

Helpful hints

This section has information about your health care centre, the Internet, and some helpful programs. Ask your team about additional services or resources which may be available in your area including:

■ *Family support groups/resources*, ■ *Newsletters*, ■ *Adult congenital heart defect support groups*, ■ *Infant Development Programs, Child Development Centres, Supported Childcare Programs, Community Mental Health Programs and other applicable community resources*, ■ *Internet resources*.

INTERNET RESOURCES

The Internet is useful for getting information quickly but you can also find some incorrect or misleading information. Anyone can put information on the Internet, so it is important to make sure that the information you are getting is accurate and relevant.

If you find information that interests you, test the reliability of the information by asking questions, such as the ones listed here.

What is the source of the information?

- Is the website hosted or managed by a well-known health organization (for example, the Heart and Stroke Foundation), a university medical school (for example, Johns Hopkins), a government agency (for example, Health Canada), or a professional organization (for example, the Society of Pediatric Cardiology Nurses)?
- Does the author include his or her medical educational and professional background?
- Is there an editorial board (a panel of experts) which periodically reviews the material for accuracy? Are their credentials listed? Is there contact information available so that a visitor can ask questions or make comments?

- Is the information referenced so that you can find it somewhere else? Do they list the source of the information? Is the source of information reputable?

- Are the claims supported by other sources?

Is there a conflict of interest (sponsors or advertising)?

- Are they trying to sell you something?
- Is there advertising on the site? This is not always negative, as long as the difference between the advertising and the site's content is clear, and as long as the author tells you about any conflict of interest.
- Does the site deliver information in a responsible way?
- Does the site have a warning or disclaimer of any kind? For example, if the author has no medical credentials, is that clearly stated? Do they warn you that the information should not be used to diagnose or treat a healthy problem? Do they advise you to talk to your doctor? Most reputable health sites will guide visitors in their use of the information.



INTERNET CONFLICT

ARE THEY TRYING TO SELL YOU SOMETHING?



IS THERE ADVERTISING ON THE SITE?



DOES THE SITE DELIVER INFORMATION IN A RESPONSIBLE WAY?



DOES THE SITE HAVE A WARNING OR DISCLAIMER OF ANY KIND?



Finding answers. For life.

INTERNET SUPPORT

USE THE INTERNET AS A VIRTUAL SUPPORT NETWORK

CHD NEWSGROUPS AND CHAT ROOMS ARE BECOMING MORE COMMON

SOME PARENTS HAVE FOUND "CHATTING" WITH OTHER PARENTS TO BE VERY HELPFUL



Finding answers. For life.

Is the site current?

■ Does the website say when it was last updated? Medical information in this field is constantly changing. If the website is not updated on a regular basis, the information may be outdated. Ideally, there should be updates at least monthly, according to the US Food and Drug Administration.

Use common sense when you evaluate a site. Some of the best sites will not meet all of the qualifications listed above, and some of the worst will. If you receive conflicting information, write down the name and address of the site, print out the information, and discuss it with your cardiologist. He or she will be able to tell you whether the information applies to your child's unique situation.

Use the internet as a source of support

The Internet can be used as a virtual support network. CHD newsgroups and chat rooms are becoming more and more common. Some parents have found "chatting" with other parents to be very helpful. However, again, you need to be careful: sharing your story online can be a source of relief, but it can also open you up to criticism and bad advice. If you get opinions that are upsetting, then it is time to withdraw and talk to the people who form your day-to-day community—the ones who can provide support in a more meaningful way. If you are making difficult ethical decisions, the Internet is not the place to seek counsel. People giving advice online cannot support you day-to-day or help you live with your decisions. Talk to someone who can.

There are many websites about congenital heart defects, and some appear and disappear with lightning speed. Rather than list sites that may not exist at the time of printing, we leave you with space to write down current sites. Please ask your health care team for site addresses familiar to them.

Websites

The following websites may be helpful to you and your family:

CHD Online Handbook
www.execpc.com/~markc/congenit.html

Congenital Heart Information Network
www.tchin.org

The Congenital Heart Disease Resource Page
www.csun.edu/~hcmth001/heart

Heart and Stroke Foundation of Canada
www.heartandstroke.ca

Variety Children's Heart Centre, Winnipeg
www.vchc.ca

Royal Children's Hospital, Melbourne, Australia
www.rch.au

Cincinnati Children's Hospital
www.cincinnatichildrens.org

Children's Heart Network, British Columbia
www.childrensheartnetwork.org

Record other sites that were helpful:



* Source: Dozois E., Kneeshaw R. *Heart Beats: A handbook for families and children with special hearts.* Edited by Word on the Street Consulting. Heart Beats - the Children's Society of Calgary, 1999 (draft).

OTHER SOURCES OF INFORMATION

Computer-aided instruction is available at: _____

Library resources are available at: _____

My own resources

REFERENCES

Ask your health professional for a list of books available in your area.

■ Cahill, M. *Everything you need to know about medical therapies*. Springhouse, Springhouse PA, 1996.

■ Kramer, G. F. and Maurer, S. *The Parent's Guide to Children's Congenital heart Defects: what they are, how to treat them and how to cope with them*. Three River's Press, NY, 2001.

