

[use current CHSS Data Center letterhead]

[insert Date]

Dear [insert Name of Parent/Guardian]:

We are contacting you on behalf of the Congenital Heart Surgeons' Society (CHSS), because we wish to stay in touch with you about your child's progress. [Your child's heart surgeon is a member of the CHSS. – *insert, if applicable*] CHSS doctors share a common interest in helping people born with heart malformations.

The **CHSS Data Center**, located at **The Hospital for Sick Children in Toronto, Ontario, Canada**, coordinates many of the CHSS studies, including gathering information about the progress of your child and other children and/or adults enrolled in the following study: [*insert study name*].

We hope that you will take the time to answer some questions about your child's health and complete the enclosed annual Follow-up Form and Questionnaires for the study. [We are also including Questionnaire(s) for your child to complete, if possible. – *insert, if applicable*]

Parent/Guardian Instructions for the PedsQL™ inventory:

The PedsQL™ is a questionnaire that assesses health-related quality of life in children, adolescents and adults. It contains questions about your child's physical, emotional, social, and school functioning **in the past one month**.

The PedsQL™ is brief and typically takes less than 5 minutes to complete. It is not a test and there are no right or wrong answers. Please be sure to read the instructions carefully and choose the response that is the closest to how you truly feel. Please fill out the Date on the first page, but do not write your name or your child's name on the PedsQL™ questionnaire(s). [Please do not compare your answers with your child's responses. We are interested in your and your child's individual perspectives. However, feel free to discuss the questionnaire with your child after you have both completed it. – *insert, if applicable*]

[If your child would be able to complete the questionnaire(s) included, please read the following to your child before you give your child the questionnaire(s):

Child Instructions for the PedsQL™ inventory:

The PedsQL™ asks you questions about how you feel and what you think about your health. It is not a test, and there are no right or wrong answers. It takes about 5 minutes to complete. Nobody will be angry or upset if you do not want to complete the questions. If you complete the questions, you should know that your help will help us to improve the care of other kids with the same condition as yours. Please do not print or write your name on the PedsQL™ questionnaire(s). We thank you for your time. – *insert, if applicable*]

Completing and Returning the Form and Questionnaires:

(1) If you want to complete the form and questionnaires in paper copy, you can return these to us:

(a) by mail (using the enclosed prepaid envelope) **OR**

(b) by secure fax (fax #: 416-813-8776)

(2) If you would prefer to provide us with some of the information over the phone (i.e., for the follow-up form and general questionnaire), please call our toll-free number at **1-866-477-2477**.

(3) If you would prefer to complete all or some of these electronically, please:

(a) call our toll-free number at **1-866-477-2477**, so we can set this up, **OR**

(b) contact us by e-mail, at chss.dc@sickkids.ca and provide directions, such as 'I wish to complete the Follow-up Form and Questionnaires by e-mail', or 'I wish to complete only the Questionnaires by e-mail', and provide us with the e-mail address where we can send these to you.

Although e-mail may be a very common method of communication, please note that the security of e-mail messages is not guaranteed. Messages sent to you or from you by e-mail may be seen by others using the Internet. E-mail is easy to forge, easy to forward, and may exist indefinitely. For this reason, do not use e-mail to communicate or discuss information you think is sensitive. By replying to this message by e-mail, or requesting that we send you information by e-mail, you acknowledge that you have read and accept the risks of using e-mail.

If you have any questions regarding this, please feel free to call our toll-free number at **1-866-477-2477**, and we will be happy to talk to you and answer your questions.

The information you provide to us, together with the information from other children and/or adults with the same diagnosis from centers throughout North America, will be securely stored and treated in a confidential manner by the study team. It will be analyzed and used as a basis for better care of individuals with congenital heart conditions.

We want to thank you for your assistance with this very important endeavor. We look forward to staying in touch with you.

Sincerely,

[insert name]

Clinical Research Project Assistant/Coordinator

Direct toll-free line: 1-866-477-2477

CHSS e-mail: chss.dc@sickkids.ca