

Follow-up Phone Script – Parent/Guardian

If the Follow-up Form and Questionnaires were mailed out more than one month ago, follow up with a phone call. Parent/Guardian of Child Participant may be called up to three times (without any communication back from him/her) for each follow-up year to try to establish contact for completing the Follow-up Form and Questionnaires.

Hi, this is [state your Name] calling from the **Congenital Heart Surgeons' Society (CHSS) Data Center in Toronto, Ontario, Canada**. I am calling in regards to the annual Follow-up Form and Questionnaires for the [state Name of Study], that you are currently participating in for your child.

- Did you receive the Follow-up Form and Questionnaires this year?

If No – Confirm: Address

- Is this a good time to answer a few questions from the Follow-up Form and General Questionnaire about your child's health?

If Yes – explain that completing the form and general questionnaire over the phone only takes a few minutes, and proceed with completing these, as applicable.

Confirm: Address, Email (as applicable), Alternate Contact and Doctors, etc.

* Explain that the other Questionnaires (PedsQL™; Conditions and Problems Questionnaire – if applicable) should be filled out and submitted to the CHSS Data Center per instructions. Re-send the materials, as needed.

If No – then enquire 'When would be a better time for us to speak with you?'

Thank you very much. We appreciate your taking the time to participate in the study. We look forward to talking with you again next year. Also, please keep in mind that if you have a change in address or contact information, please let us know. We value your participation and it is important to us that we are able to maintain contact with you for follow-up every year. You can call us toll free (**1-866-477-2477**), and provide us with your updated contact information or address change, at any time.

If you would like to communicate via e-mail, you are reminded that:

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 or communicating with us 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.

Voicemail Message (if stated Name on the voicemail message is the same as the Name on file; if no stated Name on the voicemail message)

Hi, [state Name of Parent/Guardian, if stated Name on the voicemail message is the same as

the Name on file]. This is [*state your Name*] calling from the **Congenital Heart Surgeons' Society (CHSS) Data Center in Toronto, Ontario, Canada**. I am calling in regards to the annual Follow-up Form and Questionnaires for your child's participation in [*state Name of Study*]. We can complete the follow-up form and general questionnaire over the phone as it only takes a few minutes. If you could please give us a call back, we'd really like to hear from you. Our toll free number is **1-866-477-2477**. Thank you. We look forward to speaking to you soon.

Voicemail Message (If there has been no communication back from the Parent/Guardian of Child Participant, for 2 years or more, but he/she has not withdrawn from study participation)

Hi. This is [*state your Name*] calling from the **Congenital Heart Surgeons' Society (CHSS) Data Center in Toronto, Ontario, Canada**. I am calling in regards to the annual Follow-up Form and Questionnaires for your child's participation in [*state Name of Study*]. We really value your participation, however we have not heard from you in a long time. If you are no longer interested in ongoing participation in the study, please call us and let us know. Alternatively, if you wish to resume participation, we can complete the follow-up form and general questionnaire over the phone, as it only takes a few minutes. Regardless of your decision, we'd really like to hear from you. Our toll free number is **1-866-477-2477**. Thank you. We look forward to speaking to you soon.

Note: If at any point during telephone contact, it is communicated that the Child Participant has died, extend your deepest condolences for the loss. You may ask when the child passed on, and ask the Parent/Guardian if he/she wants to provide any further information. Let the Parent/Guardian know that they may call back any time they wish to provide information, but they are not obligated to do so. No further contact with the Parent/Guardian should be attempted thereafter, unless it is at the request of the Parent/Guardian.

Note: If at any point you are left/given a message from the Parent/Guardian of the Child Participant, indicating that the child has died, you may call him/her back to extend your deepest condolences, unless the Parent/Guardian has asked you not to contact him/her again. You may ask when the child passed on, and ask the Parent/Guardian if he/she wants to provide any further information. Let the Parent/Guardian know that they may call back any time they wish to provide information, but they are not obligated to do so. No further contact with the Parent/Guardian should be attempted thereafter, unless it is at the request of the Parent/Guardian.