

Adults with Congenital Heart Defects



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The purpose of this guide is to help patients and families find sources of information and support. This list is not meant to be comprehensive, but rather to provide starting points for information seeking. The resources may be obtained at the Wellness Resource Center, room 2101 in Cardiovascular Center.

Brochures, Fact sheets

- Adult Congenital Heart Association. *ACHA Personal Health Passport*.

To view and print a PDF copy:

→ Access: <http://www.achaheart.org/>

→ Click on "Resource Center"

→ Click on "Personal Health Passport"

Provides space to fill in your own heart history as well as general information on heart health.

Web Resources

Sites focusing on congenital heart defects

- **Congenital Heart Center - University of Michigan**

Access at: <http://www.med.umich.edu/mott/chc/index.html>

This site provides extensive information about specific conditions, tests and procedures and services offered at the U-M Congenital Heart Center.

- **Adult Congenital Heart Association (ACHA)**

Access at: <http://www.achaheart.org/>

This organization aims to improve the quality of life and extend the lives of adults with congenital heart defects. The "Resource Center" section includes information on different types of defects, surgical procedures, insurance and disability concerns, the organization's newsletter and links to other relevant web resources. Free membership is required to access all sections of the site.

- **Canadian Adult Congenital Heart Network**
Access at: <http://www.cachnet.org/>
This site offers extensive information about living with and medical management of specific heart defects in adults. It also includes the adult congenital heart disease glossary.
- **Congenital Heart Information Network C.H.I.N.**
Access at: <http://www.tchin.org/>
This site has information about support services, financial assistance and resources for families of children and adults with congenital heart defects and acquired heart disease. The “Resource Room” section includes informational materials written and reviewed by health professionals
- **International Society for Adult Congenital Cardiac Disease – Patient section**
Access at: <http://www.isaccd.org/patients>
Frequently asked questions about living with a congenital heart disease including many illustrations of specific conditions.

Other sites with relevant information

- **Congenital Heart Defects - American Heart Association**
To access go to: <http://www.heart.org/>
 - Click on “Conditions”
 - Click on “Congenital Heart Defects”
This site contains sections for general information, risk factors, symptoms, diagnosis, and treatment of congenital heart defects.
- **Genetic Home Reference**
Access at: <http://ghr.nlm.nih.gov/>
This site from the National Library of Medicine provides overviews of genetic syndromes and conditions as well as in-depth explanations of genes, chromosomes, genetic counseling and links to relevant organizations.
- **National Heart, Lung, and Blood Institute (NHLBI) – Section Congenital Heart Defects**
 - Access at: <http://www.nhlbi.nih.gov/>
 - Click on “Search the Diseases and Conditions Index”
 - Click on “Congenital Heart Defects”

University of Michigan Resources

- **The Adult Congenital Heart Program**

This clinic provides outpatient evaluation and follow-up for patients, 18 and over, with congenital heart disease. It specializes in MRI scans for patients with congenital heart disease. Other services include:

- Same day surface echocardiograms
- Same day appointments with a dietician
- Continued follow-up and consultation with pediatric or adult surgery, pediatric cardiology and high-risk obstetrics
- Clinical social work

For more information, call:

Appointment Number: (734) 998-7400

Toll Free: (888) 287-1082

- **Tobacco Consultation Service**

Group and individual quit-smoking programs.

For more information access: <http://www.mhealthy.umich.edu/tobacco/> or call 734.936.5988.

Patient Support Organizations

- **Adult Congenital Heart Association (ACHA)**

Website: <http://www.achaheart.org/>

Phone: (215) 849-1260

This document is not intended to take the place of the care and attention of your personal physician or other professional medical services. Our aim is to promote active participation in your care and treatment by providing information and education. Questions about individual health concerns or specific treatment options should be discussed with your physician.

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