



# Resource Guide for Congenital Heart Patients

## SUPPORT

**California Heart Connection** - [www.caheartconnection.org](http://www.caheartconnection.org) or 949-653-6421

A non-profit support network, providing information and resources for children and adults affected by congenital heart defects. We connect heart families through special events, online support groups and matching those with similar experiences. Downloadable informational handouts and forms are available for physicians and patients online at: [www.caheartconnection.org](http://www.caheartconnection.org).

**The Congenital Heart Information Network: (TCHIN)** – [www.tchin.org](http://www.tchin.org) or 215-493-3068

Provides information and online support groups for different types of congenital heart defects.

**Little Hearts, Inc.** – [www.littlehearts.org](http://www.littlehearts.org) or 866-435-HOPE

Provides support, information and events.

**Adult Congenital Heart Association** - [www.achaheart.org](http://www.achaheart.org) or 617-325-1191

An international organization that provides information and support for adults and adolescents with congenital heart disease (CHD), their families and healthcare professionals.

## HEALTH INFORMATION

**Flu shots** - Many children with congenital heart defects can be susceptible to the flu. Ask your doctor if your child and other members of your family should get flu shots to help prevent the flu.

**RSV vaccinations** - Respiratory Syncytial Virus (RSV) is the most common respiratory virus in infants and young children, which causes symptoms resembling the common cold. RSV can be life-threatening for premature infants and/or those with chronic lung disease or heart problems. Ask your cardiologist if your baby should get the RSV vaccine, and check to see if your insurance company will cover the cost. Each monthly shot can cost over \$1,000, so getting your insurance approval in writing is extremely important prior to beginning the shots. For more information on the vaccine, contact MedImmune at [www.medimmune.com](http://www.medimmune.com) or call them at 877-633-4411.

**Decongestants** - Some children with heart defects should NOT take decongestants, as they can increase the heart rate and increase the chance of arrhythmias. Ask your child's cardiologist about using decongestants.

**Aspirin** - Ask your doctor if the aspirin should be discontinued if your child gets a fever or a viral illness, as there is a small risk of contracting Reye's syndrome, a rare, potentially fatal childhood disease. Talk with your doctor or contact the National Reye's Syndrome Foundation at [www.reyessyndrome.org](http://www.reyessyndrome.org) or call 1-800-233-7393. Also ask your doctor if aspirin should be discontinued before any medical procedures or surgeries.

**Medications** – It is important to understand what each medication does, whether to give it on a full or empty stomach, how often to give it, and if there are any reactions to other medications. If your child uses medications that are compounds, it is a good idea to check with the pharmacist and your cardiologist to make sure that all the necessary ingredients are included. (For example, if vitamin C - ascorbic acid - is not added to Captopril, it has a very short shelf-life.) Always double-check the concentration of medications - the dose you give depends upon how concentrated it is. Ask if medications should be discontinued prior to any medical procedures. Make sure to store all medications properly to ensure maximum effectiveness. . Medication summaries on several of the most common pediatric heart medications are available on the CA Heart Connection website at: [www.caheartconnection.org](http://www.caheartconnection.org).

## **FREE SERVICES**

**Regional Centers by State** - <http://www.nichcy.org/states.htm> or 800-695-0285

Regional Centers provide Occupational, Physical and Speech Therapy and other services to children from birth to age 3 who have disabilities, or are at risk of delays due to medical conditions. (For older children, services are often provided by the school system for those who qualify.) Services are free to families, regardless of income or insurance. If your child has undergone surgery, has been hospitalized or has a medical condition, you are urged to call as soon as possible for a free evaluation.

### **Individualized Education Programs (IEP's)**

[www.ed.gov/parents/needs/speced/iepguide/index.html](http://www.ed.gov/parents/needs/speced/iepguide/index.html) or 1-800-872-5327

Each public school child who receives special education and related services must have an Individualized Education Program (IEP). The IEP is an individualized document designed by teachers, parents, school administrators, related services personnel, and students (when appropriate) to improve educational results for children with disabilities. An IEP may include receiving certain therapies such as physical therapy or occupational therapy. Parents need to understand their rights and how to apply for special education services which could benefit their children with special needs.

### **504 Plans**

[www.ed.gov/about/offices/list/ocr/504faq.html](http://www.ed.gov/about/offices/list/ocr/504faq.html) or 1-800-872-5327

Section 504 is a federal law designed to protect the rights of individuals with disabilities in programs and activities that receive federal funds from the U.S. Department of Education (ED). A 504 plan may be used when an IEP is not necessary, but the child needs certain accommodations.

### **Heart Camps**

There are many camps for children with heart defects throughout the US which allow those with heart defects to meet others that have similar experiences. Some are free and some allow siblings to attend. See the Adult Congenital Heart Association website for a list of heart camps:

[www.achaheart.org/camp.php](http://www.achaheart.org/camp.php) or 215-849-1260.

**American Heart Association** [www.americanheart.org/](http://www.americanheart.org/) or 800-AHA-USA1

The AHA website has information and statistics on CHD's and offers brochures such as "If your Child Has A Congenital Heart Defect" which explains the most common types of heart defects, and "Feeding Infants With Congenital Heart Disease - A Guide for Parents".

**Care Pages** - [www.carepages.com](http://www.carepages.com)

Create a free website for your child while he or she is hospitalized to keep family and friends updated. You can upload pictures, and family and friends can post messages on the message board.

**Songs of Love** - [www.songsoflove.org](http://www.songsoflove.org) or 1-800-960-SONG

This nonprofit organization brings together volunteer musicians, singers, and songwriters to create free, personalized songs for children and adults up to age 21 with chronic or life threatening illnesses. To hear song excerpts go to their website. This is a great gift for a child, and can be wonderful to play during hospitalizations.

**Make A Wish** - [www.makeawish.org](http://www.makeawish.org) or 800-722-WISH (9474)

Any child under the age of 18 with a life-threatening illness may be eligible for a wish. Wishes granted include going on vacations, meeting professional athletes and celebrities, getting a computer, etc.

**Starlight Children's Foundation** - [www.starlight.org](http://www.starlight.org) or 323-634-0080

Starlight grants wishes for seriously ill children between the ages of 4 and 18 years old, and provides outings for families. This organization also provides special play areas and equipment for children at various hospitals.

## HELPFUL PRODUCTS

**Medic Alert bracelets** - [www.medicalert.org](http://www.medicalert.org) – or 888-633-4298

If there is an emergency, medical personnel can call the phone number on the bracelet and MedicAlert will give all pertinent medical history such as surgeries, current medications, the patient's normal oxygen saturation level, as well as physician contact information and any special instructions. Even if you are always with your child, this bracelet can help save your child's life if you are incapacitated for any reason or do not have the pertinent information on hand.

**"Vials of Life"** - [www.vialoflife.com](http://www.vialoflife.com) or 888-473-2800

Free forms and containers in which to keep a list of medications. Stickers go on your car or home window to alert medical personnel that there is medical information inside.

**Care Notebook** - [www.cshcn.org/resources/carentbk.htm](http://www.cshcn.org/resources/carentbk.htm)

The Care Notebook and Care Organizer help families keep track of important information about their child's health and care. The notebook contains forms for emergencies, appointments, medications, immunizations, growth tracking charts, as well as journals for tracking progress on daily living skills and much more. This wonderful tool makes it easier for families to find and share key information with their child's care team. The information can be printed for free from their website, or you can order a printed Care Notebook by calling (206) 987-5310.

**Sound and Motion Monitors** can be used in a baby's crib to alert you if the baby stops breathing. A sensor is put under the crib mattress, and an alarm will sound if no motion is detected. They can be purchased at stores such as Babies R Us. Some doctors do not recommend the use of these products due to the possibility of false alarms. However, some parents find the benefits of sleeping more comfortably far outweigh the chance of an occasional false alarm. Putting a flat board under the sensor can also help reduce the chance of false alarms.

**Wallet Card on Bacterial Endocarditis (B.E.)** – B.E. is a serious infection of the heart that can develop if your child receives a large cut or other injury, dental work, or other medical treatments. Ask your pediatric cardiologist if antibiotics are recommended for your child in any of these situations and obtain a wallet card. If needed, the antibiotic usually must be given just prior to medical treatments or immediately after the injury. See the AHA website for more information at [www.americanheart.org](http://www.americanheart.org).

**Tender Grips** are specially designed adhesive strips (like band-aids) that hold on NG tubes (feeding tubes) without irritating the face. Your pediatric cardiologist can order them, or you may be able to get them from the respiratory department of the hospital.

**Free syringe samples and blue caps** – Contact Baxa Corp at [www.baxa.com](http://www.baxa.com) or 1-800-567-BAXA for syringes or blue bottle caps (called Adapta-Cap Bottle Adapters) for easy filling of oral syringes. You can also ask your pharmacist for these items.

**EMLA cream** can help numb the skin before blood draws. Ask your doctor or pharmacist for more information on EMLA cream to help make getting blood draws easier.

**Wetsuits for children:** Warm Belly Wetsuits ([www.warmbelly.com](http://www.warmbelly.com)) sells wetsuits for babies and children to help keep them warm while swimming. Warm Belly will waive the shipping fee if you tell them you have a child with special needs. Right Start ([www.rightstart.com](http://www.rightstart.com)) sometimes carries wetsuits as a seasonal item and other wetsuit companies can be found on the internet.

**Shopping Cart Covers** - Covers the entire shopping cart to help protect against germs which is especially important for children with special medical needs. You can buy these through baby stores or online at various baby product stores. Some may also be used on public high chairs.

## INSURANCE/FINANCIAL INFORMATION

**Supplemental Security Income (SSI)** - [www.ssa.gov/notices/supplemental-security-income](http://www.ssa.gov/notices/supplemental-security-income)  
SSI is a federal income supplement program funded by general tax revenues (not Social Security taxes.) It is designed to help aged, blind, and disabled people, who have little or no income by providing money to meet basic needs for food, clothing, and shelter. See the website or call 800-772-1213 for more information.

**The Centers for Medicare & Medicaid Services (CMS)** - [www.cms.hhs.gov](http://www.cms.hhs.gov) or 877-267-2323  
The federal agency within the U.S. Department of Health and Human Services which runs Medicare, Medicaid, State Children's Health Insurance Program (SCHIP) and the Health Insurance Portability and Accountability Act (HIPAA) of 1996 which regulates limitations on pre-existing conditions.

### Information on Pre-existing Condition limitations

Health Insurance Portability and Accountability Act (HIPAA) of 1996 - [www.cms.hhs.gov/hipaa/](http://www.cms.hhs.gov/hipaa/)  
Insure.com article explaining HIPAA: [www.insure.com/health/hipaa.html](http://www.insure.com/health/hipaa.html)

## MEDICAL WEBSITES

### PubMed - [www.ncbi.nlm.nih.gov/PubMed](http://www.ncbi.nlm.nih.gov/PubMed)

PubMed is a service of the [National Library of Medicine](http://www.nlm.nih.gov) that includes over 15 million citations from MEDLINE and other life science journals for biomedical articles back to the 1950s. PubMed includes links to full text articles and other related resources. Abstracts are free.

### Medline Plus - [www.medlineplus.gov](http://www.medlineplus.gov)

A service of the U.S. National Library of Medicine and the National Institutes of Health. This site provides lists of hospitals and physicians, a medical encyclopedia and a medical dictionary, health information in Spanish, extensive information on prescription and nonprescription drugs, health information from the media, and links to thousands of clinical trials.

**The Cardiothoracic Surgery Network (CTSNet)** – [www.ctsnet.org](http://www.ctsnet.org)

Links to surgeons and medical journals online.

**Emedicine** - [www.emedicine.com](http://www.emedicine.com)

Articles for patients and physicians on a myriad of topics including congenital heart defects.

**Neville Thomas Adult Congenital Heart Library** - <http://www.achd-online.com>

Diagrams of the normal heart and of many different congenital heart defects.

**Cove Point/Johns Hopkins Children's Center** – [www.pted.org](http://www.pted.org)

Interactive diagrams of many congenital heart defects. Free posters of some defects.

**HeartCenter Online** – [www.heartcenteronline.com](http://www.heartcenteronline.com)

**WebMD** – [www.webmd.com](http://www.webmd.com)

**American Heart Association** – [www.americanheart.org](http://www.americanheart.org)

Descriptions of many congenital heart defects, wallet card for Bacterial Endocarditis (see above) and pamphlets on feeding issues and other topics.

**March of Dimes** - [www.marchofdimes.org](http://www.marchofdimes.org)

Basic information on congenital heart defects.

**HLHS Information Page** - [www.hlhsinfo.org](http://www.hlhsinfo.org)

Created for parents expecting a child with Hypoplastic Left Heart Syndrome (HLHS). Information on the surgical options, questions to ask the surgeon, hospital, and insurance company.

## SELECTED BOOKS

For Parents:

**The Parents Guide to Congenital Heart Defects** by Gerri Freid Kramer and Shari Mauer

**Heart of a Child** by Catherine Neill

**Heart Defects in Children, What Every Parent Should Know** by Cheryl Wild

**Your Child in the Hospital: A Practical Guide for Parents**, by Nancy Keene and Rachel Prentice

**Walk on Water: Inside an Elite Pediatric Surgical Unit** by Michael Ruhlman

**King of Hearts, The True Story of the Maverick Who Pioneered Open Heart Surgery** by G.

Wayne Miller

**Baby Hearts Press** - [www.babyheartspress.com/](http://www.babyheartspress.com/) or 888-222-4649

For Children:

**A Night Without Stars** by James Howe

**Cardiac Kids** by Vicci Elder

**Pump the Bear**, by Gisella Olivo Whittington

**The Hospital Book**, by James Howe



## Summary of Patient Education Materials

*Physicians and patients may download these handouts and forms for free from [www.caheartconnection.org](http://www.caheartconnection.org).  
All forms can be personalized to include physician contact information.*

<b>Document</b>	<b>Type</b>	<b>Description</b>	<b>Pages</b>
<b>Resource Guide</b>	Handout	Information on support groups, medical information, helpful products, Early Intervention services, insurance/financial information, and more.	5
<b>California Resource Guide</b>	Handout	Information on support groups, medical information, helpful products, Early Intervention services, insurance/financial information, and more. Includes resources specific to those in California.	6
<b>Preparing For Your Child's Hospital Stay</b>	Handout	Tips and suggestions for preparing for surgery	3
<b>Medication Tips</b>	Handout	Useful tips on administering medications properly	2
<b>Medication Summaries</b>	Form	Benefits and possible side effects of many common pediatric heart medications. Fill-in area for physicians to indicate dosage information and special instructions. <i>(Information provided by PedHeart Prints Educational Materials.)</i>	2 pages each
<b>Emergency Information</b>	Form	Information every parent should have available in case of emergency with space to fill in important information	1
<b>When to Call the Doctor</b>	Form	Form to be filled out by physician which delineates which symptoms warrant a call to the doctor, or a trip to the ER	1
<b>Medical Specialties</b>	Form	A list and description of different medical specialties to help parents ask appropriate questions of the proper medical personnel, includes space to provide contact information for each	5
<b>Follow-up Care</b>	Form	Timeline for follow-up visits, vaccinations, therapies, etc	1
<b>Physical Activity</b>	Form	Form to clarify appropriate activities for the child with CHD	1
<b>Internet Resources</b>	Handout	Selected online resources for heart diagrams and information on specific diagnoses	1
<b>Hospital Contacts</b>	Form	Form for listing hospitals which treat the specific diagnosis	1
<b>What to Ask the Surgeon and Hospital</b>	Handout	A list of questions to help compare hospitals	2
<b>Insurance Terms</b>	Handout	Important terms to better understand coverage and costs	1
<b>What to Ask the Insurance Company</b>	Handout	A list of questions to determine specific benefits, restrictions, out-of-pocket costs, etc.	5