

Holland Bloorview

Kids Rehabilitation Hospital

Outpatient Orientation

Information and resources for new Holland Bloorview families

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Scan the QR Code!*





Table of Contents:

About Holland Bloorview Kids Rehabilitation Hospital	3
Bill of Rights and Responsibilities.....	4
Patient Declaration of Values	5
Family Advisory Committee (FAC).....	6
Holland Bloorview programs and services	7
Clinician tips for your first appointment	9
Questions to ask at your first appointment.....	10
Meeting with Healthcare Professionals: Planning Guide	12
Helpful contacts at Holland Bloorview.....	15
Holland Bloorview and community services that you can access while on the waitlist	17
Tour of Holland Bloorview.....	22
Notes.....	23



About Holland Bloorview Kids Rehabilitation Hospital

Holland Bloorview Kids Rehabilitation Hospital (Holland Bloorview) is Canada's largest children's rehabilitation hospital focused on improving the lives of kids with disabilities. Holland Bloorview is a global leader in applied research, teaching and learning, and client and family centred care. We are a provincial resource transforming care for children with cerebral palsy, acquired brain injury including concussion, muscular dystrophy, amputation, epilepsy, spina bifida, arthritis, cleft-lip and palate, autism and other physical and developmental disabilities. Our vision is to create a world of possibility for kids with disability. For more information please visit www.hollandbloorview.ca

Why are we here today?

Put simply, we want to *welcome* you to Holland Bloorview!

- We want to give families the **tools** for the first appointment
- We want to give families **support** from other families who have been through the medical system
- We want to give families the **knowledge** of who and what services can be accessed here
- There is a referral for your family member to the **Communication, Learning and Behaviour Clinic** or the **Neuromotor Clinic** – these are both *outpatient clinics* at Holland Bloorview



Bill of Rights and Responsibilities

Your Rights

- Quality care and service
- Shared decision-making
- Information and answers
- Courtesy, dignity and respect
- Privacy and confidentiality
- Respect for your language, culture and religion

Our Expectations

- Courtesy, dignity and respect
- Accurate, up-to-date information
- Partnerships with staff
- Payment of costs not covered by your health card
- Feedback on how we're doing

Our Values

We believe in the uniqueness of the individual, the power of our families, and the importance of communities.

We believe in creativity, innovation and in challenging barriers.

We believe that by working together and being accountable, we CAN make a difference!



Patient Declaration of Values

The voice of our clients and their families



Quality of Care

Care is safe and based on the most current evidence available. Staff are friendly and on time. We know who to contact if we need help and are involved in care planning at the level we choose.

Respect

We have a say and are heard. Our hopes, fears and concerns are taken seriously, our privacy is protected, and our differences and choices are respected.

Information-sharing

Information is shared with us as soon as possible, and questions are answered honestly and clearly. We are informed of choices, risks and benefits of decisions, and when we have concerns, we are free to express these and will be attentively listened to.

Partnership

We know the names and roles of the members of our health care team, and they work together to support us while in care, through transitions and through difficult situations. We are equal partners of our health care team, and our unique knowledge, expertise and opinions are valued.



This orientation was created in partnership with our Family Advisory Committee (FAC)

The FAC is a devoted group of parents and youth that represent children and families who receive services at Holland Bloorview. The Family Advisory Committee:

- *Works with staff to promote family centered care: putting children and families first*
- *Helps plan, evaluate and improve services and programs*
- *Helps develop parent education sessions*
- *Shares practical information with other parents and staff*
- *Provides a family perspective on Holland Bloorview Kids Rehabilitation Hospital sub-committees*

Our FAC families want you to walk away today feeling...

prepared **reassured**
connected **knowledgeable**
positive **empowered**
supported
welcomed



There will be a “**Family Tip**” in each portion of this orientation. These are tips *by* clients and their families, made *for* clients and their families!



Holland Bloorview programs and services

The **Child Development Program** includes the following 2 clinics:

Communication, Learning and Behaviour (CLB) Clinic

The communication, learning and behaviour team assesses children who are suspected of having a developmental disorder such as autism.

Diagnostic services are provided by members of an interdisciplinary team and who your child sees depends on their needs. Clients are assessed up to and including the age of 18. Your child might be assessed at the Holland Bloorview main site, Michael Garron Hospital (formerly Toronto East General Hospital) Satellite Clinic, or Eglinton West Satellite Clinic based on their age and where you live.

After a child is diagnosed with Autism Spectrum Disorder (ASD), the Holland Bloorview team refers the child to community-based organizations to receive ongoing services locally.

Neuromotor Clinic

This Child Development team works with children who have neuromotor disorders, such as cerebral palsy, that are up to and including the age of 18 years.

To meet these complex needs, services can include assessment, diagnosis, consultation and intervention from various disciplines including medicine, occupational therapy, physiotherapy, psychology, social work and speech-language pathology. The disciplines work in collaboration with our community partners to provide a continuum of care.



Family Tip: Holland Bloorview is here to help. *You are not alone!* Talk to a Family Leader or Family Support Specialist about what is available to you and your family.



Did you know?

Did you know?

Holland Bloorview offers clients and families many programs and services that do not require a doctor's referral.



Holland Bloorview
Kids Rehabilitation Hospital

Follow us



- Free childcare for clients and their siblings who are on-site for appointments
- Parent Talks and workshops related to disabilities
- Family movie nights
- Concussion information and education sessions
- Free on-site legal help for qualifying families
- Family mentors you can talk to about your experiences
- Family support specialists you can ask about resources like funding
- Compliments and concerns facilitator
- Camp, life skills, music and arts programs*
- Day and overnight respite services*
- Swimming programs in our warm-water pool*
- "Snoezelen" sensory room and pool*
- Adapted recreation equipment loan program
- BLOOM blog about parenting kids with disabilities
- Parent Voices Facebook group for families
- On-site family accommodations*

* Some fees apply. Please contact us for more details.

connect2care

Access your Holland Bloorview health records and appointments online

Get involved

Join the Family Leadership Program and share your ideas about hospital and research programs and initiatives

Participate in research

Help us improve care today and in the future by participating in a research study

Give a "Spotlight"

Recognize an employee, student or volunteer with a client and family centred care champion

For more information

- Drop by the Grocery Foundation Resource Centre (first floor)
- Call the Warmline at 1-877-463-0365
- Email resourcecentre@hollandbloorview.ca
- Visit www.hollandbloorview.ca





Clinician tips for your first appointment

Before the appointment:

- Fill out the questionnaire that is mailed to you before your appointment (only for CLB clinic)
- Think about any questions that you might have and write them down
- Bring your health card, a list of the child's medicines and any allergies, your family doctor's name and phone number, and your health-care insurance information or drug card

What to expect:

- Come 15 minutes early so that you can register, and so that you can sign up to *Connect2Care* – our online patient portal!
- Plan to be here for at least 90 minutes
- Prepare your child for the waiting room
- At the first appointment, you will be talking to a physician to do a full history
- Your child may receive a short physical exam (height/weight)

What to bring:

- Reports, documents or letters from any service providers (e.g. Doctor, Teacher, Occupational Therapist, Physiotherapist, Speech Language Pathologist, Pharmacist, etc.)
- Immunization records
- A snack for your child
- Running shoes for your child
- Comfortable clothing for your child



Family Tip: Present a *realistic*, balanced picture of your child at your first appointment. The clinicians need to see the real picture of your child to be able to help! Bring any schedules, journals, photos, videos, and/or milestones that you have recorded.



Questions to ask at your first appointment

Some of these questions will be incorporated into the Planning Guide (pages 12-14); however families have found that these are helpful points to think about in advance.

- How long will our appointment be today?
- What will the next appointment look like:
 - When will our next appointment be?
 - How will it be structured – what will we do?
 - Who will we be seeing at the next appointment and what will they be helping my child with?
 - What should we bring to my next appointment?
- Should I monitor anything or record anything for the next appointment?
- What other services, clinics, or resources are available to me? (e.g. Social Work, Bloorview Research, financial resources)
- How do I get the reports from my appointments at Holland Bloorview? (You can request this is mailed to you or posted on Connect2Care)
- How do I contact you if I have a question after the appointment?



Family Tip: Bring a notebook and pen to your first appointment! It will be very helpful to keep track of your ideas, questions and thoughts. Or, use the planning guide on pages 12-14.



5 QUESTIONS TO ASK ABOUT YOUR MEDICATIONS

when you see your doctor, nurse, or pharmacist.

1. CHANGES?

Have any medications been added, stopped or changed, and why?

2. CONTINUE?

What medications do I need to keep taking, and why?

3. PROPER USE?

How do I take my medications, and for how long?

4. MONITOR?

How will I know if my medication is working, and what side effects do I watch for?

5. FOLLOW-UP?

Do I need any tests and when do I book my next visit?



Keep your medication record up to date.

Remember to include:

- ✓ drug allergies
- ✓ vitamins and minerals
- ✓ herbal/natural products
- ✓ all medications including non-prescription products

Ask your doctor, nurse or pharmacist to review all your medications to see if any can be stopped or reduced.

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Visit safemedicationuse.ca for more information.



Meeting with Healthcare Professionals: Planning Guide

Preparing for the meeting:

1. Write down the child's strengths and areas of development

	Strengths	Goals
Personality		
Skills		
Social		
Communication		
Other (interests)		

2. Circle the areas above where you would like to be supported. Feel free to talk to the child about the above chart.

3. What are the services that the child already receives?

4. What questions do you want to bring up at the meeting?

a. _____

b. _____



- c. _____
- d. _____
- e. _____

At the meeting:

Date: _____ **Where:** _____

Who attended: _____

Who I spoke to: _____

Reason for meeting: _____

1. Write down words and terms you do not understand.

Unclear word or term	Definition

2. Things to remember:

3. New information:



Wrapping up the meeting:

4. Repeat the main points to the providers at the meeting to be sure you understand what was said correctly. If you are not sure, ask to go over it again. The main points can be written here:

5. Make sure that you know what will happen after the meeting. Write the plan or goals down.

6. What other services/resources do we need, following this appointment? (e.g. Social Work, Family Resource Centre, suggested books)

7. How do I contact you if I have any questions?

Name of health care professional: _____

Title or role in child's care: _____

Phone number: _____

8. When will the next appointment be?

Date: _____ Time: _____

Location: _____



Family Tip: What's your child's *superpower*? Write it here and remember it 😊: _____



Family Resource Centre Tip: If you forget to bring this guide to your first appointment, visit the Family Resource Centre to get a paper copy before any appointments!



Helpful contacts at Holland Bloorview

To reach any of the following extensions, call our main line first: **416-425-6220** and feel free to visit us online at www.hollandbloorview.ca

In-Hospital Services

How we can help	Staff Name	Extension, Email and/or Webpage
To ask about your appointment date and time, talk to Client Appointment Services	n/a	416-424-3823 http://hollandbloorview.ca/programsandservices/programsservicesaz/clientappointmentservices
To provide more information on your referral, contact a CDP Intake Coordinator	Janice Jaffar Teresa Jarosz	Ext. 3334 jjaffar@hollandbloorview.ca tjarosz@hollandbloorview.ca
For information on our Music and Arts programs, contact the Program Administrator	John Taylor	Ext. 3317 musicandart@hollandbloorview.ca
For information on programs for social skills and life skills, contact our Therapeutic Recreation department	Tazeem Ismail	Ext. 3530 tismail@hollandbloorview.ca
For information on our Swimming Pool, contact our Aquatic Coordinator	Christina Neumann	Ext. 3539 swimregistration@hollandbloorview.ca
To find out about our Snoezelen Room and Pool, contact our Snoezelen Coordinator	Lorraine Thomas	Tel: First dial 1-800-855-0511 to get Bell Operator. At prompt give 416-422-7049 snoezelen@hollandbloorview.ca
To find out about research that is going on in the hospital, use the website navigator	n/a	http://research.hollandbloorview.ca/participateinresearch
To join the Parent Voices Facebook group	n/a	https://www.facebook.com/groups/532898290077876/



Family Tip: Remember: *you and your child are a part of your child's health care team!* Don't be afraid to ask questions.

*Note: This is also a tip from the Holland Bloorview clinicians!



Family Resource Centre

How we can help	Staff Name	Extension and Email
To find the right person when you need to, ask our Administrative Assistant	Sarah Fullerton	Ext. 3401 sarah.fullerton@hollandbloorview.ca
For family support, resources, information, and workshops on a variety of topics, ask a Family Support Specialist	Lorraine Thomas	Dial 1-800-855-0511. At operator prompt, give 416-422-7049 lthomas@hollandbloorview.ca
	Melissa Ngo	Ext. 6348 mngo@hollandbloorview.ca
If you have a compliment or concern about our services, ask our Client and Family Relations Facilitator	Kim Siu-Chong	Ext. 6084 feedback@hollandbloorview.ca
To get involved as a family volunteer, or attend a Parent Talk, ask a Family Centred Care Specialist	Amir Karmali	Ext. 6420 akarmali@hollandbloorview.ca
	Lori Beesley	Ext. 6337 lbeesley@hollandbloorview.ca
If you need financial help or a place to stay at the hospital, ask our Family Support Fund & Accommodations Administrator	Theresa Rojas	Ext. 6303 (Family Support Fund) or Ext. 3340 (Accommodations) trojas@hollandbloorview.ca
For information on our BLOOM Magazine, Blog and Parent Voices, ask our BLOOM Editor	Louise Kinross	Ext. 3866 kinross@hollandbloorview.ca
For childcare in the Ronald McDonald Playroom, ask our Playroom Coordinator	Daniel Scott	Ext. 3438 dascott@hollandbloorview.ca
If you need legal help, ask our Pro Bono Lawyer	Hannah Lee	Ext. 6557 hannah@pblo.org
Interim Director of Client and Family Integrated Care	Louise Kublick	Ext. 3713 lkublick@hollandbloorview.ca
To find medical journals, books, or videos for you or your children, ask our Health Sciences Library staff	Pui-Ying Wong, Manager	Ext. 3517 library@hollandbloorview.ca
	Winky Yeung, Technician	Ext. 3291 library@hollandbloorview.ca



Holland Bloorview and community services that you can access while on the waitlist

<u>Tools:</u>	Who do they serve?	How can they help?	Contact
Holland Bloorview Connect2Care	Any Holland Bloorview client (who has booked an appointment)	Access your health-care record, view your appointments, connect with members of your health-care team online	http://www.hollandbloorview.ca/connect2care
The K.I.T. (Keeping It Together) Resource	Families looking to organize their child's information	Organize information for your child that can assist you when interacting with different service systems, e.g. health, education, and recreation	https://www.canchild.ca/en/research-in-practice/the-kit
Medication logging	Anyone looking to manage medication information and records	Free and confidential MyMedRec app, print-ready booklet for managing medication information and records	http://www.knowledgeisthebestmedicine.org/

<u>Community services and information:</u>	Who do they serve?	How can they help?	Contact
211	Anyone looking for a helpline and/or online database of Ontario's community and social services	Navigate the complex network of human services quickly and easily, 24 hours a day, 7 days a week, in over 100 languages	http://www.211ontario.ca
CityKids	Children from birth to 12 years of age who live in the GTA	Find an early childhood program that will meet the developmental needs of their child	http://www.mothercraft.ca/index.php?q=ei-citykids



<u>Community services and information:</u>	Who do they serve?	How can they help?	Contact
Connectability	People of all ages who have an intellectual disability, their families, and support networks	Website and virtual community dedicated to learning, support and self-directed access to valuable information and tools	http://connectability.ca/en/
Holland Bloorview Resource Centre	Children with disabilities and their families	Browse a number of links that can be diagnosis-specific or topic-specific for online resources and information	http://hollandbloorview.ca/ClientFamilyResources/FamilyResourceCentre
Jooay	Children with disabilities and their families	App and website that helps to locate leisure opportunities in your area	http://jooay.com/
Ontario Camps Association	Families who are looking for camps for their children	The OCA Annual Camps Guide provides information about funding and camps for campers with additional needs	http://www.ontariocampsassociation.ca/find-your-perfect-camp/
Partners for Planning	Individuals with disabilities of all ages and their families	Helps families find resources, information, and workshops on planning for the future	http://www.planningnetwork.ca
Special Needs Roadmaps	Families who have children with disabilities in school or starting school	New interactive school roadmap to help parents navigate the school system	http://www.specialneedsroadmaps.ca/
Zach's List	Children with disabilities and their families	A website where families could go to trade or buy used pediatric equipment, and share advice and experience regarding equipment	http://www.zachslist.ca/



Therapies:	Who do they serve?	How can they help?	Contact
Early Abilities (Speech & Language, Vision, Hearing)	-Preschool Speech and Language program: birth to when child starts junior kindergarten -Blind-Low Vision Early Intervention Program and Infant Hearing Program: birth to 6	Provide early intervention for any concerns related to speech and language, vision and hearing	http://www1.toronto.ca/wps/portal/contentonly?vgnextoid=2b62b2f59527a410VgnVCM10000071d60f89RCRD
Canadian Association of Occupational Therapists	Anyone looking for occupational therapy services	Search for an Occupational Therapist to hire	https://www.caot.ca/
Canadian Physiotherapy Association	Anyone looking for physiotherapy services	Search for a Physiotherapist to hire	https://www.physiotherapy.ca/Finding-a-Physiotherapist.aspx
Community Care Access Centre	Seniors, adults, children and their families to help determine and provide the right care and health supports	Provide nurses, social workers, occupational therapists, physiotherapists or speech therapists who can support clients at home and in hospitals, doctor's offices, communities, and schools	http://healthcareathome.ca/torontocentral/en
Speech-Language and Audiology Canada (SAC)	Anyone looking for a speech language pathologist, audiologist, or communication health assistant	Search for a Speech Language Pathologist or Audiologist to hire	http://sac-oac.ca/public/find-professional



<u>Family Groups:</u>	Who do they serve?	How can they help?	Contact
Ability Online	Youth and young adults of all abilities, parents and professionals	Online community for kids, teens & young adults of all abilities, connections to peers & mentors for info & support	http://www.abilityonline.org/
Extend-A-Family	Families with children under 19, who have a developmental disability	Facilitate the building of relationships between individuals who have disabilities and members of the community	http://extendafamily.ca/
Holland Bloorview Parent Talks & Workshops	Parents and caregivers of children with disabilities	Meet and connect with other parents and learn about specific topics related to childhood disability	http://www.hollandbloorview.ca/familyevents
Young Carers	Children under 18 years of age who are in a caregiving role (e.g. siblings)	Therapeutic programming to help kids with adult responsibilities cope and interact with other kids in similar situations	http://www.ycptoronto.com/

<u>Advocacy:</u>	Who do they serve?	How can they help?	Contact
Access Now	Individuals with disabilities of all ages and their families	A website that uses crowdsourcing to show accessible locations on an interactive map	http://accessnow.me/
Easter Seals Kids at School	A place where parents of children with disabilities can find information on school related issues	Information, blog, and resources on how to navigate and advocate in the school system	http://education.easterseals.org/



Advocacy:	Who do they serve?	How can they help?	Contact
The Provincial Advocate for Children and Youth	Children and youth	Provides an independent voice for children and youth by responding to concerns from children, youth, and families	http://provincialadvocate.on.ca/

Blogs:	Who do they serve?	How can they help?	Contact
Holland Bloorview BLOOM Blog	Anyone who is looking for stories about families who have children with disabilities, and their lived experience	Find stories, topics and resources that interest parents of children with a wide variety of physical and developmental disabilities	http://bloom-parentingkidswithdisabilities.blogspot.ca/
Holland Bloorview CEO Blog	Anyone who would like to read about our hospital through the lens of our CEO, Julia Hanigsberg	Find out about what is important to the leader of our hospital	https://hollandbloorview.wordpress.com/
The Mighty	Anyone who is looking for a blog on families who have children with disabilities, and their lived experience	Find stories about disability and mental health	http://themighty.com/



Family Tip: Apply for services as early as possible. Many have a waitlist!



Tour of Holland Bloorview

On the tour, we will be walking by:

- The Family Resource Centre
- Swimming Pool
- Spiral Garden
- Arts Studio
- Music Rooms
- Snoezelen Room
- Lego Mural
- Ronald McDonald Playroom
- Registration
- Washrooms
- Cafeteria
- Waiting area on the 2nd floor and interactive ScreenPlay
- Waiting area on the 4th floor

If you have any questions about any of these locations within the hospital, please feel free to ask a Family Support Specialist!



Family Tip: If you end up coming in for multiple appointments, you can buy a discounted parking pass for multiple uses. See the front desk to ask about this option.

