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## Resources for families affected by acquired or congenital heart defects

**Angel Flight NE** – Providing free flights so children and adults can access medical care. Contact <http://www.angelflightne.org> or 978-794-6868.

**Adult Congenital Heart Association** – [www.achaheart.org](http://www.achaheart.org) 888-921-ACHA – National organization for “heart kids” 21 and older.

**Aspirin** – Does your child with a congenital heart defects take aspirin as a blood thinner? Ask your doctor if the aspirin should be discontinued if your child gets a fever or a viral illness. There is a small risk of contracting Reye’s syndrome – a rare and potentially fatal childhood disease. For more information, contact the National Reye’s Syndrome Foundation at [www.reyessyndrome.org](http://www.reyessyndrome.org) or 800-233-7393.

**Baby Oil** – Is the glue from the patches of the holter monitor leaving a sticky mess on your heart child? Try using baby oil and cotton balls.

### CAMPS

Boggy Creek Gang – Florida – [www.boggycreek.org](http://www.boggycreek.org) - 352-483-4200

Camp Bon Coeur – Louisiana - [www.heartcamp.com](http://www.heartcamp.com) – 337-233-8437

Camp Braveheart – Georgia – [www.campbraveheart@angelfire.com](mailto:www.campbraveheart@angelfire.com) - 888-988-9979

Camp Del Corazon – California – [www.campdelcorazon.org](http://www.campdelcorazon.org) - 888-621-0323

Camp Joyful Hearts – Ohio – [www.cincinnatichildrens.org/heart-familycamp](http://www.cincinnatichildrens.org/heart-familycamp) Email: [heartcamp@cchmc.org](mailto:heartcamp@cchmc.org)

Camp Meridian – New Hampshire - [www.campmeridian.org](http://www.campmeridian.org) – 603-740-3254

Camp Mountain Heart – West Virginia - [www.campmountainheart.org](http://www.campmountainheart.org) - 304-599-5438

Camp ODAYIN – MN – [www.campodayin.org](http://www.campodayin.org) - 866-9.ODAYIN

Camp Taylor – California – [www.kidsheartcamp.org](http://www.kidsheartcamp.org) - 209-545-4715

Cardiac Kids Camp – Tennessee – 901-572-4562

Dragonfly Heart Camp – Maryland - [www.dragonflyheartcamp.org](http://www.dragonflyheartcamp.org) - 267-426-5720

Edward J. Madden Memorial Open Hearts Camp – Massachusetts – [www.openheartscamp.com](http://www.openheartscamp.com) - 888-611-1113

Heart Institute Family Camp – Ohio – [www.cincinnatichildrens.org](http://www.cincinnatichildrens.org)

Hope with Heart – New Jersey – [www.hopewithheart@hotmail.com](mailto:www.hopewithheart@hotmail.com)

**Children’s Cardiomyopathy Foundation, Inc.** – Phone: 866-808 CURE (2873) Website: <http://www.childrenscardiomyopathy.org>

**Council of Parent Attorneys and Advocates (COPAA)** - <http://www.copaa.org/index.html>

**Congenital Heart Surgeon’s Society** - <http://www.chssdc.org/>

**Decongestants** – Check with your heart child’s pediatric cardiologist if he or she can take decongestants.

**EMLA Cream** – is a prescription item that can help numb the skin before shots or blood draws. Check with your heart child’s pediatrician.

**EUROPE PLATFORM FOR PATIENTS, PARENTS, DOCTORS, SCIENTISTS** - Corience – <http://www.corience.org/>

### FINANCIAL ASSISTANCE

Heart Support of America - <http://www.heartsofamerica.org/>

Hearts and Smiles Foundation – Philadelphia PA area - <http://www.heartsandsmiles.org/> or 215-669-4221

Jamie’s Heart Foundation – Pacific Northwest – [www.jamiesheart.org](http://www.jamiesheart.org) or 253-380-7700

*Know of other organizations that provide financial assistance? Please share it with us at [info@littlehearts.org](mailto:info@littlehearts.org)*

**Flu Shots** – Ask your pediatrician if your heart child and other members of your family should get them to prevent the flu in your household.

**Insure Kids Now!** – Health insurance program for infants, children and teens throughout USA. 877-KIDS-NOW or <http://www.insurekidsnow.gov/>

**Kids with Heart National Association for Children’s Heart Disorders, Inc.** - Offers a “CHD book store”. For a listing of their heart-related books, please see page three. To order books, go to [www.kidswithheart.org](http://www.kidswithheart.org) or phone them 800-538-5390.

**Little Hearts, Inc.** - A National CHD support organization. Toll free 866-435-HOPE or [www.littlehearts.org](http://www.littlehearts.org). Tax exempted # 06-1510739.

**Medic Alert Bracelets & Necklaces** [www.medicalert.org](http://www.medicalert.org) 888-633-4298

**Pre-Existing Conditions** – Just because your heart child was born with a CHD, it doesn't make it a pre-existing condition in the eyes of your insurance company. For example, some policies state a pre-existing condition is one where the insured has taken a prescription or seen a doctor for the condition within a 12-month period. Some policies do not care about pre-existing conditions. So don't assume it is – check with your insurance company.

**RSV Vaccinations** – Respiratory Syncytial Virus (RSV) is the most common respiratory virus in infants and young children. In infants born prematurely and/or with chronic lung disease or heart condition, RSV can cause a severe or even life-threatening disease. Ask your pediatric cardiologist if your baby should get the RSV vaccine and your insurance company for coverage information.

**Social Security Disability Income** – Contact a local SSI office nearest you or phone 800-772-1213 to see if your child qualifies.

**Starlight Children's Foundation** – Grants wishes for seriously ill children between the ages of 4 -18 years old. 323-634-0080 <http://starlight.org>

**Warm Belly Wetsuits** – Ideal for cardiac kids to keep them warm while swimming. Shipping is free if you tell them that it's for a child with a medical problem. Phone 1-888 WARM KID or online <http://www.warmbelly.com/>

**Books pertaining to Congenital Heart Defects (CHD) are available through <http://www.kidswithheart.org/> or [www.amazon.com](http://www.amazon.com).**

1. **A Night without Stars** – designed for the adolescent facing open heart surgery
2. **A Parent's guide to children's congenital heart defects** – Written by two heart parents to help others in living with CHD.
3. **Cardiac Kids** – a book written to explain heart surgery and diagnostic tests to children
4. **Every Parent's Nightmare** – Book deals with how to be your child's advocate. Written by parents whose child was told their son had an inoperable brain tumor and how they struggled to find a doctor who could help.
5. **Growing Up Strong** – A book that looks at the challenges that are shared by all children living with special health needs.
6. **Heart Defects in Children "What every parent should know"** – Explains the different types of CHDs, testing, surgeries, etc.
7. **Heart of a Child** – Beneficial for parents of children with complex congenital heart defects.
8. **Heart of a Mother** – A compilation of essays of personal experiences of mothers and others affected by congenital heart defects.
9. **HLHS** – edited by Drs. Rychik and Wernovsky of CHOP, this book explains HLHS, its surgeries, quality of life, etc. Little Hearts' picture of HOPE from 2002 picnic is on page 418! Can be purchased at [www.amazon.com](http://www.amazon.com) (key in Drs. Names).
10. **HLHS** - edited by Drs. Bove and Hennein. Can be purchased at [www.amazon.com](http://www.amazon.com) (key in Drs. Names & HLHS).
11. **In a Heartbeat** – Inspirational story written by a CHD survivor born in 1960. A must read! Purchase [www.KimsHeartbeat.com](http://www.KimsHeartbeat.com)
12. **Jeff's New Pacemaker** – Book designed to explain pacemakers to children.
13. **Kara Mia** – Book dealing with Long QT Syndrome and a 14 year-old girl's story.
14. **Matty's Heart and Catherization coloring book** – Written by a grandmother to a child with CHD, this book is designed to prepare children for open-heart surgery.
15. **My Brother needs an operation** – This interactive book provides parents and children affected by CHD an opportunity to talk about feelings and experiences
16. **My Heart Story** – This book is designed as a journal/memory book for the parent to keep while the child is in the hospital.
17. **To Mend a Broken Heart** – This book is designed to prepare parents facing their child's first open-heart surgery.
18. **Young People & Chronic Illness** – Designed for adolescents and teens living with CHD.
19. **The ADD Answer** by Dr. Frank Lawlis. Drawing upon 35 years of experience as a clinical and research psychologist, Dr. Lawlis offers alternative methods for those looking for an alternative to drug therapy. This book discusses the role of nutrition, environmental modifications and biocleansing, advances in biofeedback and neurotherapy and much more!
20. **The Rally Board** - A dad's 1997 log and experience following the birth of his heart child. Available [www.eRallyBoard.com](http://www.eRallyBoard.com)
21. **Walk on Water "Inside an Elite Pediatric Surgical Unit"** by Michael Ruhlman
22. **When Molly was in the Hospital** – This book is written to help siblings understand what happens when their brother/sister is hospitalized.
23. **Zip-Line** Written and illustrated by David Humpherys. [www.ziplinebook.com](http://www.ziplinebook.com) Adorable book for the little ones. Nicely done.

#### **Helpful hints while hospitalized**

- Onesies that button in front
- Take things familiar to baby such as beanie babies, toys, blankets, books, music, video tapes, & batteries.
- Bring your child's favorite Band-Aids (Blues Clues, Sesame Street, etc).
- Calling Cards
- Bring a notebook for notes or questions and/or a journal to help you remember daily events.
- Bring change for vending machines
- Bring a magazines or a book to read
- Bring a camera and take lots of photos
- Ask about a long term parking pass or validate parking
- You're your child's advocate. Don't be shy with questions and don't hesitate to obtain a second opinion in you want one.

HAVE A RESOURCE THAT WAS HELPFUL TO YOU? PLEASE SHARE WITH US AT [INFO@LITTLEHEARTS.ORG](mailto:INFO@LITTLEHEARTS.ORG).