



Holland Bloerview

Kids Rehabilitation Hospital

Family Leadership Program

Year in Review 2018–2019

“

I am humbled that my voice matters in the decisions made to improve the quality of client care and family experience. Authentic partnerships, co-creation, co-design, and meaningful impact have been the key driving forces behind the Family Leadership Program. By embedding the experiential expertise of children, youth and families into decision-making, we're moving the dial for capacity on systemic changes in all facets that directly relate to client and family experience.”

Alifa Khan, 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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“We are so grateful for the amazing support and responsiveness of the Family Leadership Program. This year, we worked in partnership to deliver monthly sessions to support families through the changes in autism funding. The sessions had a huge positive impact on our families’ lives and the teamwork that has been created between our family leaders and clinicians is indispensable. Thank you!”

Lindsey Crawford, senior director, ambulatory care services

“I continue to be inspired by the depth of time, energy and ideas that child, youth and family leaders invest at Holland Bloorview. Over the past two decades they’ve partnered with hospital staff, students and volunteers to define what meaningful co-design means, not just at Holland Bloorview but in the health system at large.

Aman Sium, director of client and family integrated care

“The Family Leadership Program is an impressive and enthusiastic group that bring a unique understanding of what is important to families and the quality of the outcomes is always enhanced by their contributions. This year we have had many opportunities to improve the quality of life families experience on the inpatient unit, such as co-designing new sleeper chairs, introducing relaxation kits to enhance the quality of sleep, and enhancing the family dining experience for families over holidays (to name just a few!). It is an honour to work with them and I look forward to more exciting projects in the next year.

Elaine Widgett, senior director of rehabilitation and complex continuing care



Letter from the President and CEO

Another year has come and gone and, thinking about the impact we have made together, I feel proud and humbled to partner alongside such an extraordinary group of child, youth and family leaders.

Through your commitment to excellence and inclusion, we have created a family- and client-centred program that is the envy of the health care sector.

Between being recognized for organizational leadership by Children's Healthcare Canada, working together to reimagine hospital food and successfully launching the third year of the *Dear Everybody* anti-stigma campaign, there is so much that has made the last year a memorable one for the Family Leadership Program. You should be so proud of all that you've accomplished and the support you've provided to other Holland Bloorview families throughout the year. You are truly making an impact.

The efforts of our child, youth and family leaders are deeply appreciated at Holland Bloorview. Thank you for partnering with us to become leaders in patient engagement and for ensuring that families are at the heart of care, services, research and more.

I also want to recognize the Client and Family Integrated Care team for consistently providing exceptional support to our Family Leadership Program, clients, their families and the entire Holland Bloorview community. Our organization is stronger for your work advocating for and fostering client and family-centred care, listening to clients and families and ensuring they are heard, and embedding the perspectives of the children, youth and families we serve at all levels of the work of the hospital in care, services and research.

The Family Leadership Program and its integrated approach to client and family-centred care at Holland Bloorview continues to thrive and grow every year in no small part thanks to the generous support of our donors. Thank you to the community for helping us to create a world of possibility for children, youth and families.

Congratulations to everyone for another outstanding year together.

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 the Bloorview Research Institute (BRI) to shape and improve policies, programs and services, and advance client and family-centred care.

Volunteer family leaders participated on
over 268
new projects, initiatives and committees



Children, youth, and families
volunteered for a total of approx

2750
hours

Families recognized

1,069

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



236

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

*Number reflects parents who have
attended more than once

136

staff and students trained
using client and family-
centred care simulations

52
families attended
**Outpatient Welcome
Orientation**
co-hosted by family leaders



Family as faculty shared
their family story

28

times at educational activities,
internal/external presentations
or public relations initiatives

There were
88
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 Bloorview Research Institute

41
family leaders
shared experiences and ideas
on the research process, and
advised Bloorview Research
Institute Leadership



30
hospital documents
were reviewed by
family leaders for
health literacy

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 Over 70 clients, families and youth leaders joined forces to raise over \$60,000 for Holland Bloorview through *Capes for Kids* in 2019. *Capes for Kids*, originally co-created and developed with family leaders, has raised over \$1.7 million in three years to fund programs like arts and music, Spiral Garden, the family support fund, the independence program and so much more. Clients and families also played an active role in fundraising through *Lemonade for Possibility* and at the first ever *Leaside Block Party*.



2 Family leader Susan Cosgrove provided her lived experience perspective on the MRI Steering Committee, tasked with oversight on the overall design and execution of the Bloorview Research Institute's new world-class, fully accessible and pediatric-friendly MRI suite. Susan offered critical insight for the new MRI suite, including the installation of an innovative glass door on the MRI scan room itself.



3 Family leaders Oksana Romanov and Angel Chu were integral to the adjudication process as members of the Graduate Student Awards Review Committee. Oksana and Angel reviewed 10 award applications and worked with the committee to award seven prestigious awards to seven graduate students studying under the supervision of BRI scientists.

4 From its early development, child, youth and family leaders advised on the hospital's *Dear Everybody* anti-stigma campaign. In the first two years of the campaign, we used the words and images of children and youth with disabilities to challenge stigma.

This year, we are calling on Canadians to imagine how our visual landscape might be different if it were more inclusive and sign a pledge to include disability in the picture. *Dear Everybody* is part of the hospital's five-year anti-stigma strategy.

5 The Client and Family Integrated Care (CFIC) team and the Family Leadership Program hosted Client and Family-Centred Care Day to recognize the ongoing commitment of staff and hospital leaders to client and family-integrated care and to recognize the contributions of family leaders at Holland Bloorview.

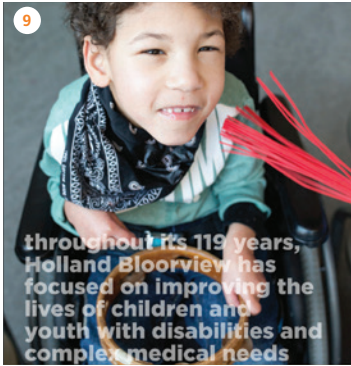


6 On January 31, 2019, the Youth Advisory Council Executives served as the hospital's Youth CEOs for the day. In their tenure, the Youth CEOs offered consultations on a number of hospital projects and initiatives, such as the Mental Health Strategy and the Transition Strategy. They also hosted a Cookie Mix and Mingle for all staff, students and trainees. It was a great opportunity for Emily, Logan, Samantha, and Jessica (and their Most Senior Executive Assistant, Julia) to promote the Youth Engagement Strategy and share yummy cookies!

7 CFIC staff and Family Leaders participated in the Institute for Patient and Family-Centred Care Conference in Baltimore.

Family leader, Adrienne Zarem, co-presented with the Health Standards Organization team about "Patients as Full Partners in Standards Development". *L to R: Aman Sium, Alifa Khan, Sharon Gabison, Zach Lawrence, Joshua Engel-Yan.*

8 Holland Bloorview Kids Rehabilitation Hospital received the Innovative Team Award from The Beryl Institute. This award recognizes the quality, safety and performance (QSP) team at Holland Bloorview and their leadership in creating the Family Leader Accreditation Group (FLAG), which improves quality across Holland Bloorview by bringing clients and families together as full and equal partners.



9 The Change Foundation featured Holland Bloorview as one of three case studies on collaborating with patients and families in the provision of pediatric care in their report, "Achieving True Partnership: Three case studies of patient and family-centred pediatric care in Ontario"

10 Global News talks about the importance of self-care and mental health for caregivers of children with a disability. Holland Bloorview's Jean Hammond is quoted as well as family leaders, Payal Khazanchi and Amy Illingworth.

11 Holland Bloorview Kids Rehabilitation Hospital wins Children's Healthcare Canada Award for Organizational Leadership. Holland Bloorview's Client and Family-Centred Care Training Program was recognized for its leadership in inspiring change and innovation and its ongoing commitment to partnerships and collaboration within the healthcare community.

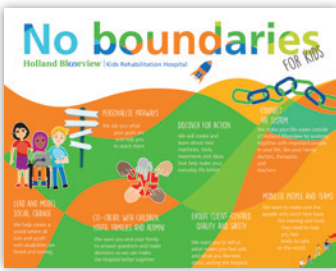
12 Suzanne Jorisch is the first appointee to the Board of Trustees from the family leadership program, bringing her expertise in finance and business from her long career in the private sector, but also her lived experience as a parent/caregiver and her experience as a committed family leader.

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 2018-2019 the CAC had 61 members and its membership continues to grow.



How we've made a difference

Creation of Holland Bloorview's 1st Kids Strategic Plan

Working in partnership with our Communications team, Health Literacy lead, and members of the CAC, Holland Bloorview transformed our five-year Strategic Plan into a kid-friendly puzzle. The goal was to create something fun and interactive that would allow kids and families to access the information in a new way. This was an extension of the work that members of the CAC did to help shape the plan and our goal was to ensure that the information was accessible to as many of our stakeholders as possible.

Nintendo Switch Commercial

Members of our CAC and FLP were invited to take part in filming a commercial as part of a national advertising campaign for Nintendo Switch. The goal was to authentically show how video games have been a part of their social and play experience in the Ronald McDonald playroom and was a great opportunity to increase disability representation in the media.

Nourish Symposium

Members of the CAC and FLP were invited to participate in an event imagining what hospital food could look like in the year 2030. The goal was to come up with sustainable, easy and convenient meal ideas. Kids and families got to work with professional chefs to come up with real meal ideas and a member of the CAC was on a panel discussion about how important kid-friendly hospital food is.

What's next

- Continue our partnership with the BRI when we host another video game Beta Test night
- Evolve our intake process and request form
- Give feedback on how to make the MRI suite kid-friendly

To learn more, contact the Family Leadership Team at familypartner@hollandbloorview.ca

Youth Advisory Council

Who we are

The Youth Advisory Council (YAC) is part of Holland Bloorview's Youth Engagement Strategy (YES). As part of YAC, 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 2018-2019 there were 26 YAC members.



How we've made a difference

- Hosted the onsite art exhibit entitled 18| eighteen that coincided with International Day of Persons with Disabilities
- Held a dedicated working meeting to provide input into the creation of the Alumni Network
- Supported the annual Transition, Life Skills and Recreation Fair
- Hosted a number of guests at the meetings including Larissa Haluszka-Smith (volunteer resources coordinator), Diane Savage (vice president, programs and services), Meenu Sikand (executive lead, equity, diversity, and inclusion), FAC co-chairs, FLP team members, BRI staff members, and the Foundation
- Consulted with the Transitions Strategy employment stream to determine priorities for Holland Bloorview's employment programs
- Consulted with Surrey Place to develop youth programs
- Supported Capes for Kids

- Represented YAC and welcomed the community to the onsite ReelAbilities Screening on May 24th
- Contributed to the Quality Improvement Plan
- Contributed to BRI research projects and initiatives, including the MRI suite

What's next

- Partnering with the Koffler Centre of the Arts to launch series of art workshops
- Continue to embed youth voices into hospital projects and initiatives

To learn more about the Youth Engagement Strategy, contact youthleader@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 2018-2019 the FAC had over 50 members (35 family leaders, 2 Youth Advisory Committee members, 6 leadership team members, at every meeting)

How we've made a difference

- Provided input on over 10 major projects, including:
 - The hospital's transition strategy
 - Holland Bloorview's Always Events
 - Bloorview Research Institute expansion
 - Family-reported patient safety concerns
 - Meditech Expense (electronic health record upgrade)
 - Evolving client-centred quality and safety
 - #HBWelcome (client and family orientation)
 - Client experience survey questions
 - Youth employment services and supports
 - Health Quality Ontario's resource on patient partnering in quality improvement
- Continued to support caregivers through our Care for the Caregiver initiative, which included:
 - Launched weekly, free, yoga classes for caregivers of all experience levels to provide them with an opportunity to relax and recharge in a nurturing environment



- Hosted caregiver booth at Respite and Recreation Fair, providing resources and information specific to caregivers at this popular annual event
- Hosted caregiver workshop for families on self-care, nutrition and compassion fatigue, where approximately 20 caregivers were given resources, education and the chance to connect with one another
- Facilitated sibling caregiver support group running concurrently with nine family workshops, giving siblings of Holland Bloorview clients the chance to connect with one another and share feelings and experiences unique to being a sibling caregiver
- Co-developed and facilitated Solution-Focused Conversations for Families workshop series. Created a five part training workshop on solution-focused conversations for families and how to have these conversations with family members, care providers, schools and community service providers
- Implemented ways to enhance Holland Bloorview's Family Leadership Program and the client and family experience:
 - Launched the Virtual Advisory Committee
 - Co-chairs delivered update on the Family Advisory Committee to all staff at HB Live!
 - Family leaders partnered with Holland Bloorview and Foundation staff to introduce 63 new inpatient sleeper beds and relaxation kits in March 2019
 - Hosted inpatient potluck dinner – a chance for approximately 60 inpatient family members to share a home-cooked meal and network with family leaders and each other
 - Hosted inpatient coffee night – a chance for inpatient family members and staff on the inpatient units to have a “night off” to connect with each other and family leaders and enjoy some delicious treats

What's next

- Explore opportunities for improving the inpatient and outpatient food experience in partnership with hospital staff
- Partner with staff to implement components of the Transitions Strategy
- Grow and develop the Family Leadership Program

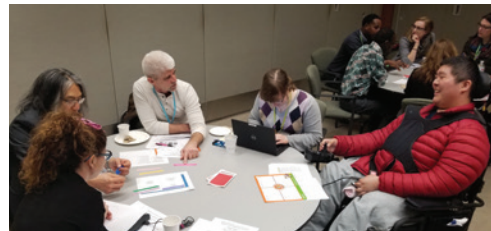
To learn more, contact the Family Leadership Team at familypartner@hollandbloorview.ca

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 2018-2019, 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.



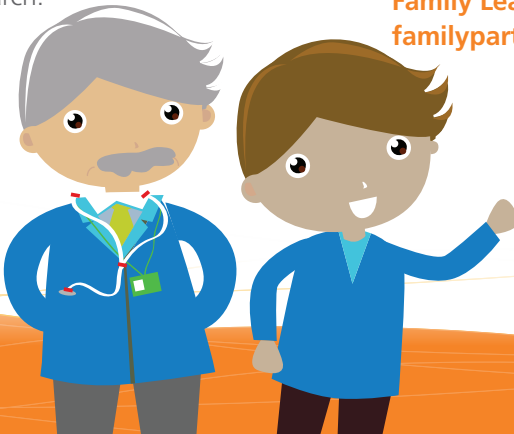
- Family leaders Suzanne Jorisch (family leader and member, board of trustees), Kyoko Davis and Rebecca Nesdale-Tucker were part of a multidisciplinary team that launched 'Research Unlocked' in June of 2019. This RFEC initiated project ensures that scientific publications by Holland Bloorview scientists are accessible and relevant to clients and families. As part of this pilot project, 11 summaries will be made available over the course of this year.
- Family leaders, including the RFEC Chair Sharon Gabison, co-presented with BRI staff at a number of important internal and external events including the BRI symposium, the Ward Summer Student Program Orientation Day, the Clinical Trials Ontario Conference and the University of Toronto Rehabilitation Sciences Institute Research Day.

- The RFEC reviewed and provided feedback on the CIHR ethical framework for family engagement in research, including a number of specific insights that reflected the needs of clients and families impacted by pediatric disability.
- The BRI, in partnership with the RFEC, commissioned an external evaluation of our Family Engagement in Research Program which included a literature review, environmental scan and interviews with clients, families and scientists. The evaluation validated many aspects of our current program and led to a number of valuable recommendations that were incorporated into the 2019-2020 RFEC goals.
- The BRI was successful in securing external, peer-reviewed grant funding from CHILD-BRIGHT Network, a SPOR-funded initiative, to create and evaluate a suite of five simulation-based learning modules to address complex relational challenges experienced by clients, families and scientists while engaging in family-centered research.

What's next

- Publish the results from our external evaluation of our Family Engagement in Research Program
- Review and update the current family engagement in research framework to better meet the needs of our clients, families and scientists
- Develop a suite of resources to provide increased support for partnerships between scientists and clients and families who are partnering in the research process
- Family leaders will continue to consult with BRI leadership to support the Grow Holland Bloorview Research strategy. This strategy will expand our efforts in innovative, applied and client and family-centred research and intensify our efforts to discover for action with the ultimate goal of improving care, informing personalized pathways and enhancing quality of life for all kids, youth and families.

To learn more, contact the Family Leadership Team at 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 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