

Virtual Heart Camp for Fontans

WCCHN sends 66 kids to heart camp.



Congenital heart disease (CHD) is the most common birth anomaly occurring in 1 of every 100 live births. A rare and complex form of CHD is the single ventricle, occurring in about 5 per 10,000. These children undergo three operations during infancy and childhood to separate the flow of oxygenated and deoxygenated blood through the heart. The third of these surgeries is called the Fontan.

With advances in medical and surgical care, outcomes for children after Fontan have improved significantly, and many are now living to adulthood. But because this form of CHD is so rare, we know that some people who have had a Fontan never get to meet another person with similar lived experience. We also know that living with cardiac disease, physical limitations, and any chronic condition in general can have psychological and quality of life implications.

Dr. Tham and her team at the Stollery Congenital Heart Program decided to intervene early for their Fontan kids. They knew that connecting children and adolescents with others just like them could help to extend social-emotional support, introduce them to new resources, give them a safe place to ask questions and learn more, and encourage early exposure to the concepts of self-care and self-management.

Limitations imposed by the pandemic created a few challenges for Dr. Tham and her team, forcing them to get a bit creative. Dr. Tham decided to pilot a couple of small virtual day camps locally called Virtual Heart Connection. They invited children to join online, made introductions, broke the ice, played medical Jeopardy, and got creative together.



The first iteration of this event was very well received, and so the team began to wonder, “How can we go bigger and do better?”

As an organization that values equal access to resources and opportunity, support throughout the entire lifelong continuum of care, and the power of ongoing and high quality education, the WCCHN was quick to sponsor the next two iterations of this Virtual Heart Camp for Children with Fontan.

With WCCHN’s support, Dr. Tham and team were able to expand their camp clear across Canada, offering a full day virtual event for any child aged 8 – 15 with Fontan. Both iterations were well attended particularly for those with a residential address in BC (57.1% and 31.3% respectively). Data demonstrates a trend towards younger audiences (two-thirds of participants were between the ages of 8 and 11) with an even distribution between genders (49% identified as male and 51% identified as female).



The results:

95%

SAID THAT THE EVENT
MET THEIR EXPECTATIONS
AND THEY WOULD
ATTEND AGAIN

86%

TOLD US THEY LEARNED
SOMETHING NEW ABOUT
THEIR HEART

95%

REPORTED FEELING A
CONNECTION WITH OTHER
KIDS LIKE THEM

2/3

WOULD LIKE TO STAY IN
TOUCH WITH SOMEONE
THEY MET AT CAMP

95%

AGREED IT WAS HELPFUL
TO HEAR FROM AN ADULT
WHO HAD THE SAME
SURGERY WHEN THEY
WERE A KID

“ This virtual approach to delivery has opened up greater opportunities to connect children from remote areas and across the country for those who cannot travel to in-person camps. Expanding the social support network for these children and their families can help to promote healthy psychosocial adjustment to their chronic condition. The ability to connect children across Canada so that Fontan children can meet not just one, but many other children just like them can show them that they are not alone in their heart journey.

Dr. Edythe Tham, Pediatric Cardiologist, Associate Professor of Pediatrics, Director of Pediatric Cardiology Residency Program, Division of Pediatric Cardiology and Diagnostic Imaging

What parents had to say about it:

“This was the first camp my child has attended with other kids with a heart condition. She has been wanting to meet other kids with a ‘special heart’ and she’s been wanting to talk with other people with a similar heart condition. This event gave her the opportunity to do both of these things. I’m so grateful.”

“It helped my son understand his condition and know that there are other people like him who are brave and strong.”

What kids had to say about it:

“It was a very good day, filled with fun and great activities and laughter.”

“It was an amazing way to shed a positive light on the trauma I’ve been through.”

“I liked the hip hop dancing because it was good exercise.”

How can we let more people know about this amazing opportunity?

The number one most effective form of advertising and recruitment was by word of mouth from a cardiologist or from someone within their office (34.8%), followed by the WCCHN website (19.6%), and email (17.4%).

For more details and information about future events, follow along on their Facebook and Instagram pages called “Virtual Heart Connection”.

