



Resource Guide for Congenital Heart Patients

CALIFORNIA HEART CONNECTION - www.caheartconnection.org or 949-653-6421

A non-profit support network for children and adults throughout the U.S. who have congenital heart defects (CHD). Founded by parents of children with CHD, it is run solely by volunteers and provides free support and information through these programs:

- Matching of families/individuals with similar heart defects
- Events such as our Annual Heart Picnic, occasional seminars
- An online support group
- Teddy Bears to children undergoing heart surgery
- FREE, downloadable handouts and forms for physicians and patients
(Please see the last page of this guide for a list of printable materials available.)

HEALTH INFORMATION

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

RSV vaccinations - Respiratory Syncytial Virus (RSV) is the most common respiratory virus in infants and young children, which causes symptoms resembling the common cold. In infants born prematurely and/or with chronic lung disease or heart problems, RSV can be a life-threatening illness. Ask your cardiologist if your baby should get the RSV vaccine, and check to see if your insurance company will cover the cost, which can be over \$1,000 for each monthly shot. For more information on the vaccine, contact MedImmune at 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 and other remedies that can help with congestion.

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 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, 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 compounded medications, check with the pharmacist and your cardiologist to make sure that all the necessary ingredients such as preservatives are included, to extend the shelf-life. Always double-check the concentration of medications - the dose you give depends upon the concentration. Ask if medications should be discontinued prior to any medical procedures. Liquid medications can cause tooth decay. Make sure to brush or wipe teeth after administering medications. More medication tips and summaries on several of the most common pediatric heart medications are available on the CA Heart Connection website at: www.caheartconnection.org

HELPFUL PRODUCTS

Medic Alert bracelets - 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. Phone: 1-888-473-2800. These are forms and containers in which to keep a list of any medications that any family members take. Put stickers on your car or home window to alert medical personnel of medical information inside.

CA Heart Connection's Free Handouts and Forms – www.caheartconnection.org or 949-653-6421
For physicians and patients. See the last page of this form for a complete list of materials.

Care Notebook - <http://www.cshcn.org/resources/carentbk.cfm> or (206) 987-5735

The Care Notebook and Care Organizer help families keep track of important information about their child's health and care including forms for emergencies, appointments, medications, immunizations, growth tracking charts, and more.

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 and online. There is a possibility of "false alarms", for example, when the baby rolls to the far side of the crib, off of the sensor. However, most parents find the peace of mind obtained far outweighs an occasional "false alarm". Putting a flat board under the sensor can also help reduce the chance of false alarms.

Bottle Adapters – different types of medicine bottle caps allow for filling oral syringes directly from the bottle without spilling. Ask your pharmacist for these items or contact these companies:

Medidose: www.medidose.com or 1-800-523-8966 or

Abundant Health: www.abundanthealth4u.com or 888-718-3068

(Please note: these caps may not be child-proof.)

EMLA cream can help numb the skin before blood draws. Ask your doctor for more information.

Bionix ShotBlocker – A small plastic disk that can be put on the skin during a shot which may reduce the pain and anxiety of receiving a shot. Search these websites for "shotblocker."

Fifty50 Pharmacy: <http://www.fifty50pharmacy.com/index.mvc?p=SHOTBLOCKER>

Insulin Case Shop: <http://www.insulincase.com/detail.aspx?ID=313> or 1-(877)-829-8024

Tender Grips are specially designed adhesive strips (like band-aids) that hold on NG tubes (feeding tubes) without irritating the face. Ask your physician or pharmacist about these.

Pulse Oximeter –measures the amount of oxygen in the blood through the skin. A tiny light is taped to the baby's finger, toe, foot or hand. A wire connects the light to the monitor where it displays the amount of oxygen in the baby's red blood cells. Ask your doctor if having a home pulse oximeter would be beneficial. Some insurance companies will cover the cost of a portable unit.

Wallet Card on Bacterial Endocarditis (B.E.) – www.americanheart.org

B.E. is a serious infection of the heart that can develop if someone with congenital heart defects receives a large cut or other injury, dental work, or other medical treatments. Ask your cardiologist if antibiotics are recommended for you or your child in these situations and to obtain a wallet card.

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

Wetsuits for children: Wetsuits can help keep babies and children warm while swimming. Some companies that sell infant and child wetsuits are: Warm Belly Wetsuits (www.warmbelly.com) and Right Start (www.rightstart.com). Ask if free shipping is provided for those with special needs.

FREE SERVICES

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

Regional Centers provide Early Intervention services to children from birth to age 3 who have disabilities, or are at risk of delays due to medical conditions. Occupational, Physical and Speech Therapy (including help with feeding issues) and other services are free to families, regardless of income or insurance. For older children, services are often provided by the school system for those who qualify. 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. Look up the program in your state, and county to find the Early Intervention services nearest you and ask to apply for an evaluation.

Individualized Education Programs (IEP's) - U.S. Department of Education

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, occupational therapy or speech services. Parents need to understand their rights and how to apply for special education services which could benefit their children with special needs.

504 Plans – U.S. Department of Education

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 helps ensure that children are not excluded from activities due to their disability. A 504 plan may be used when an IEP is not necessary, but the child needs certain accommodations. Examples may include: being allowed to walk instead of run during physical education, being allowed to rest if tired after physical activity, having access to shade and water at all times, having a second set of books at home so he or she does not have to carry heavy books back and forth to school, allowing for more absences etc. Parents need to meet with the school officials to get a written plan in place which includes a plan for alerting substitute teachers to the plan and any necessary accommodations.

Heart Camps

Camps for children with congenital heart defects can provide an opportunity for children to meet others who also may have surgical scars, take medications, or may have some physical limitations. For some children, camp can be the first place where they don't feel different, or have to worry about being teased about their heart condition. They can experience the thrill of camp in a safe environment, meet other children who have had similar experiences, and make lifelong friendships. Many heart camps are free or low cost, and some may allow siblings to also attend. To see a list of heart camps, go to www.tchin.org.

Make A Wish - www.makeawish.org or (800) 722-WISH (9474)

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

Care Pages - www.carepages.com/caheartconnection

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. It is a very easy way to keep connected without making repeated phone calls, allowing you to concentrate on your child.

Starlight Children's Foundation - www.starlight.org or (800) 315-2580

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

Songs of Love - www.songsoflove.org or 1-800-960-SONG

This nonprofit organization brings together volunteer musicians, singers, and songwriters to create free, personalized songs those up to age 21 with chronic or life threatening illnesses.

INSURANCE/FINANCIAL INFORMATION**Insure Kids Now** - www.insurekidsnow.gov or call 1-877-KIDS-NOW

From the site: "Most states cover children up to their nineteenth birthday with family incomes of up to \$34,100 a year (for a family of four). Some states cover children whose families have higher incomes. Your income and family size will determine whether or not your children qualify." Check the website or call for more information on the program in your state.

Supplemental Security Income (SSI) - 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.

Centers for Medicare & Medicaid Services - www.cms.hhs.gov or call 1-800-MEDICARE

This is 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/

Search for "Pre-existing" to see the current regulations.

Insure.com article explaining HIPAA: www.insure.com/health/hipaa.html

MEDICAL WEBSITES

(Please note: Even reputable websites may contain outdated or inaccurate information on specific heart conditions. Always check with your doctor for accuracy of any information you find.)

PubMed - 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. Journal abstracts are usually free.

Emedicine - www.emedicine.com

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

Medline Plus - 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

Links to surgeons and medical journals online.

Neville Thomas Adult Congenital Heart Library - 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

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

American Heart Association - www.americanheart.org - Basic information on congenital heart defects, pamphlets and bacterial endocarditis wallet card.

WebMD – www.webmd.com - Information for physicians and patients.

Pioneers of Heart Surgery - www.pbs.org/wgbh/nova/heart/pioneers.html

This PBS NOVA Online series discusses surgeons who pioneered heart surgeries on adults and children despite great obstacles. An excellent history of congenital heart surgery and transplants.

HLHS Information Page - www.hlhsinfo.org

Created for parents expecting a child with Hypoplastic Left Heart Syndrome (HLHS). Includes information on the surgical options for babies with HLHS as well as questions to ask the surgeon, hospital, and insurance company in preparing for the baby's birth and surgery.

SELECTED BOOKS

For Parents:

Heart of a Child by Catherine Neill

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

King of Hearts, The True Story of the Maverick Who Pioneered Open Heart Surgery

by G. Wayne Miller

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

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

For Children:

Cardiac Kids by Vicci Elder

Pump the Bear, by Gisella Olivo Whittington

The Hospital Book, by James Howe

A Night Without Stars by James Howe (for preteens or older)



Summary of Patient Education Materials

Physicians and patients may download these handouts and forms for free from www.caheartconnection.org. All forms can be customized to include physician contact information and personalized for patients.

Document	Type	Description	Pages
Resource Guide	Handout	Information on support groups, medical information, helpful products, Early Intervention services, insurance/financial information, and more. <i>(Also available in Spanish)</i>	5
California Resource Guide	Handout	Information on support groups, medical information, helpful products, Early Intervention services, insurance/financial information, and more. <i>Includes resources specific to those in California.</i>	6
Emergency Information	Form	Information every parent should have available in case of emergency with space to fill in important information	1
When to Call the Doctor	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
Follow-up Care	Form	Timeline for follow-up visits, vaccinations, therapies, etc	1
Physical Activity	Form	Form to clarify appropriate activities for the child with CHD for parents, schools, and other caretakers.	1
Medication Tips	Handout	Useful tips on administering medications properly	2
Medication Summaries	Form	Benefits and possible side effects of many common pediatric heart medications, with fill-in area for physicians to indicate dosage information and special instructions such as what to do if a dose is missed	2 pages each
Preparing For Your Child's Hospital Stay	Handout	Tips and suggestions for preparing for surgery	3
Medical Specialists	Form	A list and description of different medical specialists. Includes questions to ask each specialist. Space is provided to include contact information for each.	5
Internet Resources	Handout	Selected online resources for heart diagrams and information on specific diagnoses	1
Diagnosis and Hospital Contacts Form	Form	Form for listing hospitals which treat the specific diagnosis	1
What to Ask the Surgeon and Hospital	Handout	A list of questions to help compare hospitals	2
What to Ask the Insurance Company and Common Insurance Terms	Handout	Important terms to better understand coverage and costs with a list of questions to determine specific benefits, restrictions, out-of-pocket costs, etc.	4