



**Holland Bloerview**

Kids Rehabilitation Hospital

## **Family Leadership Program**

**Year in Review 2016 - 2017**



“

Words can't express how honoured and privileged I feel to have the opportunity to engage, converse and collaborate with people at Holland Bloorview who exude such passion and conviction. Thank you doesn't even begin to scratch the surface for all the invaluable work you're all doing to create meaningful impact for all clients and families.”

Alifa Khan, family leader

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“Family leaders have been an integral part of enhancing my work. They bring a perspective I otherwise would not get and have helped me in many ways to engage more effectively and compassionately with families. Any work that I do is greatly improved with input from families and family leaders. Thanks for all that you do.”

Salina Eldon, research coordinator

“We have strong, enduring and meaningful partnerships with family leaders. It is inspiring to see us work as one to advance the hospital’s important initiatives.”

Stewart Wong, vice president of communications, marketing and advocacy

“Family leaders bring a perspective that as staff we can only otherwise guess at. Our family leaders have been so committed to the work and have been such incredibly valuable partners.”

Sarah Keenan, life skills coach

“Thank you for embracing the Foundation and being the best partners we could ever dream of. Your ideas, experiences and stories make our work possible. Joining forces with you on Capes for Kids, Round of Applause, Care for the Caregiver and so many other initiatives was the highlight of my year at Holland Bloorview.”

Lindsey Hutchison, manager of philanthropy, Holland Bloorview Foundation

# Letter from the President and CEO

Holland Bloorview Kids Rehabilitation Hospital would not be what it is today without the valuable time child, youth and family leaders contribute to making care, services and research better for all, here and beyond our walls. Congratulations to all of you for your outstanding accomplishments over the past year. We are so lucky to partner with such engaged child, youth and family leaders who advance and co-create incredible projects and who make us all better at what we do.

Your impact stretches far beyond the four walls of this hospital – you are also helping to shape the community, education and health-care systems by sharing your knowledge with other organizations and government representatives.

Your efforts will continue to have an impact in the years to come. Child, youth and family leaders were instrumental in helping shape our five year strategic plan, **No Boundaries**. Over the next five years, your commitment to building a more connected system and a more inclusive world will shift how people think, how people act and help to create a more just and fair society.

Thank you to our client and family integrated care team for supporting our clients, families and the entire Holland Bloorview community with the expertise and dedication needed to keep children, youth and families at the heart of all that we do.

I would also like to thank our generous donors for their support of the Family Leadership Program and client and family centred care at Holland Bloorview – your contributions create a world of possibility for all children, youth and families.

Sincerely,



Julia Hanigsberg  
President and CEO

# Family Leadership Program

## Who we are

The Family Leadership Program is the framework through which 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 183**  
special projects, initiatives and committees

Hospital advisors  
shared experiences  
and ideas on

**65**  
hospital initiatives

Research advisors  
shared experiences  
and ideas on

**30**  
research initiatives

Peer mentors  
provided

**343**  
peer to peer  
consultations

**167\***  
parents attended  
the inpatient parents  
talks co-led by  
peer mentors

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



Family leaders co-developed the hospital's client and family centred care simulation training for employees, which won the international Sherman Award for Excellence in Patient Engagement in 2017

**17**

family and youth advisors are full partners in Accreditation planning to continually improve quality and safety

**149**

staff and students trained using client and family centred care simulations

Research reviewers brought the family perspective to

**18**

research proposals

**52\*\***

families attended an outpatient welcome orientation

Families as faculty shared their family story

**68**

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

Research communicators helped make research understandable and shared research with other families on

**35**

communication initiatives

**212**

families received free legal assistance from the onsite program offered by Pro Bono Ontario

\*\*Program started in January 2017

8 family leaders reviewed

**24**

hospital documents for  
health literacy

Children, youth and families  
volunteered for a total of

**3,232**

hours

Families recognized

**754**

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



Family leaders increased  
their total number of  
hours volunteered by

**40%**

in the last year



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

BLOOM has

**1,121**

followers on Facebook

There are

**565**

members on the  
Parent Voices Facebook group

In the last year,  
BLOOM published

**24**

stories by parents or about  
parent's experiences

BLOOM has readers in

**181**

countries

# Spotlight on engagement

Child, youth and family leaders are often involved in projects and initiatives that aren't part of 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** Family and youth leaders participated in a simulation development to help train educators and health and service providers across Ontario in child, youth and family centred care. This training was developed by Holland Bloorview in partnership with the province's Ministry of Children and Youth Services.

**2** Family leaders joined forces in support of Holland Bloorview's Capes for Kids, a fundraising campaign, in March 2017.

**3** Accreditation is a review process of our quality and safety practices. This Accreditation cycle family leaders are participating on six Accreditation teams and in the Family Leader Accreditation Group (FLAG). Pictured here is Adrienne Zarem (*third from left*), chair of FLAG, at an Accreditation launch event.

► FLAG member Alifa Khan partnered with the Canadian Patient Safety Institute to update the existing patient safety education modules to reflect the patient and family perspective.



4 Family leaders participate in speaking engagements at Holland Bloorview and beyond. Alifa Khan spoke at the **No Boundaries** five-year strategic plan launch in June.

5 Family and youth leaders also frequently participate in tours when government officials come to visit Holland Bloorview. Pictured here is youth leader Emily Chan speaking to the Patient Ombudsman of Ontario, Christine Elliott.

6 Pictured here is a family leader and Holland Bloorview staff speaking with the Honourable Mitzie Hunter, M.P., Minister of Education.

7 Family leader Susan Cosgrove spoke at Queen’s Park during a Council of Academic Hospitals of Ontario (CAHO) Health Research Showcase for over 30 Ministers, Members of Provincial Parliament and government officials.



8 Child, youth and family leaders have been instrumental to the development of the hospital's Dear Everybody anti-stigma campaign and position paper. The campaign brings people face to face with their biases towards kids and youth with disabilities by putting the voices of children, youth and families front and centre. Dear Everybody is part of the hospital's five-year anti-stigma strategy.

9 Child, youth and family leaders participated in a fun engagement event where they repainted the hospital's accessible parking spots with the Dynamic Symbol of Access. This event was organized in partnership with The Forward Movement, an accessibility advocacy and awareness campaign working to bring the updated symbol to Ontario and Canada to change perceptions about disability.

# 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 2016-2017, the CAC had 58 members.

## How we've made a difference

- Explored our hopes, perspectives and experiences in a video series to inform and help set tone for the **No Boundaries** strategic planning process.
  - The videos were screened throughout the planning process to ensure our voices were front and centre as the Holland Bloorview community came together to plan the hospital's direction for the next five years.
- Partnered with the hospital to help shape the organization's quality improvement plan to reflect our needs.
  - Pictured here is our easy-to-understand Kid's Quality Improvement Plan. (*image 1*)
- Discussed our past experiences with child centred care for a video series used in training sessions for educators, health and service providers across Ontario. (*image 2*)
  - These training sessions were developed by Holland Bloorview in partnership with Ontario's Ministry of Children and Youth Services.
- Shared our stories to help develop the hospital's Dear Everybody campaign and anti-stigma position paper with the goal of creating a more fair and inclusive world for all children and youth with disabilities. (*image 3*)

**Holland Bloorview Kids Rehabilitation Hospital's Quality Improvement Plan (QIP) for 2017-2018**  
**Excellent care and safety is #1**

We want to make sure you are getting the best care possible. Every year, we make a plan called the Quality Improvement Plan about how we are going to do that. This year, we are going to do a lot:

**SAFETY**  
**Medication safety**  
 Talking more about taking medication safely and offering a step-down to oral home.

**ACCESS**  
**Wait time improvements**  
 Making it easier to get an appointment by staying open on weekends and evenings in some clinics.

**CLIENT AND FAMILY-CENTRED CARE**  
**Feedback follow up**  
 Always listening about what you like about your care and what you want to change.

**TRANSITION**  
**Transition support**  
 Going out a handy booklet called the Transition Passport to make going home easier.

**EFFECTIVENESS**  
**Goal setting**  
 Setting a smart goal based technology to track fitness goals between appointments.

**COMMUNICATION**  
 Kids are partners in care. Every year, our child, youth and family leaders tell us how we can make care better at Holland Bloorview. Here are our key focus priorities for 2017-2018.

**CLIENT AND FAMILY-CENTRED CARE**  
**Feedback follow up**  
 Always listening about what you like about your care and what you want to change.

**GOALS**  
**Goal setting**  
 Setting a smart goal about setting goals that you want and sharing that information with your whole care team.

**COMMUNICATION**  
 Kids are partners in care. Every year, our child, youth and family leaders tell us how we can make care better at Holland Bloorview. Here are our key focus priorities for 2017-2018.

**1** **Holland Bloorview**  
 Kids Rehabilitation Hospital

Holland Bloorview Kids Rehabilitation Hospital is a charity (registered in Ontario) and a not-for-profit organization. We are a member of the Holland Bloorview Kids Rehabilitation Hospital Foundation (not-for-profit) and a member of the Holland Bloorview Kids Rehabilitation Hospital Foundation (not-for-profit). For more information, please visit our website at www.hollandbloorview.ca. The full Quality Improvement Plan is available at www.hollandbloorview.ca.



- CAC members presented to the Board of Trustees on the CAC's involvement in hospital decision-making. They talked about their input into the Ronald McDonald Playroom design, food services choices, the hospital's quality improvement plan and the five-year strategic plan, **No Boundaries**.

## What's next

- Exploring opportunities to evolve client centred quality and safety through patient safety education.
- Playtest and advise on therapy-based video games in partnership with the Bloorview Research Institute.

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 years) work on hospital goals with families, clinicians and hospital leadership. These goals include:

- Developing programs and policies
- Implementing and evaluating programs and policies
- Assessing how hospital services are offered
- 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 2016-2017, YAC had 27 members.

## How we've made a difference

### Provided exceptional client and family centred care

- Assisted with two youth drop-in social events held at Holland Bloorview.
- Volunteered at the Recreation, Respite and Life Skills Information Fair for clients, families and community members.
- Contributed 258 volunteer hours to Holland Bloorview through regular meeting attendance.

### Helped shape the future of Holland Bloorview

- Offered our ideas, hopes and insights at a strategic planning idea generation session for Holland Bloorview's five-year strategic plan.
- Helped create the Holland Bloorview **No Boundaries** strategic plan through representation on an eight-month strategic planning task force. (*image 2*)
- YAC members are providing a youth voice to the new Transition Strategy and the hospital's Dear Everybody anti-stigma campaign.

**To learn more, contact Dolly Menna-Dack, clinical bioethicist, youth engagement strategy lead, at [dmennadack@hollandbloorview.ca](mailto:dmennadack@hollandbloorview.ca) or 416-425-6220 ext. 3292**



### Partnered in the community

- Members of the YAC weighed in on National Accessibility Legislation by creating a video submission about what an accessible Canada means to them. *(image 1)*
- YAC chair Julia Kowal facilitated the youth panel, featuring other Holland Bloorview youth, for the ReelAbilities Family Film and Arts Day at the hospital. *(image 3)*
- YAC participated in the Capes for Kids fundraiser by creating the League of Youth Leaders team.

### Fostered meaningful engagement

- Partnered with the hospital to help shape the organization’s quality improvement plan to reflect our needs.
- Contributed our thoughts to four research institute projects and initiatives.

### What’s next

- Help bring the new **No Boundaries** strategic plan to life.
- Continue to provide insight on hospital priorities and initiatives.

# 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 sets their own yearly goals that help advance clients and family centred care at the hospital and in the wider community. In 2016-2017 the Family Advisory Committee had 40 members (30 family leaders, 1 Youth Advisory Committee member, 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 and guidance on 11 major projects, including:
  - ▶ Capes for Kids fundraising campaign
  - ▶ Holland Bloorview's **No Boundaries** five-year strategic plan
  - ▶ The hospital's Transitions Strategy
  - ▶ Holland Bloorview's Mental Health Strategy
  - ▶ Dear Everybody anti-stigma campaign
- Partnered with the client and family integrated care team to plan PACE Forum (Patients and Providers Advancing Care Experiences) in November 2016.
  - ▶ PACE Forum brought together 76 service providers and family advisors from 30 organizations across Ontario to share best practices in patient engagement.
- Participated on the hiring panel for the hospital's director of client and family integrated care, Aman Sium.
- Launched the welcome orientation for outpatient families in January 2017 to help them prepare for appointments and access resources both at the hospital and in the community.
- Hosted two coffee nights where families and clinicians had a chance to take a break and connect with each other.
- Planned the Client and Family Centred Care Day in June 2017. Family leaders handed out over 800 chocolate bars to thank staff for putting client and family centred care into action every day and enjoyed a family leaders appreciation event in the evening. (*image 1*)
- Launched the Care for the Caregiver Hub, an online resource to connect parents and siblings with the supports they need to look after themselves as caregivers. (*image 2*)



- Partnered with the hospital to advance options for flexible hours of service so families can have better access to the care and services they need. (image 3)
- Delivered an educational workshop for schools about creating inclusive classrooms, titled *“The Parent Perspective: Inclusion and Acceptance in the Classroom,”* to nearly 100 educators in the Greater Toronto Area.
- Shared expertise with the Ministry of Health and Long-Term Care in Patients First Act consultations.
- Collaborated with the Holland Bloorview Foundation to inform fundraising goals and strategy.

## What’s next

- Continue building our Care for the Caregiver program.
- Explore opportunities to grow and innovate the Family Leadership Program.
- Implement communication whiteboards to help improve information transfer for inpatient families.

**To learn more, contact Amir Karmali, family centred care specialist, at [akarmali@hollandbloorview.ca](mailto:akarmali@hollandbloorview.ca) or 416-425-6220 ext. 6420.**

# Bloorview Research Institute Family Engagement Committee (RFEC)

## Who we are

The 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 2016-2017, the Research Family Engagement Committee had 24 members that included 12 family leaders, the vice president of research, BRI team members and client and family integrated care team members.

## How we've made a difference

- Provided input and guidance on BRI research projects, including:
  - A trial assessing states of rest and exertion for kids with concussions, called PedCARE
  - Module development for the creation of a patient-oriented research curriculum
- Completed nine family research reviews of grant proposals:
  - Provided letters of support for proposals
  - Contributed to successful Canadian Institutes of Health Research (CIHR) grants
- Gideon Sheps was honoured with the John Whittaker Memorial Award at the 2016 BRI Symposium for his active role in establishing the Research Family Engagement Framework. (*image 1*)
- Collaborated with partners, including researchers at the Hospital for Sick Children, on a national Strategy for Patient-Oriented Research (SPOR) grant to develop a patient-oriented research curriculum for children, families and clinician-scientists in child health. (*image 2*)
- Held focus groups with BRI scientists to get input on how to create research ideas with children, youth and families.



## What's next?

- Developed a survey to better understand the experiences and interests of families participating in research throughout Holland Bloorview.
  - Successfully published a framework for health-care organizations on how to engage children, youth and families in rehabilitation research.
    - Presented the framework externally at symposiums and conferences.
  - Were instrumental in the creation of an environmental scan of BRI research submissions that will track the populations and research topics conducted. This data will be collected on an ongoing basis.
- Develop a process to promote new BRI publications to families within Holland Bloorview and beyond our walls
  - Partner with the BRI to develop a strategy for study recruitment and consent.
  - Continue to advance the SPOR grant partnership by developing family-oriented curriculum modules.
  - Advise and partner on promotional activities to increase participation in research.

**To learn more, contact Lori Beesley, family centred care specialist, [lbeesley@hollandbloorview.ca](mailto:lbeesley@hollandbloorview.ca) or 416-425-6220 ext. 6337.**



## Thank you to our donors

We are immensely grateful to our donors for their 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.

### **Holland Bloorview** Kids Rehabilitation Hospital

A teaching hospital fully affiliated  
with the University of Toronto

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