Title of Research Project:

Identifying Determinants and Optimizing Rehabilitation of Physical Activity for Children after the Fontan Procedure.

Investigator(s):

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Dr. Jennifer Russell, Corresponding Investigator, Tel: 416-813-7467
Ms. Patricia Longmuir, Project Coordinator, Tel: 416-813-7617 or 877-267-4530

Confidentiality:

The pictures and stories used for this study will be stored in a secure, locked location. Only members of the research team (and maybe the SickKids monitor, or employees of the company sponsoring the study or the regulator eg., Health Canada) will have access to them for use and/or distribution. The photos and/or stories will not contain any identifying information (e.g., names, close up views of the participant’s face). Digital copies of original photos will be cropped or altered to the satisfaction of the family providing the material to ensure that the identity of the child is protected to their satisfaction. Original photos will be returned to the owner once the digital copy has been made.

These materials will be used only as part of the education intervention for this research project. Through the education intervention, the materials may be distributed to families participating in this research who have a child that is interested in similar activities. For example, a photo of a child participating in swimming lessons would be shared with a family participating in the education intervention whose child was interested in learning to swim but had not yet been able to participate.

Following completion of the study the pictures and stories will be kept as long as required in the SickKids “Records Retention and Destruction” policy. They will then be destroyed according to this same policy. Any use of the photos and/or stories other than for the purposes of the education intervention of this research project will require a separate consent.
**Consent:**

By signing this form,

1) I agree to allow my child to be photographed or to provide photographs of my child that will be used during the education intervention of this study. These photographs will be used to encourage families participating in this research regarding the participation of children with heart defects in a wide variety of physical activities.

2) I understand that both I and my child have the right to refuse to provide photographs for use in this study. We also have the right to withdraw from this part of the study at any time. e.g., before or even after the tapes or photographs are made. My decision will not affect my child’s health care at SickKids.

3) I am free now, and in the future, to ask questions about the taking or use of these pictures of my child.

4) I have been told that my child’s medical records will be kept private. You will give no one information about me or my child, unless the law requires you to.

5) I understand that no information about me or my child (including these pictures) will be given to anyone other than participants in the education intervention of this research project and no information will be otherwise published without first asking my permission.

6) I have read and understood pages 1 to 3 of this consent form. I agree, or consent, to having my child’s picture taken/providing photographs of my child as part of the study.

_________________________________
Printed Name of Child  Child’s signature of assent

_________________________________
Printed Name of Parent/Legal Guardian  Parent/Legal Guardian signature & date

_________________________________
Printed Name of person who explained consent  Signature & date

_________________________________
Printed Witness’ name (subject does not read English)  Witness’ signature & date
In addition, I agree or consent for this tape(s)/photograph(s) to be used for:

1. Other studies on the same topic _______________________________
2. Teaching and demonstration at SickKids. _______________________
3. Teaching and demonstration at meetings outside SickKids. _________
4. Not to be used for anything else. _______________________________

In agreeing to the use of the photograph(s) for other purposes, I and my child have been offered a chance to view the photograph(s). I also have the right to withdraw my permission for other uses of the photograph(s) at any time.

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