



California Resource Guide for Congenital Heart Patients

CALIFORNIA HEART CONNECTION - www.caheartconnection.org Toll free: 877-824-3463

A non-profit support network for children and adults with congenital heart defects (CHD). Founded by parents of children with CHD, it is run solely by volunteers. CA Heart Connection has provided support and information for over 10 years through these programs:

- A free online support group to talk with others
- Events such as our Annual Heart Picnic, occasional seminars
- Free, downloadable handouts and forms for physicians and patients
(Please see the last page of this guide for a list of printable materials available.)
- Teddy Bears to children undergoing heart surgery

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. Ask about the flu nasal spray – some children/siblings should not receive this spray. Know the signs and symptoms of the flu, when to call the doctor, and if you should discontinue aspirin with a fever (see below.)

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. Make sure to get any insurance approvals in writing prior to receiving the injection.

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.

Care Notebook – <http://cshcn.org> (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 baby stores and online. There is a possibility of "false alarms," if the baby rolls to the far side of the crib, off the sensor. However, most parents find the peace of mind far outweighs an occasional "false alarm." Putting a board under the sensor can 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 at www.medidose.com or 1-800-523-8966 or Baxa at www.baxa.com (*Please note: these caps may not be child-proof.*)

EMLA cream can help numb the skin before blood draws, decreasing the pain and trauma of "sticks." Ask your doctor for more information about this cream and how it works.

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 attached to the baby's finger, toe, foot or hand, and the monitor 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 may cover the cost of a portable unit.

Wallet Card on Infective (or Bacterial) Endocarditis (I.E.) – www.americanheart.org

I.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 children 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 with heart defects warmer while swimming. Check online or contact Warm Belly Wetsuits (www.warmbelly.com - 1-888 WARM KID). 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

California Department of Developmental Services – contact the Early Start Program at 1-800-515-2229 or see the website at: <http://www.dds.ca.gov/EarlyStart/EShome.cfm>

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

Wrights Law - <http://www.wrightslaw.com/info/iep.index.htm>

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

Wrights law - <http://www.wrightslaw.com/info/sec504.index.htm>

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 – California

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.

- **Camp Del Corazon** – www.campdelcorazon.org or 888-621-4800

A free, nonprofit ACA accredited camp for children Ages 7 - 17 years old with heart disease or with a history of heart disease. The camp is held on beautiful Catalina Island.

- **Camp Taylor** - www.kidsheartcamp.org or 209-545-4715
A non-profit free camp for those with heart defects and their siblings ages 7-17. The camp is located at Camp Arroyo nestled in the beautiful foothills of Livermore, California.

For a list of heart camps in other states, please see: <http://www.congenitalheartdefects.com>

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.

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

Starlight offers programs for seriously ill children through outpatient and hospital-based programs in addition to outings for families.

Songs of Love - www.songslove.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

California Children's Services (CCS) - <http://www.dhs.ca.gov/pcfh/cms/ccs/>

CCS is a statewide program managed by California Department of Health Services that treats children with certain physical limitations and chronic health conditions or diseases. CCS can authorize and pay for specific medical services and equipment provided by CCS-approved specialists. Contact the Los Angeles office at: 800-288-4584 and ask about programs in your area.

California Healthy Families Program - www.healthyfamilies.ca.gov or 800-880-5305

The Healthy Families Program is a state and federally funded health coverage program for children with family incomes above the level eligible for no cost Medi-Cal and below 250% of the federal income guidelines. Call 877-KIDS-NOW to find out about the Insure Kids Now national program.

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 (as of Jan. 2011)

- Insurance Protections for Children in the Affordable Care Act -
- www.healthcare.gov/law/provisions/ChildrensPCIP/childrenspcip.html
- Pre-Existing Condition Insurance Plan: www.pcip.gov/
- Health Insurance (About.com) healthinsurance.about.com/
- Health Insurance Portability and Accountability Act (HIPAA) www.cms.hhs.gov/HIPAAGenInfo/
- Insure.com article explaining HIPAA: www.insure.com/articles/healthinsurance/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.

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.

Emedicine - www.emedicine.com

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

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 Foundation/Johns Hopkins Children's Center – www.pted.org

Interactive diagrams of many congenital heart defects, mouse-over to compare defect with the normal heart.

American Heart Association - www.americanheart.org

Basic information on CHDs, pamphlets and infective/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 by the founders of California Heart Connection 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.

Please see back for a list of free handouts and materials available on CAHeartConnection.org

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> | 6 |
| 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 |