

Congenital Heart Defects in Adults

INFORMATION GUIDE



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 Mardigian Wellness Resource Center located off the Atrium on Floor 2 of the Cardiovascular Center. Visit our website at <http://www.umcvc.org/mardigian-wellness-resource-center> and online Information guides at <http://infoguides.med.umich.edu/home>

Michigan Medicine Resources

- **The Adult Congenital Heart Program**
<http://www.uofmhealth.org/medical-services/congenital-heart-disease>
This clinic provides outpatient evaluation and follow-up for patients, 18 and over, with congenital heart disease.
For more information, call: 877.720.3983
- **C.S. Mott Children's Hospital Congenital Heart Center**
<http://www.mottchildren.org/medical-services/ped-heart>
This site provides extensive information about specific conditions, tests and procedures and services offered at the U-M Congenital Heart Center.
- **Tobacco Treatment Programs**
Group and individual quit-smoking programs.
For more information, go to <http://hr.umich.edu/mhealthy/programs/tobacco/>, call (734) 998-6222 or email at quitsmoking@med.umich.edu

Brochures, Fact Sheets

- Adult Congenital Heart Association
 - **ACHA Personal Health Passport**
<https://www.achaheart.org/media/1215/php2018web.pdf>
Provides space to fill in your own heart history as well as general information on heart health.
 - **Adult Congenital Heart Fact Sheet**
<https://www.achaheart.org/media/1203/fact-sheet.pdf>



Web Resources

- **Adult Congenital Heart Association (ACHA)**
<http://www.achaheart.org/>
This organization aims to improve the quality of life and extend the lives of adults with congenital heart defects. Their site has information on different types of defects, and surgical procedures. There is also information on quality of life as well as insurance and disability concerns.
- **American Heart Association: Congenital Heart Defects-**
<http://www.heart.org/>
→ Click on “**Conditions**”
→ Click on “**Congenital Defects Children & Adults**”
This site contains sections for general information, risk factors, symptoms, diagnosis, and treatment of congenital heart defects.
- **Canadian Adult Congenital Heart Network**
<http://www.cachnet.org/>
This site offers extensive information about living with and medical management of specific heart defects in adults. It also includes an adult congenital heart disease glossary.
- **Genetics Home Reference**
<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.
- **International Society for Adult Congenital Cardiac Disease: Patient section**
<http://www.isachd.org/>
Frequently asked questions about living with a congenital heart disease including many illustrations of specific conditions.

Congenital Heart Defects in Adults

INFORMATION GUIDE



- **National Heart, Lung, and Blood Institute (NHLBI): Congenital Heart Defects**

<http://www.nhlbi.nih.gov/>

→ Under “**Health Topics**” click on “**View all Health Topics**”

→ Click on “**C**”

→ Click on “**Congenital Heart Defects**”

This site provides information on types of congenital Heart Defects as well as causes, risk factors, screening, diagnosis, signs and symptoms, and treatment.

Patient Support Organizations

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

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

Phone: (888) 921.ACHA

This document contains information and/or instructional materials developed by the Michigan Medicine for the typical patient with your condition. It may include links to online content that was not created by Michigan Medicine and for which Michigan Medicine does not assume responsibility. It does not replace medical advice from your health care provider because your experience may differ from that of the typical patient. Talk to your health care provider if you have any questions about this document, your condition or your treatment plan.

©2018 The Regents of the University of Michigan

Document #223

Compiled by Amy Hyde, MLIS, Wellness Resource Center Librarian