.faces-cranio.org/)
- Fighters for Encephaly Defects Support (FEDS)
(412) 687-6437

Microcephalus

- Microcephaly Group
(microcephaly@yahoo.com)
- Microcephaly Group
(<http://groups.yahoo.com/group/microcephaly/>)
- Mild Micro Group
(<http://groups.yahoo.com/group/mildmicro/>)

EYE

Anophthalmia / micorophthalmia

- International Children's Anophthalmia Network
(www.anophthalmia.org/)
- Micro and Anophthalmic Children's Society
(www.macs.org.uk/)
- Microphthalmia Group
(<http://groups.yahoo.com/group/Microphthalmia>)

Congenital cataract

- Congenital Cataract
(www.qualityhealth.com/health-encyclopedia/multimedia/congenital-cataract)
- Cataracts Support Group
(www.drugs.com/answers/support-group/cataract/)
- Cataracts Support Group
(www.dailystrength.org/c/Cataracts/support-group)

Aniridia

- Aniridia Foundation International
(www.aniridia.net/)
- Aniridia Foundation International Facebook
(www.facebook.com/pages/Aniridia-Foundation-International/183649933901)
- Aniridia Network
(<http://aniridia.org/>)

Having a Baby with a Birth Defect: A mom's thoughts

At 19 weeks of her second pregnancy, Julie Mayberry and her husband were excited because they were having an ultrasound to learn the sex of their second child. They never imagined the test would reveal anything more dramatic; however, the Mayberry's were told their baby would be born with spina bifida.

The Mayberry's daughter was born December 26, 2001. She is now 10 years old and has enjoyed "dancing" with the help of her wheelchair since the age of 3, inspiring other children with disabilities to dance as well. Katie is a straight "A" student who also plays baseball, soccer, takes music classes, sings in the church choir, and goes to a spina bifida camp each summer.

There is nothing she has wanted to do, that we haven't been able to get her to do with some modifications. "Do I wish she did not have spina bifida and could run and play like other children? Yes. Life is tough for her. Simple things like pulling up her own pants can take a half-hour. She has had 15 surgeries and numerous hospitalizations because of infections," says Julie. "But our family has learned to appreciate the small things in life more. She has been a blessing to our family."

"I encourage other women to take 400 micrograms of folic acid if you are able to get pregnant, even if you are not planning a pregnancy. Studies have shown that it can help prevent spina bifida in many cases," said Julie. "If you've already had a child with a neural tube defect, it is recommended you take 4,000 micrograms of folic acid. That's what I did, and my next two children were not born with spina bifida."



Note: We thank Julie for giving us permission to share her family story.

CARDIOVASCULAR

- Congenital Heart Information Network
(<http://tchin.org/>)
- Little Hearts (www.littlehearts.org/)
- Congenital Heart Defect Group
(<http://health.groups.yahoo.com/group/congenitalheartdefectsupport/>)
- It's My Heart
(www.itsmyheart.org/imh-chapters/)
- American Heart Association
(www.heart.org/HEARTORG/Conditions/CongenitalHeartDefects/AboutCongenitalHeartDefects/About-Congenital-Heart-Defects_UCM_001217_Article.jsp)
- Mended Little Hearts
(www.mendedlittlehearts.org/chdresources.shtml)
- Cove Point Foundation
(www.pted.org/)

Common truncus

- HeartPoint
(www.heartpoint.com/congheartdx.html)
- The Heart Institute for Children
(www.thic.com/)
- National Center for Biotechnology Information
(www.ncbi.nlm.nih.gov/sites/ga?disorder=Persistent%20truncus%20arteriosus)

Transposition of great arteries

- The Heart Institute for Children
(www.thic.com/transposition.htm)
- HeartPoint
(www.heartpoint.com/congtranspos.html)
- Little Hearts
(www.littlehearts.org/)

Tetralogy of Fallot

- The Heart Institute for Children
(www.thic.com/tetralogy.htm)
- HeartPoint
(www.heartpoint.com/congtetralogy.html)
- Medline Plus
(www.nlm.nih.gov/medlineplus/ency/article/001567.html)
- National Heart Lung and Blood Institute
(www.nhlbi.nih.gov/health/health-topics/topics/tof/)

Ventricular septal defect

- HeartPoint
(www.heartpoint.com/congvsd.html)
- Medline Plus
(www.nlm.nih.gov/medlineplus/ency/article/001099.htm)

Atrial septal defect

- HeartPoint
(www.heartpoint.com/congasd.html)
- Medline Plus
(www.nlm.nih.gov/medlineplus/ency/article/000157.htm)
- Atrial Septal Defect Survivors
(www.asdsurvivors.org/)

Atrioventricular septal defect (endocardial cushion defect)

- The Heart Institute for Children (www.thic.com/coarctation.htm)
- Medline Plus
(www.nlm.nih.gov/medlineplus/ency/article/007324.htm)

Pulmonary valve atresia and stenosis

- The Heart Institute for Children
(www.thic.com/patent.htm)

Tricuspid valve atresia and stenosis

- Medline Plus
(www.nlm.nih.gov/medlineplus/ency/article/001110.htm)

Ebstein anomaly

- HeartPoint
(www.heartpoint.com/congepstein.html)

Aortic valve stenosis

- Medline Plus ~ scroll down to Specific Conditions list
(www.nlm.nih.gov/medlineplus/congenitalheartdefects.html)

Hypoplastic left heart syndrome

- Congenital Heart Information Network
(<http://tchin.org/>)
- Little Hearts
(www.littlehearts.org/)
- Children with HLHS
(<http://health.groups.yahoo.com/group/childrenwithlhs/>)
- HLHS Group
(<http://health.groups.yahoo.com/group/chdwebringlhs/>)
- The Heart Institute for Children
(www.thic.com/hypoleft.htm)
- Medline Plus
(www.nlm.nih.gov/medlineplus/ency/article/001106.htm)

Patent ductus arteriosus

- The Heart Institute for Children
(www.thic.com/patent.htm)
- HeartPoint
(www.heartpoint.com/congpda.html)
- Medline Plus
(www.nlm.nih.gov/medlineplus/ency/article/001560.htm)

Coarctation of aorta

- Medline Plus
(www.nlm.nih.gov/medlineplus/ency/article/000191.htm)
- The Heart Institute for Children (www.thic.com/coarctation.htm)
- The Heart Institute for Children
(www.thic.com/coarctation.htm)
- HeartPoint
(www.heartpoint.com/congheartdx.html)

Anomalous pulmonary venous return

- Medline Plus – Scroll down to Specific conditions list
(www.nlm.nih.gov/medlineplus/congenitalheartdefects.html)

OROFACIAL

Cleft palate, cleft lip

- Cleft Palate Foundation
(www.cleftline.org/)
- Children's Craniofacial Association
(www.ccakids.com/)
- American Cleft Palate-Craniofacial Association (ACPA)
(www.acpa-cpf.org/)
- Pierre Robin Network
(www.pierrerobin.org/)
- CleftClub.com
(<http://health.groups.yahoo.com/group/cleftclub/>)
- Cleft Talk
(http://groups.yahoo.com/group/cleft_talk/)
- Cleft Chat
(<http://health.groups.yahoo.com/group/cleftchat/>)
- FACES
(faces@faces-cranio.org)
- Cleft Lip and Palate Association
(www.clapa.com/)

Choanal atresia

- Children's Choanal Atresia Foundation
(www.babynose.org/index.html)

GASTROINTESTINAL

Esophageal atresia, tracheoesophageal fistula

- EA/TEF Support Connection
(www.eatef.org/)
- Tef Vater Web
(www.tefvater.org/index2.html)

RECTAL AND LARGE INTESTINAL ATRESIA/STENOSIS

- IA (Imperforate Anus) Parents Support Group
(<http://health.groups.yahoo.com/group/IA-parents/>)
- Rainbow Kids (http://specialneedsadoption.rainbowkids.com/Anal_Atresia_-_Imperforate_Anus.aspx)
- Pull-Through Network
(www.pullthrunetwork.org/)

Pyloric stenosis

- Pyloric Stenosis Support
(www.cafemom.com/group/113668)
- American Pediatric Surgical Association
(www.pediatricsurgerymd.org/AM/Template.cfm?Section=List_Of_Conditions1&ContentID=1619&template=/CM/ContentDisplay.cfm)
- Infant Reflux Disease
(www.infantrefluxdisease.com/forums/)

Hirschsprung disease (congenital megacolon)

- American Pediatric Surgical Association
(www.pediatricsurgerymd.org/AM/Template.cfm?Section=List_Of_Conditions1&template=/CM/ContentDisplay.cfm&ContentID=1395)
- National Digestive Diseases Information Clearinghouse (NDDIC)
(http://digestive.niddk.nih.gov/ddiseases/pubs/hirschsprungs_ez/)
- National organization for Rare Diseases (NORD)
(www.rarediseases.org/rare-disease-information/rare-diseases/byID/727/viewAbstract)
- The Mayo Clinic
(www.mayoclinic.com/health/hirschsprungs-disease/DS00825)

Biliary atresia

- American Pediatric Surgical Association
(www.pediatricsurgerymd.org/AM/Template.cfm?Section=List_Of_Conditions1&ContentID=1316&template=/CM/ContentDisplay.cfm)
- American Liver Foundation
(www.liverfoundation.org)
- Children's Liver Disease Foundation
(www.childliverdisease.org)
- Children's Liver Association for Support Services
(www.classkids.org)
- Biliary Atresia Network
(<http://health.groups.yahoo.com/group/BiliaryAtresiaNetwork/>)

GENITOURINARY

Renal agenesis/hypoplasia

- Potter's Syndrome
(www.potterssyndrome.org/)
- National Kidney Foundation
(www.kidney.org)
- American Association of Kidney Patients

(www.aakp.org)

- NIH/National Institute of Diabetes, Digestive & Kidney Diseases
(<http://kidney.niddk.nih.gov/>)

Bladder extrophy

- Association for Bladder Exstrophy Community (www.bladderexstrophy.com/)
- The Pull-Thru Network
(www.PullthruNetwork.org)
- Children's Hospital Boston
(www.childrenshospital.org/clinicalservices/Site1697/mainpageS1697P4.html/)

Obstructive genitourinary defect

- healthtreatment's Obstructive Genitourinary Defect community
(www.healthtreatment.com/community/obstructive-genitourinary-defect/)
- National Kidney and Urologic Diseases Information Clearinghouse (NKUDIC)
(<http://kidney.niddk.nih.gov/kudiseases/pubs/newborns/>)

Hypospadias

- Hypospadias Support Group
(www.hypospadias.co.uk/)

Epispadias

- Hypospadias and Epispadias Association
(www.heainfo.org/)

MUSCULOSKELETAL

- Helping Hands Foundation
(www.helpinghandsgroup.org/)
- Superhands Network
(www.superhands.us/)
- STEPS
(www.steps-charity.org.uk/)

Limb reduction deformity

- Limb Differences
(<http://limbdifferences.org/>)
- Adams Oliver Syndrome Support Group
(Email: sandy.ivins@btinternet.com)
- AOSupport
(www.aosupport.org/)
- Making Contact (AOS)
(www.makingcontact.org/)

Gastroschisis

- Avery's Angels
(www.facebook.com/averysangels#!/photo.php?fbid=10151175942114874&set=a.10150789513484874.464836.243044679873&type=1&theater)
- GEEPS
(www.geeps.co.uk/gastroschisis.htm)

- American Pediatric Surgical Association
(www.pediatricsurgerymd.org/AM/Template.cfm?Section=List_Of_Conditions1&template=/CM/ContentDisplay.cfm&ContentID=1311)
- Gastroschisis Support Group
(www.gastroschisismiracles.webs.com/)

Omphalocele

- American Pediatric Surgical Association
(www.pediatricsurgerymd.org/AM/Template.cfm?Section=List_Of_Conditions1&template=/CM/ContentDisplay.cfm&ContentID=1598)

Congenital hip dislocation

- Gillette Children's Specialty Healthcare
(www.gillettechildrens.org/default.cfm?PID=1.17.4.14.5.2.1)
- Baby Center
(http://community.babycenter.com/post/a25941553/congenital_hip_dislocation_anyone)
- Children's Orthopaedic Associates
(www.orthokids.org/CHD)

Congenital diaphragmatic hernia

- American Pediatric Surgical Association
(www.pediatricsurgerymd.org/AM/Template.cfm?Section=List_Of_Conditions1&template=/CM/ContentDisplay.cfm&ContentID=1359)
- CHERUBS
(www.cherubs-cdh.org/)
- Support Group
(<http://groups.yahoo.com/group/cherubs/>)

CHROMOSOMAL

Trisomy 13 (Patau syndrome)

- Support Organization for Trisomy 18, 13, and Related Disorders (SOFT)
(www.trisomy.org/)
(www.trisomy.org/wp-content/uploads/2012/09/Trisomy-13-Facts-8-20-12.pdf)

Trisomy 21 (Down syndrome)

- National Down Syndrome Congress
(<http://ndsccenter.org/>)
- National Association for Down Syndrome
(www.nads.org/)
- Kids Health
(http://kidshealth.org/parent/medical/genetic/down_syndrome.html)
- The National Down Syndrome Society
(www.ndss.org/)
- Trisomy 18 (Edwards syndrome)Chromosome 18
(www.chromosome18.org/)
- Support Organization for Trisomy 18, 13, and Related Disorders (SOFT)
(www.trisomy.org)
(www.trisomy.org/wp-content/uploads/2012/09/Trisomy-18-Facts-8-20-12.pdf)

Fetal alcohol syndrome

- Family Resource Institute
(www.fetalalcoholsyndrome.org/)
- FAS Forum
(<http://health.groups.yahoo.com/group/FASForum/>)
- FAS Link
(www.acbr.com/fas/faslink.htm)
- The Family Empowerment Network (FEN) (<http://pregnancyandalcohol.org/>)
- Fetal Alcohol and Drug Unit (FADU)
(<http://depts.washington.edu/fadu/>)
- Fetal Alcohol Spectrum Disorders (FASD)
(<http://fasdcenter.samhsa.gov/>)
- Fetal Alcohol Syndrome Consultation, Education and Training Services (FASCETS)
(www.fascets.org/)

Amniotic bands

- Amniotic Band Syndrome
(www.amnioticbandsyndrome.com/)
- Superhands Network
(www.superhands.us/)