

On behalf of the Congenital Heart Surgeons' Society (CHSS) Data Center, we warmly welcome your participation in our research. The responses you provide will be important for the future care of children with heart conditions.

CHSS DATA CENTER HISTORY & BACKGROUND

The CHSS was founded in the 1960's as an effort for pediatric cardiac surgeons to improve the care of children with heart malformations. By combining the experience from many hospitals, sufficient data is collected to create new research to improve the care for children with congenital heart defects.

Drs. John Kirklin and Eugene Blackstone established the (CHSS) Data Center at the University of Alabama, Birmingham in 1985. In 1997, the CHSS Data Center was relocated to The Hospital for Sick Children in Toronto, Canada. Today, the CHSS is a group of over 170 surgeons from more than 70 hospitals who share a common

interest in helping children born with heart defects.

WHAT'S INVOLVED

On a yearly basis, specially trained personnel from the CHSS Data Center or from your child's hospital will contact you by questionnaire or a telephone call to check on your child's progress.



Figure 1: CHSS Member Institutions

Information such as your current address, family doctor, cardiologist, copies of reports from echocardiograms, chest x-rays, cardiac catheterizations and operations are recorded and stored under lock and key. Information from them is entered into a secure and confidential computer file and de-identified for analysis.

All reports and publications by the CHSS follow the rules of patient confidentiality so that no patient identifying information leaves the CHSS Data Center.

RESEARCH HELPS CHILDREN

Many children today benefit from research that was done for children in the past and present.

Over the years, the CHSS Data Center has entered over 6,000 neonates, children and adults into research studies and maintains long-term follow-up information on each participant. Twelve studies of children born with specific congenital cardiac malformations have been initiated to date. These studies have resulted in many presentations at national and international meetings and several publications informing the medical community of important findings. All findings are summarized and reports can be viewed on our website www.chssdc.org



CONTACT US

We are always happy to hear of your child's progress and want to stay in touch with you. Please let us know any updates you would like to share, along with any change of contact information that has taken place.

You may contact us by telephone, toll-free **1-866-477-2477**, or by email at **chss.dc@sickkids.ca**

The CHSS Data Center staff would like to thank you for your interest and continued assistance with this very important endeavor.

CHSS Data Center

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Toll Free: **1-866-477-CHSS (2477)**

Fax: **416-813-8776**

Email: **chss.dc@sickkids.ca**

Website: **www.chssdc.org**

WEBSITES WITH CONGENITAL HEART INFORMATION

Canadian Congenital Heart Alliance

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

Pediatric Congenital Heart Association

<http://conqueringchd.org/>

Little Hearts: A Support Network for Parents of
Children with CHD <http://www.littlehearts.net>

American Heart Association

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

The Congenital Heart Library

www.achd-library.com

The Children's Heart Foundation

<http://www.childrensheart.com>

Children's Heart Society

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

Heart Kids of SA Inc.

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

Children's Heart Link

<http://www.childrensheartlink.org>

Canadian Adult Congenital Heart Network

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

Cardiac Kids

<http://www.cardiackids.ca/>



**CHSS
Data Center**

Our Research Saves Lives

www.chssdc.org