



**Holland Bloerview**

Kids Rehabilitation Hospital

## **Family Leadership Program**

Year in Review 2017 - 2018



I have seen firsthand how incredibly unique and system-leading our Family Leadership Program truly is. The commitment to authentic partnership that every member of the Holland Bloorview team has is not seen at most organizations. Holland Bloorview should take great pride in the program we have co-created. Our partnerships make an incredible impact on the children and youth who depend on us, and contribute to realizing our ultimate vision: *the most meaningful and healthy futures for all children, youth and families.*"

Adrienne Zarem, family leader

## Thank you to our donors

We are extremely grateful to our donors for their dedicated support of the Family Leadership Program. Their generosity helps ensure children, youth and families can meaningfully partner with Holland Bloorview in the development and delivery of care and programs at the hospital and beyond.

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“All the work that we do is centred around making our digital spaces more user-friendly and accessible for our clients and families – this would not be possible without the perspective and partnership of our youth and family leaders. Thank you for your commitment to excellence – you have been, and continue to be, incredible partners.”

Nadia Van, senior digital associate

“Working with our dedicated family, youth and child leader volunteers has been a complete game changer for me! Through meaningful partnership we have been able to take projects and quality improvement initiatives to a level that would have never been attained in their absence and we have been recognized across the system because of it. I am excited to continue to grow the partnership in quality, safety and performance.”

Laura Oxenham-Murphy, interim director of quality, safety and performance

“I am blown away by the collaboration between multiple departments and our family leaders on our outpatient orientation. Family leaders and I get to see the shift where new families feel better equipped to handle their first appointment here, have moments of understanding or relief, and also feel comfortable to ask for help from their new connections.”

Melissa Ngo, family support specialist



## Letter from the President and CEO

Every day I am reminded how privileged we are at Holland Bloorview Kids Rehabilitation Hospital to partner with such a dedicated group of child, youth and family leaders. Thanks to your hard work and commitment we are able to co-create solutions that truly put families at the heart of care, services, research and more.

Your willingness to share knowledge and insights is helping to drive inclusion beyond our walls in health care, education and in your communities. Your efforts are deeply appreciated at Holland Bloorview and highly regarded across the health system.

This year with your support Holland Bloorview achieved 100 per cent in our quality and safety review by Accreditation Canada. Our surveyors noted the authentic partnership shared by client and family leaders and hospital staff. They also remarked on the significant impact your active participation, input and leadership has had on Holland Bloorview. Thank you for partnering with us to become leaders in patient engagement.

I also want to recognize the client and family integrated care team for always providing excellent support to our clients, their families and the entire Holland Bloorview community. Thank you for ensuring that the perspectives of the children, youth and families we serve are embedded at all levels of the organization, including at our Board of Trustees, and for advancing client and family centred care at every opportunity.

Lastly, both the Family Leadership Program and client and family centred care at Holland Bloorview continue to thrive and grow every year in no small part thanks to the generous support of our donors – thank you for helping us to create a world of possibility for children, youth and families.

Congratulations to each and every one of you on another outstanding year.

Sincerely,



Julia Hanigsberg  
President and CEO

# Family Leadership Program

## Who we are

The Family Leadership Program is the framework through which volunteer child, youth and family leaders partner with the hospital and Bloorview Research Institute to shape and improve policies, programs and services, and advance client and family centred care.

Volunteer family leaders participated on  
**over 140**  
new projects, initiatives and committees

Hospital advisors  
shared experiences  
and ideas on

**73**  
hospital initiatives

Research advisors  
shared experiences  
and ideas on

**49**  
research initiatives

Peer mentors  
provided

**426**  
peer to peer  
consultations

**184\***  
inpatient parents attended  
the inpatient parent  
talks co-led by  
peer mentors

*\*Number reflects parents who have  
attended more than once*

Youth facilitators conducted  
**138**  
interviews with clients and families to improve quality of care and services

**17**  
family and youth advisors were full partners in Accreditation planning and helped us achieve a 100 per cent score in the October 2018 quality survey

**127**  
staff and students trained using client and family centred care simulations

Research reviewers brought the family perspective to  
**15**  
research proposals

**57**  
families attended Outpatient Welcome Orientation co-hosted by family leaders

Families as faculty shared their family story  
**50**  
times at educational activities, internal/external presentations or public relations initiatives

Research communicators co-delivered presentations and co-designed information to make  
**25**  
research initiatives more understandable to families

**143**  
families received free legal assistance from the on-site program offered by Pro Bono Ontario

**55**

hospital documents were reviewed  
by family leaders for health literacy

Children, youth and families  
volunteered for a total of

**3,125**  
hours

Families recognized

**517**

staff, students and volunteers  
as client and family centred  
care champions

In 2017, there were

**64**

requests for  
youth mentors  
for activities including:

- 1:1 mentoring with current clients
- small group mentoring with current clients and families
- participating in workshops, panels and presentations
- collaborating with the research institute



BLOOM is a blog that  
unites parents of children with  
disabilities and clinicians in a  
community of support

BLOOM has

**1,467**

followers on Facebook

BLOOM has readers in

**146**  
countries

In the last year,  
BLOOM published

**36**

stories by parents and grandparents  
about their experiences

There are

**612**

members on the Parent Voices at  
Holland Bloorview Facebook group

# Spotlight on engagement

Child, youth and family leaders are often involved in projects and initiatives in addition to their work with the Children's Advisory Council, Youth Advisory Council, Family Advisory Committee or the Bloorview Research Institute Family Engagement Committee. Check out some of the interesting events and initiatives children, youth and families have participated in this year.



**1** In 2017 Holland Bloorview received 100 per cent in a quality survey by Accreditation Canada. Family leaders participated on six Accreditation teams and in the Family Leader Accreditation Group (FLAG). Pictured at a celebration following the hospital's Accreditation survey in October is Cally Hunt, hospital board chair 2016-18; Sherri-Ann Stringer, FLAG member; Alifa Khan, vice-chair of FLAG; Lies Ferriman, FLAG member; Holly Yip, FLAG member; and Julia Hanigsberg, president and CEO (*left to right*).

**2** Family and youth leaders often participate in tours when government officials come to visit Holland Bloorview. Pictured here is Sageth Ravendran (*second from right*), a youth leader and youth employment program participant, taking part in a discussion about the importance of early work experience with Holland Bloorview staff and Susan Picorello, Assistant Deputy Minister of Ontario Public Service Accessibility and Employment Strategy for People with Disabilities Division.

**3** Child, youth and family leaders often participate in speaking engagements at Holland Bloorview and beyond. Here, family leader Cheryl Peters and CAC member Jillian Peters share their story at a fundraising event for the Bloorview Research Institute.



Adrienne Zarem and Alifa Khan, FLAG chair and vice-chair, are among the first patient surveyors with Accreditation Canada.

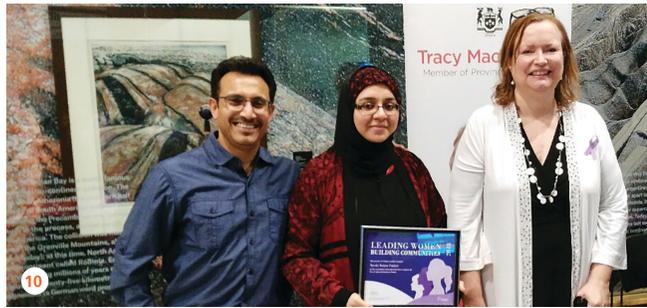


4 The Youth Feedback Corner pilot launched in April 2018, facilitated by Leading the Way intern and youth leader Mathias Castaldo (*pictured here*). The idea for the project was brought forward by youth leader Jadine Baldwin. Youth clients and their siblings could record videos to share compliments and improvement ideas about the hospital as well as their ideas to create a world without disability stigma.

5 From its early development, child, youth and family leaders advised on the hospital's **Dear Everybody** anti-stigma campaign. In its second year, the campaign returns with powerful

imagery that challenges Canadians to rethink their perceptions of disability. Dear Everybody is part of the hospital's five-year anti-stigma strategy. Pictured here are youth ambassadors Jadine Baldwin and Casey MacKay at the CF Toronto Eaton Centre installation.

6 Family, child and youth leaders joined forces to fundraise for Holland Bloorview through **Capes for Kids** in 2018. Family leaders co-created **Capes for Kids** with the Foundation and outside partners, and the program has gone on to raise over \$1 million for Holland Bloorview in just two years.



**7 & 8** The Family Leadership Program was recognized:

- Received the Merck Patients First Award in 2018 for advancing client and family centred care at all levels of the hospital. Pictured here is Aman Sium, director of client and family integrated care, and Heather Evans, family leader, accepting the award.
- Received an honourable mention for the Institute for Patient and Family Centred Care's Partnership Award for the innovative training for leaders in education, health, children and community services

that child, youth and family leaders co-created and delivered. Pictured here are the project leads: Jean Hammond, Amir Karmali and Kathryn Parker (left to right).

- **9 & 10** Family leaders have been recognized for their significant volunteer contributions. Pictured here are Sharda Ali-Ramjattan (image 9) and Saima Azhar (image 10, middle), family leaders, receiving the Leading Women, Building Communities Award from their local Members of Provincial Parliament for their exceptional leadership and volunteer work to improve the lives of others in their communities.

# Children's Advisory Council

## Who we are

Members of the Children's Advisory Council (CAC) are clients and their siblings who range in age from 3 to 13 years. CAC members share their unique perspectives, experiences and ideas to shape hospital improvements and research projects. The CAC uses a strengths-based and play-based engagement model, meaning that members can provide their feedback in ways that work for them.

In 2017-2018 the CAC had 61 members and its membership continues to grow.



**This is what an inventor looks like.**

**Holland Bloorview**  
Kids Rehabilitation Hospital  
#DearEverybody @   

**SEE WHAT A WORLD WITHOUT STIGMA LOOKS LIKE AT DEAREVERYBODY.CA**



**This is what an athlete looks like.**

**Holland Bloorview**  
Kids Rehabilitation Hospital  
#DearEverybody @   

**SEE WHAT A WORLD WITHOUT STIGMA LOOKS LIKE AT DEAREVERYBODY.CA**

Holland Bloorview Kids Rehabilitation Hospital's **QUALITY IMPROVEMENT PLAN (QIP)** overview for kids

## Making our care better every day

Quality and safety is our #1 priority. Here are some ways we are making care better in 2018-2019:

<p><b>SAFETY</b></p> <p>Before you leave the hospital, your family and your care team will talk about how to safely take your medications at home. We will also call your family at home to ask if you have any questions.</p>	<p><b>SEAMLESS</b></p> <p>We are making it easier for you and your family to move from The Hospital for Sick Children (SickKids) to Holland Bloorview. You, your family and your care team will use a book to talk about ways to make it easier to go back to your home and school when you leave Holland Bloorview.</p>	<p><b>WORKING TOGETHER</b></p> <p>Every year, our child, youth and family leaders tell us how we can make care better at Holland Bloorview.</p>
<p><b>CLIENT AND FAMILY CENTRED</b></p> <p>We will go around the hospital and ask for your opinion about how we can help make things in your life better like therapy sessions or making friends.</p>	<p><b>EQUITY</b></p> <p>We will make sure important information, like how to take medications safely, is in many different languages.</p>	<p><b>Here are our kids' top priorities for 2018-2019:</b></p> <p>Understanding Information Communication</p>
<p><b>ACCESS</b></p> <p>You, your family and your care team will work together to choose the right therapies and devices to help you reach your goals.</p>		

**3** **Holland Bloorview**  
Kids Rehabilitation Hospital

Holland Bloorview Kids Rehabilitation Hospital creates a world of possibility by supporting children and youth living with disability, medical complexity, chronic and/or life-threatening illnesses. The only pediatric inpatient children's hospital in the world dedicated to quality of life for children with chronic illness. The full Quality Improvement Plan is available at [www.hollandbloorview.ca](http://www.hollandbloorview.ca).

Questions? Contact: Mrs. Linda Owen, Quality Improvement Manager, at [linda.owen@hollandbloorview.ca](mailto:linda.owen@hollandbloorview.ca) or 416-243-6222 ext. 7037

## How we've made a difference

- Shared our stories to help develop year two of the hospital's **Dear Everybody** anti-stigma campaign with the goal of creating a more inclusive world for all children and youth with disabilities.
  - Members of the CAC engaged in the creation of the hospital's advertising campaign, which included radio, print and TV creative (*images 1 and 2*).
- Partnered with the hospital to help shape the organization's quality improvement plan to reflect our needs (*image 3*).
  - Kids as young as 8 years old took part in interviews to talk about what safe, high quality health care experiences look and feel like to them and helped create this one-pager just for kids.
  - CAC members also presented to the Quality Committee of the Board of Trustees.

## What's next

- For the 2018-2019 year, we will be helping to release Holland Bloorview's first kid-friendly strategic plan.
  - This kid-friendly version of the hospital's **No Boundaries** plan is designed so young clients

can understand where we are heading in the coming years, and can see how the feedback we provided in the strategic plan engagement process was integrated into the final plan.

- We are also hoping to create a virtual tour of Holland Bloorview that will be led by us and help kids get to know what they can expect when they come to Holland Bloorview for the first time.
- We will continue our partnership with the Bloorview Research Institute with another video game testing event.

**To learn more, contact Daniel Scott, CAC coordinator, at [dascott@hollandbloorview.ca](mailto:dascott@hollandbloorview.ca).**



# Youth Advisory Council

## Who we are

The Youth Advisory Council (YAC) is part of Holland Bloorview's Youth Engagement Strategy (YES). As a part of YES, youth leaders (current and former Holland Bloorview clients, aged 14 to 29) work on hospital goals with families, clinicians, scientists and hospital leadership. These goals include: developing programs and policies, implementing and evaluating programs and policies, assessing how hospital services are offered, and partnering to develop teaching and learning initiatives.

Youth leaders get to build leadership and advocacy skills through participating in YAC meetings, group projects and other hospital events.

In 2017-2018 there were 32 YAC members.



## How we've made a difference

- Partnered to support the Accreditation survey of the hospital's quality and safety practices by:
  - Acting as Accreditation Navigators to provide clients and families with information about Accreditation during the on-site survey (*image 1*).
  - Participating in meetings with Accreditation Canada surveyors.
- Successfully completed the No Boundaries Fund kids and youth inpatient teen lounge re-design, which includes:
  - a new green presentation wall
  - new TVs and video game stations
  - new chairs
- Worked with Bloorview Research Institute Trainee Executive (BRITE) on two education sessions for BRITE members:
  - 'How to work with youth leaders'
  - 'Making research project thank you letters meaningful to youth participants'
- Partnered with the hospital to help shape the organization's quality improvement plan to reflect our needs.

- Provided feedback and input to four research institute projects and initiatives.
- Suggested the name 'connect2research' for the new BRI permission-to-contact platform (see the RFEC section for more details on connect2research).
- Partnered with Koffler Centre of the Arts on a vibrant and powerful art show documenting the unique experiences of young people with disabilities as they transition to adulthood called '18 | eighteen: a collaborative studio art project' (*image 2*).
- Supported the Unmasking Brain Injury mask-making project to raise awareness about brain injury and what it means to those who have one (*image 3*).

## What's next

- Continue to provide insight on hospital priorities and initiatives.
- Provide educational opportunities to hospital and research institute staff on how to best engage youth in their projects.
- Continue to work with external partners to increase and enhance opportunities for youth engagement.

**To learn more, contact Dolly Menna-Dack, clinical bioethicist and YES lead, at [dmennadack@hollandbloorview.ca](mailto:dmennadack@hollandbloorview.ca).**

# Family Advisory Committee

## Who we are

The Family Advisory Committee (FAC) helps ensure client and family centred care is at the heart of everything that Holland Bloorview Kids Rehabilitation Hospital does. FAC members share their expertise and provide guidance on major hospital projects and initiatives, and set their own yearly goals that help advance client and family centred care at the hospital and in the wider community.

In 2017-2018 the FAC had 40+ members (30+ family leaders, 2 Youth Advisory Committee members, 6 senior management team members, 1-2 Board of Trustee representatives and 2-3 programs and services managers at every meeting).

## How we've made a difference

- Provided input on 11 major projects, including:
  - The hospital's digital health strategy
  - Holland Bloorview's values
  - **Dear Everybody** anti-stigma campaign
  - Holland Bloorview's mental health strategy
  - The hospital's transition strategy
  - Inpatient communication whiteboards
  - **Capes for Kids** fundraising campaign



- Continued to support caregivers through our Care for the Caregiver initiative, which included:

- Hosting an information booth at Holland Bloorview's 2018 Recreation, Respite and Life Skills Information Fair (*image 1*).
- Hosting an outpatient coffee talk attended by 30 people (*image 2*).
- Partnering with hospital teams to pilot the Saturday Night Fun program – 10 parents enjoyed a well deserved break while their children, including siblings, attended the respite program for free (*image 3*).
- Facilitating education for Holland Bloorview's Board of Trustees on caregiver needs and how Holland Bloorview is responding.
- Hosting a resiliency workshop, which included mindfulness, yoga and diet education.

- Identified opportunities to enhance Holland Bloorview's Family Leadership Program:

- Completed a literature review to identify areas of improvement.
- Made recommendations to the client and family integrated care team around family engagement.

- Provided pediatric caregiver's priority feedback to the Minister's Patient and Family Advisory Committee, which reports to the Ministry of Health and Long-Term Care.
- Hosted two inpatient coffee nights where families and clinicians had a chance to take a break and connect with each other.
- Successfully piloted the Outpatient Welcome Orientation in two clinics.

### What's next

- Explore opportunities for a technology-based initiative in partnership with hospital staff.
- Grow and innovate the Family Leadership Program.
- Host a dinner for inpatient families.
- Partner with staff on the inpatient units to replace current inpatient sleeper beds.

**To learn more, contact Amir Karmali, manager of client and family centred care and partnerships, at [akarmali@hollandbloorview.ca](mailto:akarmali@hollandbloorview.ca).**



# Bloorview Research Institute Family Engagement Committee (RFEC)

## Who we are

Bloorview Research Institute Family Engagement Committee (RFEC) works in partnership with the Bloorview Research Institute (BRI) to engage families in all aspects of research. The RFEC advises and makes recommendations to promote family engagement in research and impact research decisions to ensure that research will make a difference in the lives of children, youth and families at Holland Bloorview and beyond.

In 2017-2018, the RFEC had 24 members that included 12 family leaders, the vice president and director of research, BRI team members and client and family integrated care team members.



connect2research

3

## How we've made a difference

- The RFEC identified the need to develop a process to translate research into understandable information for clients and families. We were awarded a grant to create a suite of lay summaries, to break down barriers and ensure all families have access to research findings that have the potential to make a difference in their lives. To date the RFEC has:
  - Developed evaluation criteria to select research publications from the BRI and selected the first 12 publications using this criteria.
  - Co-developed research lay summaries with the input and expertise of clients and families, a knowledge translation specialist and scientists (*image 1*).

- Established a research journal club for RFEC members, co-led by a family leader and BRI scientist, to expose family leaders to research publications from the BRI and provide education on different research methodologies.
- Co-chair of the RFEC, Sharon Gabison, was invited to join the Canadian Academic Hospitals of Ontario (CAHO) patient engagement in research community of practice:
  - Gabison presented Holland Bloorview's Family Engagement in Research framework and committee structure and shared best practices, key successes and challenges.
- Members of the RFEC presented at Holland Bloorview's 12th annual research symposium:
  - Susan Cosgrove was the first family leader to present research results from a study she contributed to: 'How should we talk about obesity and weight-related topics with children with autism spectrum disorders and their families?' (*image 2*).
  - Manuela Comito co-hosted the event with Dr. Tom Chau, vice president and director of research.
- Partnered with the BRI to develop and launch a permission-to-contact program, connect2research, which will provide all clients and families the opportunity to learn about and participate in the innovative and life-changing research at Holland Bloorview (*image 3*).
- Provided input and guidance on the BRI growth strategy.

### What's next

- Complete an evaluation of the Family Engagement in Research framework and structure to define the value of family engagement in research and to make improvements.
- Advise and partner with BRI on the planning and development of a fully accessible, child-friendly on-site MRI facility for research.
- Explore opportunities and best practices for engaging clients and families in identifying research priorities.
- Continue to advance the lay summaries initiative and promote the first 12 research lay summaries internally and externally.

**To learn more, contact  
Beth Dangerfield, family  
partnerships specialist, at  
[familypartner@hollandbloorview.ca](mailto:familypartner@hollandbloorview.ca).**



# About Holland Bloorview Kids Rehabilitation Hospital

Holland Bloorview Kids Rehabilitation Hospital creates a world of possibility by supporting children and youth living with disability, medical complexity, illness and injury. Holland Bloorview is a top 40 Canadian research hospital that is fully affiliated with the University of Toronto and serves over 7,500 families annually. Providing both inpatient and outpatient services, Holland Bloorview is renowned for its expertise in partnering with clients and families to provide exceptional care and is the only organization to ever achieve 100 per cent in two successive quality surveys by Accreditation Canada. Holland Bloorview is a founding member of Kids Health Alliance, a network of partners working to create a high quality, consistent and coordinated approach to pediatric health care that is centred around children, youth and their families. For more information or to donate, please visit [hollandbloorview.ca](http://hollandbloorview.ca) or connect on Twitter, Facebook, Instagram, LinkedIn and parent-blog BLOOM.



**Holland Bloorview**  
Kids Rehabilitation Hospital

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A teaching hospital fully affiliated with the University of Toronto