

Resources on the Internet –

*"And the Beat Goes on...
Looking to the Future for Healthy Hearts"*

This list features a wide variety of resources on topics ranging from promotion of healthy pregnancy and specific prenatal risk factors to information on specific birth defects, support and advocacy. The information and resources listed here are intended for educational use only and are provided solely as a service. The information provided should not be used for diagnosing or treating a health problem or disease, and is not a substitute for professional care. These links do not constitute an endorsement of these organizations or their programs by the National Birth Defects Prevention Network (NBDPN) and none should be inferred. The NBDPN is not responsible for the content of the individual organizations' web pages found at these links.

Terms used for congenital heart defects include: Congenital Heart Defects, Critical Congenital Heart Defects, Congenital Heart Disease, Cardiac Malformations, Cardiovascular Defects and Heart Defects.

Birth Defects Research and Prevention Information

International Clearinghouse for Birth Defects Surveillance and Research:

This site is dedicated to sharing data, news and views on the research, monitoring, and prevention of congenital malformations. It provides information about the Clearinghouse, membership directory, publications/papers, and birth defects links for professionals and general audiences.

<http://www.icbdsr.org>

March of Dimes (MOD) Foundation:

This site contains a wealth of information about MOD, birth defects, and infant health statistics. There are also additional links to other sources of birth defects data.

<http://www.marchofdimes.com>

National Birth Defects Prevention Network (NBDPN):

NBDPN is a national organization of individuals at the local, state, and national level working in birth defects surveillance, research, and prevention. This site offers organizational information, newsletters, a list-serv, and related links to state birth defects monitoring programs and other national organizations. <http://www.nbdpn.org>

Consensus Statement (DRAFT) Regarding Genetic Testing:

This consensus statement, in draft, addresses genetic testing in channelopathies and cardiomyopathies (potentially prevention), which is written by the Heart Rhythm Society and the European Heart Rhythm Association

http://www.hrsonline.org/ClinicalGuidance/genetic_testing.cfm

Genetic Alliance:

Genetic Alliance is the world's leading nonprofit health advocacy organization committed to transforming health through genetics and promoting an environment of openness centered on the health of individuals, families, and communities.

<http://www.geneticalliance.org>

Congenital Heart Disease

The International Birth Defects Information Systems (IBDIS) has information on congenital heart disease including topics such as Cardiac Malformations, Cardiovascular Defects, Congenital Heart Disease and Heart Defects. IBDIS is a multilingual website dedicated to promoting better care and prevention of birth defects through information sharing.

<http://ibis-birthdefects.org/start/conheart.htm>

SADS video on cardio listserv

This video is produced by the Canadian SADS Foundation on TheCanSADS's Channel SADS stands for Sudden Arrhythmia Deaths Syndrome. This is an excellent resource for prevention and provides information for the general public about this often undetected cardiac problem.

http://www.youtube.com/watch?v=hUDWUbnlCuY&feature=channel_video_title

CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD)

This website provides statistical information about the occurrence of heart defects and the public health impact as well as causes and prevention strategies. Information is provided for health professionals, parents and women of childbearing age.

www.cdc.gov/ncbddd/birthdefects/default.htm

Congenital Heart Defects: Resources for Families and the General Public**Adult Congenital Heart Association:**

The Adult Congenital Heart Association (ACHA) is a national 501(c)(3) not-for-profit organization dedicated to improving the quality of life and extending the lives of adults with congenital heart defects (CHD). ACHA serves and supports the more than one million adults with congenital heart defects, their families and the medical community—working with them to address the unmet needs of the long-term survivors of congenital heart defects through education, outreach, advocacy, and promotion of ACHD research.

www.achaheart.org

Congenital Heart Public Health Consortium

This consortium is a group of organizations uniting resources and efforts in public health activities. Its' mission is to prevent the occurrence of CHD and to enhance and prolong the lives of those with CHD through surveillance, population-based research, education, health promotion, advocacy, and policy development.

www.chphc.org

Adult Congenital & Cardiovascular Genetics Clinic:

This clinic website, housed at the University of Minnesota at Fairview, Cardiovascular Division, is a resource for families. It shows diagrams of heart defects compared to normal hearts, procedures,

medications, etc. The Adult Congenital and Cardiovascular Genetics Clinic offers comprehensive cardiovascular care for persons over age 16 who were born with congenital cardiovascular anomalies that require ongoing evaluation and treatment in adolescence and adulthood.
<http://umn-accgc.congenital.org/>

American Heart Association, About Congenital Heart Defects:

The American Heart Association provides current information about congenital heart defects. Links can be clicked for various defects. These are excellent resources for health professionals, families and the general public.

http://www.heart.org/HEARTORG/Conditions/CongenitalHeartDefects/AboutCongenitalHeartDefects/About-Congenital-Heart-Defects_UCM_001217_Article.jsp

Seattle Children's Hospital, Congenital Heart Defects:

This web page provides information about congenital heart defects for professionals and researchers.
<https://www.seattlechildrens.org/kids-health/page.aspx?id=59713>

March of Dimes' Pregnancy and Newborn Health Education Center:

Find information about heart defects for expectant and new parents and health professionals.
www.marchofdimes.com/pnhec/4439_1212.asp

Helen B. Taussig Children's Heart Center:

This site has comprehensive information on the anatomy of the heart and heart defects, diagnostic and surgical procedures, adults and heart defects, and health and nutrition issues for individuals with heart defects.
[English and Spanish]

www.pted.org

Information about Congenital Heart Defects

Congenital Heart Public Health Consortium

This consortium is a group of organizations uniting resources and efforts in public health activities. Its mission is to prevent the occurrence of CHD and to enhance and prolong the lives of those with CHD through surveillance, population-based research, education, health promotion, advocacy, and policy development.

www.chphc.org

Congenital Heart Information Network:

C.H.I.N. is a national organization that provides reliable information, advocacy, support services, financial assistance and resources to people affected by congenital heart defects.
www.tchin.org

Congenitalheartdefects.com

This site is devoted to providing information to members of the world-wide congenital heart defect (CHD) community. www.congenitalheartdefects.com

Sudden Arrhythmia Death Syndromes (SADS) Foundation:

Individuals with heart arrhythmias are often born with the predisposition, but may not develop symptoms for some time. Heart arrhythmias are often inherited. Knowing family history and having early screening and diagnosis are the most important prevention strategies. <http://www.sads.org/>

American Heart Association, Congenital Heart Disease Fact Sheet:

This web page provides easy to read information about the various types of heart defects. The individual can click on any defect link for information regarding that type of heart defect.

http://www.heart.org/HEARTORG/Conditions/CongenitalHeartDefects/AboutCongenitalHeartDefects/About-Congenital-Heart-Defects_UCM_001217_Article.jsp

National Heart Lung Blood Institute, What Are Congenital Heart Defects?

This National Institutes of Health (NIH) website contains information about Congenital Heart Defects and how the heart works.

http://www.nhlbi.nih.gov/health/dci/Diseases/chd/chd_what.html

Congenital Heart Defects:

This website provides easy reading for parents and young people about the different types of congenital heart defects.

http://kidshealth.org/parent/medical/heart/congenital_heart_defects.html

March of Dimes, Congenital heart defects:

This website provides information about heart defects for expectant and new parents and health professionals.

www.marchofdimes.com/Baby/birthdefects_congenitalheart.html

UCSF Fetal Treatment Center, Congenital Heart Disease, Learn More:

This site has complete easy to read information about congenital heart diseases, treatments, outcomes and other information for health professionals.

http://fetus.ucsfmedicalcenter.org/heart/learn_more.asp

CHD Awareness:

This site has information such as Frequently Asked Questions about Congenital Heart Defects for Media Interviews to assist health professionals' work with the media and create awareness efforts.

www.congenitalheartdefects.com/aware.html

Mayo Clinic, Common types of congenital heart defects:

This site provides a slide show about the common types of congenital heart defects that can occur as the heart forms during fetal development.

www.mayoclinic.com/health/congenital-heart-defects/CC00026

Mayo Clinic, Congenital heart defects in children:

The Mayo Clinic website provides user-friendly information for parents and the general public. Comprehensive overview covers symptoms, causes, treatments of congenital heart defects in children.

www.mayoclinic.com/health/congenital-heart-defects/DS01117

Robert Wood Johnson, High-Risk Newborn – Congenital Heart Disease:

The Robert Wood Johnson University Hospital provides detailed information for the general population and health professionals on congenital heart disease, including patent ductus arteriosus, atrial septal defect, ventricular septal defect, atrioventricular canal, tricuspid atresia, and other information.

https://www.rwjuh.edu/health_information/centers_pregnancy_chd.html

MedlinePlus, Congenital Heart Defects:

The Medline Plus website provides easy to use links about congenital heart defects for health professionals, parents, families and the general public.

www.nlm.nih.gov/medlineplus/congenitalheartdefects.html

CDC Features, Congenital Heart Defects:

The Center for Disease Control and Prevention (CDC) provides updated information about congenital heart defects.

<http://www.cdc.gov/Features/HeartDefects/>

Little Hearts Congenital Heart Defects, HLHS in Newborns & Children, Family:

Little Hearts Inc. provides hope and support for those affected by congenital heart defects or CHD in newborns, infants and children. Little Hearts, Inc. is a national organization providing support, education, resources, networking, and hope to families affected by congenital heart defects. Membership consists of families nationwide who have or are expecting a child with a congenital heart defect.

www.littlehearts.org/?utm_group=Support&utm_link=Home

University of Maryland Medical Center:

The University of Maryland Medical Center, in partnership with the University of Maryland, School of Medicine, provides an overview of congenital heart defect corrective surgeries and other information.

www.umm.edu/ency/article/002948.htm

Massachusetts General Hospital, Congenital Heart Defects Conditions and Treatments:

The Massachusetts General Hospital provides information about congenital heart defects and explains the different types.

www.massgeneral.org/conditions/condition.aspx?id=112

Children's Heart Institute - Congenital Heart Defects:

The Children's Heart Institute is a pediatric cardiology facility in MD and VA that provide comprehensive diagnostic and therapeutic services for children currently diagnosed with, or are suspected of having, heart disease. This particular page of the website has patient education in an easy to read format for families and the general public.

www.childrensheartinstitute.org/educate/defects/defects.htm

Professionals and Researchers

Congenital Heart Public Health Consortium

This consortium is a group of organizations uniting resources and efforts in public health activities. Its' mission is to prevent the occurrence of CHD and to enhance and prolong the lives of those with CHD through surveillance, population-based research, education, health promotion, advocacy, and policy development.

www.chphc.org

March of Dimes, Congenital Heart Defects:

This provides information about what constitutes a congenital heart defect, how the heart works, how heart defects affect a child and what tests are used to diagnose heart defects.

www.milesforbabies.org/professionals/14332_1212.asp

PedHeart Resource:

This website provides a wealth of information for medical providers and provider education concerning congenital heart defects, their diagnosis and treatment.

www.heartpassport.com

Regence, Cyanotic heart disease:

ADAM provides easy to understand information about cyanotic/congenital heart disease. The site also has an image of the heart and of a child with symptoms.

<https://ssl.adam.com/content.aspx?productId=39&pid=1&gid=001104&site=regence.adam.com&login=REGE0336>

Congenital Heart Defects, References

Congenital heart disease

Webb GD, Smallhorn JF, Therrien J, Redington AN, Zipes DP, Libby P, Bonow RO. eds. *Braunwald's Heart Disease: A Textbook of Cardiovascular Medicine*, 8th ed. St. Louis, Mo; WB Saunders; 2007:chapter 61.

Cyanotic congenital heart disease: Evaluation of the critically ill neonate with cyanosis and respiratory distress. In: Kliegman RM, Behrman RE, Jenson HB, Stanton BF, eds. *Nelson Textbook of Pediatrics*. 18th ed. Philadelphia, Pa: Saunders Elsevier; 2007: chapter 429.

NYU, Congenital Heart Disease – Frequently Asked Questions:

From the New York University Langone Medical Center, 530 First Avenue, New York, NY 10016, Phone: 1-866-399-HEART. FAQ about congenital heart defects.

<http://cardiac-surgery.med.nyu.edu/congenital-heart-disease-frequently-asked-questions>

Adult Congenital Heart Defects Resources

University of Ottawa, Adult Congenital Heart Defects:

The University of Ottawa Heart Institute (UOHI) provides information for patients, professionals, and the public about adult congenital heart defects. Topics include definitions, causes, treatments, and living with adult congenital heart disease.

http://ottawaheart.ca/heart_disease/adult-congenital-heart-defects.htm

Cleveland Clinic, Adult Congenital Heart Disease:

The Cleveland Clinic website provides information for the adult with Congenital Heart Defects and has various national and international organizational links.

<http://my.clevelandclinic.org/heart/disorders/congenital.aspx>

AHA/AAP Scientific Statement

Role of Pulse Oximetry in Examining Newborns for Congenital Heart Disease: Scientific Statement From the American Heart Association and American Academy of Pediatrics

The scientific statement is published in doi: 10.1161/CIRCULATIONAHA.109.192576 *Circulation* 2009, 120:447-458: originally published online July 6, 2009.

It is located on the World Wide Web at: <http://circ.ahajournals.org/content/120/5/447>

The abstract is located at <http://circ.ahajournals.org/content/120/5/447.abstract>

A test that measures oxygen levels in newborns can detect “critical” congenital heart disease, but there are variables involved with the test that require more study before it is adopted for universal newborn screening, according to a joint statement from the American Heart Association and the American Academy of Pediatrics.

The Adult Congenital and Cardiovascular Genetics Center:

The center is located at the University of Minnesota and provides information resource for pediatric and adult congenital heart defects.

www.umn-accgc.congenital.org/

Legislation on Screening for Critical Congenital Heart Disease

Maryland Governor Signs Bill that Will Help Newborn Screening for Congenital Heart Disease

May 19, 2011, Maryland Governor Martin O’Malley signed into law a bill that will help implement congenital heart disease screening for all newborns in the state. The bill, House Bill (HB) 714/Senate Bill (SB) 786, was passed by the Maryland General Assembly and is the result of an ongoing advocacy and research effort at Children’s National Medical Center that examined newborn congenital heart disease screening.

Maryland is the first state to consider newborn screening for critical congenital heart disease. Most infants with critical congenital heart disease are identified before birth or because they have symptoms soon after they are born. However, about 10 to 20 babies a year in Maryland do not show any symptoms until they are sent home. While screening can save lives, the professional groups that usually establish standards of care for newborns have not yet recommended pulse oximetry

screening for critical congenital heart disease as standard of care. Since there are many issues to consider in adding a new test for newborn screening, legislators, advocates and public health professionals worked together on House Bill 714 to move forward on this important issue in a thoughtful manner. The result was the legislation signed May 19, 2011 by the Governor which directs the State Advisory Council on Hereditary and Congenital Disorders to convene a panel of experts to review available information on pulse oximetry screening for critical congenital heart disease and provide a report to the State Legislature by December 2011. This is similar to what is going on at a national level. In a letter dated April 20, 2011, Secretary Sebelius asked for the Interagency Coordinating Committee on Newborn and Child Screening to review the information on this screening and recommend a plan of action in 90 days.

The legislation signed May 19, 2011 does state that Maryland will begin pulse oximetry screening for newborns if this test is adopted by the Secretary of Health and Human Services. To read the entire bill, see <http://mlis.state.md.us/2011rs/bills/hb/hb0714t.pdf>

Research Literature Related to Congenital Heart Defects

Review Article: Impact of Congenital Heart Disease on Brain Development and Neurodevelopmental Outcome

By Donofrio, M.T. and Massaro, A.N.

Children's National Heart Institute, Children's National Medical Center, 111 Michigan Avenue NW, Washington, DC 20010, USA

International Journal of Pediatrics, Volume 2010, Article ID 359390, 13 pages, doi:10.1155/2010/359390

This is an open access article distributed under the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited. Advances in cardiac surgical techniques and perioperative intensive care have led to improved survival in babies with congenital heart disease (CHD). While it is true that the majority of children with CHD today will survive, many will have impaired neurodevelopmental outcome across a wide spectrum of domains. While continuing to improve short-term morbidity and mortality is an important goal, recent and ongoing research has focused on defining the impact of CHD on brain development, minimizing postnatal brain injury, and improving long-term outcomes. This paper will review the impact that CHD has on the developing brain of the fetus and infant. Neurologic abnormalities detectable prior to surgery will be described. Potential etiologies of these findings will be discussed including altered fetal intrauterine growth, cerebral blood flow and brain development, associated congenital brain abnormalities, and risk for postnatal brain injury. Finally, reported neurodevelopmental outcomes after surgical repair of CHD will be reviewed.

Brain maturation is delayed in infants with complex congenital heart defects,

Licht, D.L., Shera, D.M. Clancy, R.R., et al. *The Journal of Thoracic and Cardiovascular Surgery* (2009);137:529-537.

This article looks at the maturation of the brain and the relationship with congenital heart defects. Small head circumferences and white matter injury in the form of periventricular leukomalacia have

been observed in populations of infants with severe forms of congenital heart defects. This study tests the hypothesis that congenital heart defects delay in utero structural brain development

Pulse oximetry screening as a complementary strategy to detect critical congenital heart defects

academic.research.microsoft.com/Paper/11742351.aspx

By Meberg, A., Andreassen, A., and Brunvand, F. et al.

This study was to compare strategies with and without first-day of life pulse oximetry screening to detect critical congenital heart defects (CCHDs). Conclusions indicate that the first-day of life pulse oximetry screening provides early in-hospital detection of CCHDs and may reduce the number missed and diagnosed after discharge. Correspondence should be made to Alf Meberg, MD, PhD, Department of Paediatrics, Vestfold Hospital, 3103 Tønsberg, Norway. Tel: +47 33 34 20 00, Fax: +47 33 34 39 63, : alfmeb@start.no. DOI:10.1111/j.1651-2227.2008.01199.x

Maternal treatment with opioid analgesics and risk for birth defects

Broussard CS, Rasmussen SA, Reefhuis J, et al. Maternal treatment with opioid analgesics and risk for birth defects. *Am J Obstetric Gynecology*, 2011;204:314.e1-11.

This study was conducted to examine whether maternal opioid treatment between 1 month before pregnancy and the first trimester was associated with birth defects. Conclusions were consistent with some previous investigations; their study shows an association between early pregnancy maternal opioid analgesic treatment and certain birth defects. This information should be considered by women and their physicians who are making treatment decisions during pregnancy.

Pulse Oximetry Screening at 4 Hours of Age to Detect Critical Congenital Heart Defects

By Sendelbach, D.M., Jackson, G.L., Lai, S.S., et al

PEDIATRICS Volume 122, Number 4, October 2008 **e815** Downloaded from

pediatrics.aappublications.org on July 28, 2011

Delineation of the Critical Deletion Region for Congenital Heart Defects on Chromosome 8p23.1

www.ncbi.nlm.nih.gov/pmc/articles/PMC1377836

By Devriendt, K., Matthijs, G., Van Dael, R., et al.

Deletions in the distal region of chromosome 8p (del8p) are associated with congenital heart malformations. Other major manifestations include microcephaly, intrauterine growth retardation, mental retardation, and a characteristic hyperactive, impulsive behavior. We studied genotype-phenotype correlations in nine unrelated patients with a de novo del8p, by using the combination of classic cytogenetics, FISH, and the analysis of polymorphic DNA markers. With the exception of one large terminal deletion, all deletions were interstitial. In five patients, a commonly deleted region of »6Mb was present, with breakpoints clustering in the same regions. One patient without a heart defect or microcephaly but with mild mental retardation and characteristic behavior had a smaller deletion within this commonly deleted region. Two patients without a heart defect had a more proximal interstitial deletion that did not overlap with the commonly deleted region. Taken together, these data allowed the authors to define the critical deletion regions for the major features of a del8p.

Hand factors as regulators of cardiac morphogenesis and implications for congenital heart defects:

By Vincentz, J.W., Barnes, R.M. and Firulli, A.B.

Article first published online: 1 APR 2011 onlinelibrary.wiley.com/doi/10.1002/bdra.20796/abstract. This review summarizes the insight that animal models have provided into the regulation and function of these factors during heart development, in addition to the recent findings that suggest roles for *HAND1* and *HAND2* in human congenital heart disease. *Birth Defects Research (Part A)*, 2011.

Prevalence of Congenital Heart Defects in Metropolitan Atlanta, 1998–2005:

www.ncbi.nlm.nih.gov/pmc/articles/PMC2613036

By Reller, M.D., Strickland, M.J., Riehle-Colarusso, T., et al

This study was conducted to determine an accurate estimate of the prevalence of congenital heart defects (CHD) using current standard diagnostic modalities, using data on infants with CHD delivered during 1998–2005 identified by the Metropolitan Atlanta Congenital Defects Program active, population-based birth defects surveillance system. Selected infant and maternal characteristics of the cases were compared with those of the overall birth cohort. This study, using a standardized cardiac nomenclature and classification, provides current prevalence estimates of the various CHD subtypes. These estimates can be used to assess variations in prevalence across populations, time or space. *Journal of Pediatrics*. 2008 December; 153(6): 807–813. doi:10.1016/j.jpeds.2008.05.059. Correspondence: Mark Reller MD, Division of Pediatric Cardiology, CDRC-P, Oregon Health & Science University, 707 SW Gaines Rd, Portland, Oregon, 97239, rellerm@ohsu.edu, Office: (503) 494-2192, Fax: (503) 494-2824. *Journal of Pediatrics*. Author manuscript; available in PMC 2009 December 1. Published in final edited form as: *J Pediatrics*. 2008 December; 153(6): 807–813. doi:10.1016/j.jpeds.2008.05.059.

International Sources of Information about Heart Defects

Heart Rhythm Society and the European Heart Rhythm Association:

http://www.hrsonline.org/ClinicalGuidance/genetic_testing.cfm

The Heart Rhythm Society is the international leader in science, education and advocacy for cardiac arrhythmia professionals and patients, and the primary information resource on heart rhythm disorders. Its mission is to improve the care of patients by promoting research, education and optimal health care policies and standards.

CORIENCE: <http://http://www.corience.org/research/research-news/new-method-to-detect-congenital-heart-defects>

CORIENCE is an independent European platform on congenital heart defects for patients, parents, doctors and scientists. They have information about the pulse oximetry as a tool to detect critical congenital heart defects.