



19th Annual Bloorview Research Institute Symposium

Innovating for Global Impact: 20 years of transforming childhood-onset disability research with families and communities

Thursday, November 7 and Friday, November 8

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November 7 – 8, 2024

A MESSAGE FROM PREMIER DOUG FORD

Hello and welcome to everyone taking part in the 19th Annual Bloorview Research Institute Symposium.

In the spirit of this year's theme, Innovating for Global Impact, this event showcases the tremendous advances made by the Bloorview Research Institute in the field of childhood disability.

Over the past few decades, we've come a long way in understanding the challenges faced by individuals with physical and developmental disabilities such as autism, cerebral palsy, spina bifida, muscular dystrophy, and brain and spinal cord injuries.

Through research and innovation and family engagement, we can create an environment where children with disabilities achieve their full potential. Together, we can build a stronger, more inclusive Ontario, now and for future generations.

Best wishes for another successful gathering of minds and hearts.

A handwritten signature in black ink, appearing to read "Doug Ford".

Doug Ford
Premier



November 7–8, 2024

**A MESSAGE FROM THE HONOURABLE RAYMOND CHO
MINISTER FOR SENIORS AND ACCESSIBILITY**

***19th Annual Bloorview Research Institute Symposium
Holland Bloorview Kids Rehabilitation Hospital***

As Ontario's Minister for Seniors and Accessibility, it is my immense pleasure to welcome everyone participating in the 19th Annual Bloorview Research Institute Symposium.

During this landmark 125th anniversary year of the Holland Bloorview Kids Rehabilitation Hospital and the 20th year of the Bloorview Research Institute, it is indeed fitting that this year's theme, "Innovating for Global Impact: 20 Years of Transforming Childhood-onset Disability Research with Families and Communities," emphasizes the institute's sustained success in transformative care.

The leading-edge research by the Bloorview Research Institute supports families and communities by creating countless possibilities for children and youth with disabilities while helping to realize a more accessible and inclusive Ontario.

This focus on families and communities while promoting innovative childhood disability research – on both a local and global scale – speaks to the heart of the ground-breaking work you do.

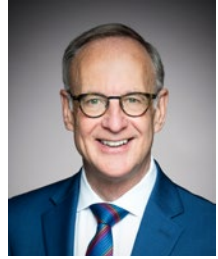
I would like to offer my sincere gratitude to all those involved with the organization and development of the symposium programming that highlights the innovative research in pediatric disabilities and developmental differences by the Bloorview Research Institute.

Please accept my heartfelt congratulations on these remarkable achievements and my best wishes for an informative and engaging event!

Sincerely,

A handwritten signature in black ink that reads "Raymond Cho".

Honourable Raymond Cho
Minister for Seniors and Accessibility



Holland Bloorview Kids Rehabilitation Hospital
150 Kilgour Road
Toronto, ON
M4G 1R8

19th Annual Bloorview Research Institute Symposium – Innovating for Global Impact: 20 years of transforming childhood-onset disability research with families and communities

It is my distinct pleasure to offer greetings to Holland Bloorview on the occasion of the 19th Annual Bloorview Research Institute (BRI) Symposium.

Holland Bloorview is a world class, international leader in health care dedicated to children with disabilities and has contributed greatly to research in the area of childhood disability. I am very pleased that the theme of the 19th Annual BRI Symposium will highlight the groundbreaking advances in childhood disability research and innovation taking place at Bloorview Research Institute.

I wish you a successful Symposium and look forward to working with Holland Bloorview in the months and years to come.

Sincerely,

The Honourable Robert Oliphant P.C., M.P.
Don Valley West

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Stephanie Bowman, MPP

Don Valley West



September 12, 2024

Dear Friends at Holland Bloorview,

I am writing to extend my best wishes for the upcoming 19th annual Bloorview Research Institute Symposium. This conference is a critical opportunity for researchers across this country to exchange ideas, discuss their findings, and take action on the most cutting-edge Canadian research, and I commend you for these important contributions to children's health.

For over 100 years, the Holland Bloorview Kids Rehabilitation Hospital has been a beacon of hope for children, their caregivers, and their loved ones. Your emphasis on research and innovation has been critical to the success of this mission, and has tangibly benefited the thousands of children who walk through your doors every year to receive help and healing. Your commitment to our community and our children inspires me in my own work, and I am very grateful for your service.

As you meet this year under the banner of *Innovating for Global Impact: 20 years of transforming childhood-onset disability research with families and communities*, I am reminded of the profound impact your research has far beyond the grounds of Holland Bloorview. Your focus on collaboration, creativity, and compassion has changed lives here in Canada and abroad.

Thank you for the invaluable contributions you have made and continue to make in our community. Your work and your research make the people of Don Valley West, this city and this province very proud, as we know children around the world benefit from your research. I wish you every success with this year's symposium and in the vital work that lies ahead.

Warm regards,

A handwritten signature in blue ink that reads "Stephanie Bowman".

Stephanie Bowman
MPP Don Valley West

20 years of innovating for global impact

Welcome to the 19th annual Bloorview Research Symposium, a day to share cutting-edge research and innovations, as well as cross-disciplinary collaborative global partnerships.

This is a significant year. We are celebrating 20 years at the Bloorview Research Institute (BRI). That is two decades of innovating for global impact to transform childhood onset disability research with families and communities – which is fitting for this year’s conference theme.

From its early roots in the early 1960s as a prosthetic research and training centre, the institute has grown into a research powerhouse – the only research-affiliated institute in Canada dedicated to pediatric disability and one that is ranked among Canada’s top research hospitals for more than a decade.

With a \$32-million recent expansion funded entirely by donors, including the addition of the Jason Smith Research Tower, top scientists and their teams are co-creating world-class research with clients and families, clinicians, educators, academic partners, and international collaborators to name a few. Their research touches on a wide array of areas from acquired brain injury and neurodevelopmental conditions to rare disease and assistive technologies.

This significant milestone in BRI’s history is one of the many milestones that Holland Bloorview is proud to celebrate as it marks its 125th anniversary.

I look forward to two days of incredible conversations, connections and insights that await us during this symposium.



A handwritten signature in black ink that reads "Julia Hanigsberg". The signature is fluid and cursive, with a long, sweeping tail on the final letter.

Julia Hanigsberg
President and CEO

20 years of transforming childhood-onset disability research with families and communities

Welcome to the 19th Annual Bloorview Research Institute Symposium (BRI).

This year's symposium marks an important historical milestone in celebrating 20 years from the launch of our research institute, Canada's only academic research institute dedicated to pediatric disability, and embedded in one of Canada's top research hospitals.

Throughout the next two days, you will hear from both our scientists, researchers and trainees as well as national and international collaborators as they present on their research discoveries, cutting-edge innovations, and provide thought leadership on what's to come. We are honoured to have several guests. Dr. Robert Bortolussi, professor emeritus, Dalhousie University and co-founder of MicroResearch Centre, IWK Health Centre, will deliver the Mickey Milner International Professorship keynote on the global impact of micro research programs in improving health-care outcomes. Dr. Sobia Khan, director of implementation at The Center for Implementation will give the keynote address on reflections on equity and justice in implementation science and practice. Dr. Tim Benke will provide insights on partnerships that deliver for children and families with rare conditions, including Rett syndrome.

For the first time this year, we are pleased to host our Pursuit Award in Childhood Disability competition at the symposium. Proudly sponsored by the Ward Family Foundation, the Pursuit Awards recognizes PhD students around the world for their outstanding achievements in childhood disability research. We look forward to acknowledging and celebrating with this year's BRI award recipients including scientists and students for their various academic accomplishments.

As your event co-hosts, we hope you have a chance to attend the presentations, engage in meaningful discussions with our scientists, researchers and trainees, and envision with us next steps for enabling personalized versions of a good life for all who experience neurodevelopmental differences, injuries and disability and their families. We look forward to building new connections with everyone during the proceedings.



Dr. Evdokia Anagnostou
Vice President, Research
Event Co-Host



Peter Welsh
Family Leader
Event Co-Host



Austin Cosgrove
Youth Research Advisor
Event Co-Host

Thursday, November 7

Mickey Milner International Professorship Lecture

MicroResearch: Community Health Research and Opportunities to Improve Disability Care in Africa

Dr. Robert Bortolussi, FRCP(C), professor emeritus, Dalhousie University and co-founder of MicroResearch Centre, IWK Health Centre



This session will explore the MicroResearch Community Health Research program. MicroResearch ensures small research projects will have a real impact on health. This talk will specifically highlight potential opportunities to improve disability care in Africa by using local health care professionals to find sustainable solutions to local health problems using community focused research.

Biography

Dr. Bortolussi is a former vice president of research of the IWK Health Centre and is professor emeritus of paediatrics at Dalhousie University. He edited "The Handbook for Clinician Scientists" which is used in many universities in Canada and as part of the MicroResearch curriculum. He is a fellow of Canadian Academy of Health Sciences and president of the global health section of the Canadian Paediatric Society. He is presently the editor of Clinical and Investigative Medicine (CIM).

Leveraging Local and International Resources in Rare Neurodevelopmental Disorders Toward New Therapies

Dr. Tim Benke, the Ponzio Family Endowed Chair in Neurology Research; medical director, Rett Clinic and research director, Neuroscience Institute, Children's Hospital Colorado; professor of pediatrics, neurology, pharmacology and otolaryngology, University of Colorado School of Medicine.



This talk will describe how specific resources supported the path towards approval of new therapies in rare neurodevelopmental disorders. These resources included local and international patient support groups and clinical resource infrastructures. The focus is on the challenges of uniting patient-centric priorities with local infrastructure and regulatory (FDA) requirements.

Biography

Tim Benke is the Ponzio Family Chair in Neurology Research and professor of pediatrics, pharmacology, neurology and otolaryngology at University of Colorado School of Medicine. He joined the University of Colorado School of Medicine and Children's Hospital Colorado (CHCO) in 2002 where he is research director of the Neuroscience Institute. He initiated the multi-disciplinary Rett/CDKL5/FOXG1 Clinic in 2011 at CHCO (recognized as a center of excellence), where he is the medical director. Dr. Benke was site principal investigator for the NIH-funded Natural History Study and collaborated in clinical trials and outcome measure development in RTT and CDKL5. He is leading the male RTT project funded by IRSF and RMRA. His translational lab collaboratively studies the impact of early-life seizures and CDKL5 on synaptic plasticity.

Breakout Sessions

Breakout Session #1

Global Impact and Opportunities for Growth in Pediatric Disability, Rehabilitation and Neurodevelopmental Conditions

Breakout Session #2

Establishing a Learning Health System at Holland Bloorview

Breakout Session #3

Transforming Pediatric Innovations into Global Solutions: Practical Advice for Bridging Research and Industry

Breakout Session #4

Setting Research Priorities for Minimally/Non-Verbal Individuals

BRI Research Talks

It was twenty years ago today: The research journey from earliest detection to early intervention for toddlers with emerging autism and related social communication needs

Dr. Jessica Brian, senior clinician scientist; psychologist, Bloorview Research Institute

This presentation will take attendees along a research journey from investigating the very earliest signs of emerging autism in babies and toddlers, through the development of a caregiver-mediated intervention and its implementation in Canada and beyond. The presentation will highlight the developmental trajectory of this longitudinal program of research, concluding with lessons learned and next steps.



Biography

Dr. Jessica Brian is a clinical psychologist and senior clinician scientist at Holland Bloorview, where she co-leads the Autism Research Centre at the Bloorview Research Institute. Dr. Brian is also associate professor, University of Toronto, Department of Paediatrics, with affiliations at Hospital for Sick Children and the Ontario Institute for Studies in Education (OISE/UofT). She specializes in neurodevelopmental disabilities with a particular interest in early identification and intervention in autism spectrum disorder (ASD). Dr. Brian has spent the past 25 years collaborating in a pan-Canadian longitudinal research program that explores the development of children at elevated likelihood for ASD (Infant Siblings Study), who are followed from infancy into adolescence. Informed by this early identification work, Dr. Brian co-developed the Social ABCs, a caregiver-mediated intervention for toddlers with emerging autism or related challenges. She has a long history of teaching graduate students, clinical trainees, and community providers in topics related to early detection, assessment, diagnosis, intervention, and supports for autistic children and youth and their families.

20/20 hindsight: fabrics, fractality & forces – where we should have gone

Dr. Tom Chau, distinguished senior scientist, Bloorview Research Institute

Reflecting upon the last 20 years of research in pediatric rehabilitation intelligent systems (PRISM Lab) at Holland Bloorview, this talk will present a central thread that perhaps has been stringing together, inconspicuously, many seemingly disparate scientific investigations, from conductive cover stitches to covert speech brain-computer interfaces. Key advances in pediatric access technologies as well as relatively obscure contributions will be highlighted, illustrating how they have collectively and synergistically provided the scaffolds for our present research efforts.



Biography

Dr. Tom Chau is a distinguished senior scientist at Bloorview Research Institute and a full professor in the Institute of Biomedical Engineering at the University of Toronto. His research investigates novel access pathways for non-speaking children and youth with severe physical impairments. He has published many journal articles relating to pediatric rehabilitation engineering and has developed numerous assistive technologies aimed at enabling communication and control for children with disabilities. Dr. Chau's contributions to childhood disability research have been recognized nationally and internationally.

Friday, November 8

Pursuit Award in Childhood Disability Competition

Proudly sponsored by the Ward Family, the Pursuit Award in Childhood Disability Competition recognizes PhD students for their outstanding achievements in childhood disability research.

Patricia Kipkemoi

From Genes to Behaviour: Diagnosis, genetic and phenotypic architecture and environmental influences of neurodevelopmental disabilities

In many parts of Africa, the diagnosis of neurodevelopmental disabilities (NDDs) such as autism and intellectual disability is challenging, in part, due to a lack of culturally appropriate and adequately standardised screening and diagnostic tools.

The validation of screening and diagnostic tools is crucial as we move towards better care for affected families. Many recent studies have tried to understand the genetic causes of these conditions, mostly in high-income countries including North American and Western European populations but rarely in the context of African populations. Understanding how common and rare genetic variations relate to neurodevelopmental traits not only helps bridge this gap but also paves the way for the development of targeted interventions and management strategies for affected children. This talk will explore several key areas: the importance of validating autism screening and diagnostic tools for phenotypic characterization, the genetic, phenotypic architecture associated with NDDs in Kenya, and the prenatal, perinatal, and postnatal factors linked to autism in children from Kilifi and Mombasa counties in Kenya, as well as Cape Town, South Africa. To close out the talk, Kipkemoi will contextualize our findings within current global discourse on NDDs and highlight areas for future research that can build on the insights gained from this work.



Biography

Patricia Kipkemoi is a final-year PhD candidate with the KEMRI-Wellcome Trust Research Programme, Kilifi, Kenya, and an incoming post-doctoral researcher with Aga Khan University, Nairobi, Kenya. Her research focuses on neurodevelopmental disorders (NDDs) in low-resource settings, specifically in African populations. Her work has involved validating screening tools, understanding environmental and genetic risk factors, and contributing to the NeuroDev Project, which explores the genetic and phenotypic architecture of NDDs in Kenya and South Africa. Kipkemoi was nominated to be a research fellow in a program called Global Initiative for Neuropsychiatric Genetics Education in Research (GINGER), which trains young African researchers in neuropsychiatric genetics analysis. Through the GINGER program, facilitated by Harvard TH Chan and the Broad Institute, she received training in epidemiology, biostatistics, and statistical genetics, graduating from the program in May 2024. In 2022, she was nominated to be an autism spectrum disorder representative for the Psychiatric Genetics Consortium (PGC)- Africa working group. This role involves forming a database of autism-related studies on the African continent and diaspora.

Dr. Madison Giles

We're not some cute little naïve innocent beings: Exploring the sexuality of youth with physical disabilities

Dr. Madison Giles will share the stories of youth with physical disabilities, focusing on their sexual identities, needs, hopes, dreams and desires. These stories come from her PhD research where she used an arts-based methodology to highlight unique forms of knowledge and employed an Intersectional framework to center youth with intersecting identities, such as Black, Indigenous, and youth of colour, as well as LGBTQ+ youth. Through the youth's stories, Giles saw how society limits their sexuality by largely viewing them as vulnerable and not fully sexual beings. The youth had to navigate and resist this desexualization and find creative ways to assert their value and desirability as sexual beings.



Biography

Dr. Madison Giles is a project manager at the Sex Information and Education Council of Canada. She holds a PhD in public health sciences from the University of Toronto's Dalla Lana School of Public Health and a postdoctoral fellowship from Unity Health Toronto. Giles's research explores the complexity of human sexuality using critical qualitative and arts-based methodologies. In addition to producing scientific publications and presentations, she is committed to co-creating community-facing and youth-focused products, such as art galleries and digital storybooks. Giles's research always involves people with lived experience, aiming to examine how power operates over others while simultaneously acknowledging the power we hold with others.

Dr. Marlee Vandewouw

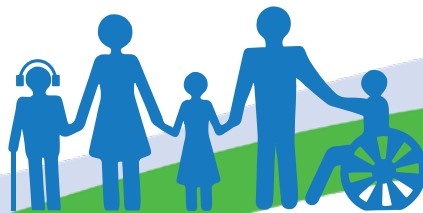
Characterizing diversity in brain function and structure to advance personalized health

Despite having distinct diagnostic labels, neurodevelopmental conditions such as autism, attention-deficit/hyperactivity disorder, and obsessive-compulsive disorder vary significantly in their brain and behaviour within each condition, and also overlap across conditions. This highlights the need for personalized health approaches, where care is tailored to each individual's unique biology, rather than their diagnostic label. In this talk, Dr. Marlee Vandewouw will present work from her thesis which used state-of-the-art approaches to deepen our understanding of neurobiological variability and improve our ability to predict adverse outcomes in neurodiverse children and youth. This work paves the way for more precise and effective approaches to care, ultimately improving outcomes for neurodiverse children.



Biography

Dr. Marlee Vandewouw has over eight years of experience in neuroimaging research where her work has primarily focused on understanding the neurobiology of neurodevelopmental conditions. She recently obtained her doctoral degree from the Institute of Biomedical Engineering at the University of Toronto under the supervision of Dr. Azadeh Kushki. Here, her work focused on characterizing neurobiological diversity and improving our ability to predict adverse outcomes in neurodivergent children and youth. Ultimately, her work has taken an initial step towards personalized health, where care is tailored to an individual's biology, strengths and needs.



Family Engagement and Lived Experience Session

This session will highlight the notable accomplishments of Holland Bloorview's Research Family Engagement Committee and the work underway to boldly re-imagine the role of the committee in advancing research for all children with disabilities. This session will also feature a lived experience talk and musical performance.

Dr. Tim Ross, scientist, assistant professor, Bloorview Research Institute, scientist co-chair, Research Family Engagement Committee

Dr. Tim Ross is a scientist in the Bloorview Research Institute, assistant professor in the Department of Geography and Planning and the Rehabilitation Sciences Institute at the University of Toronto, and he is the scientist co-chair of the Research Family Engagement Committee. Dr. Ross leads the Engagement & Planning for Inclusive Communities Lab, which explores experiences of disability and ways to advance more accessible, inclusive, and diverse communities. Four of his key research areas are: (1) education access, (2) transportation and mobility, (3) inclusive play, and (4) institutional ableism.



Questions about ableism and its normalcy within the planning and design of our built environments, services, and systems are central to Dr. Ross' research.

Suzanne Jorisch, family leader co-chair, Research Family Engagement Committee

Suzanne Jorisch is a financial executive who has over 20 years of senior management experience. She is exceptionally motivated to seek, identify, develop, and implement organizational improvements, with a focus on quality, profit opportunities, and cost savings. Her areas of expertise include accounting and administrative management, human resources and payroll management and financial planning, budgeting, reporting, and analytics. Jorisch has been an extremely active part of the Holland Bloorview Family Leadership Program since 2013 serving on numerous committees including the Hospital Board of Directors, Business & Audit Committee, Research Teaching and Learning Committee, Quality Committee, Family Advisory Committee, and the Research Family Engagement Committee, among others.



Adrian Anantawan, violinist, associate professor, Berklee College of Music

Adrian Anantawan is an acclaimed violinist and associate professor at Berklee College of Music. He holds degrees from the Curtis Institute of Music, Yale University and Harvard Graduate School of Education where he studied with musical greats like Itzhak Perlman and Pinchas Zukerman. Adrian has performed at prestigious venues, including the White House, the United Nations and the Olympic Games. In Canada, he has been a soloist with major orchestras such as those in Toronto, Vancouver and Montreal.



A passionate advocate for accessibility in the arts, Adrian co-founded the Virtual Chamber Music Initiative and the Music Inclusion Program, which help children with disabilities engage with music. Among his many honours are a Juno nomination, induction into the Terry Fox Hall of Fame, and the Queen's Diamond Jubilee Medal for his contributions to both music and disability advocacy.

As a former out-patient client at Holland Bloorview, the orthotics & prosthetics team built a customized prosthetic so that he could play the violin when he was a child. Inspired to give back to the hospital, he was introduced to cutting-edge technology developed by the PRISM Lab, Virtual Music Instrument, a device that translates movements into music. Together with a team of doctors, musicians, music therapists and educators, he explored the device's potential for kids with disabilities to express themselves through music.

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Implementation Science Keynote Presentation

Reflections on equity and justice in implementation science and practice

Dr. Sobia Khan

Director of Implementation, The Center for Implementation



This talk will provide an introduction to implementation science and practice, focusing on the importance of equity and justice throughout the implementation process, in the development of relationships, and in the systems, structures and ideologies that underpin implementation work. Dr. Khan will provide an overview of the equity iceberg to dive deeper into these topics, and will introduce key reflection questions and considerations to embed equity and justice into all aspects of implementation research and practice.

Biography

Dr. Sobia Khan is an award-winning global expert on how to practically implement complex interventions in complex systems. Dr. Khan emphasizes pragmatic and equity-driven approaches, with a particular focus on the need for relationship building, advocacy, and collective action to create change at all levels of the system. Dr. Khan has worked on over 100 implementation research and practice projects in multiple fields and various levels of the system. In addition, Dr. Khan is internationally recognized for transforming the landscape of implementation training by distilling science into practice. She has developed world-renowned courses on how to practically implement in organizations, communities, and systems — the only training of its kind. She holds an MPH from the University of Waterloo and a PhD from the Institute for Health Policy, Management and Evaluation at the University of Toronto.

BRI Research Talks

Dystonia in Cerebral Palsy: Driving Global Change in Care over Two Decades

Working together, Brenda Agnew (parent stakeholder) and Darcy Fehlings (clinician scientist) will discuss why dystonia is important to recognize and manage for individuals with cerebral palsy. The presenters will take the audience on a 20-year journey from clinicians and families missing or not knowing their child had dystonia to driving change in the clinical and research arena by the development of the Hypertonia Assessment Tool and leading the development of an international clinical practice guideline and AACPDM (American Academic in Cerebral Palsy and Developmental Medicine) 'Dystonia in CP' Care Pathway on pharmacologic and neurosurgical management.

Biography

Dr. Darcy Fehlings

Dr. Darcy Fehlings is a developmental pediatrician and professor in the Department of Paediatrics at the University of Toronto. She is a senior clinician scientist in the Bloorview Research Institute at Holland Bloorview Kids Rehabilitation Hospital. Her clinical and research work focuses on the innovation and evaluation of interventions for children with cerebral palsy including hypertonia interventions, early detection, constraint therapy, dystonia and pain management. She has led the AACPDM Care Pathways for 'Dystonia in CP'. She has held positions as the inaugural head of the U of T Division of Developmental Paediatrics (2006-2022) and president of the American Academy of Cerebral Palsy and Developmental Medicine (2015).



Brenda Agnew, parent and family advocate and marketing manager, Gluckstein Lawyers

Brenda Agnew is the proud mother of two sons, Chase and Maclain. Her younger son Maclain is a former 29-week-old twin-to-twin transfusion survivor. He has quadriplegic dyskinetic cerebral palsy and profound hearing loss as a result of a condition known as Kernicterus, a brain injury that results from untreated jaundice. Since Maclain was diagnosed, Agnew has been tireless in advocating for better systems and programs for children with neurodiverse needs. There is much personal empowerment in having the ability to provide substantial input on how policies, programs, and priorities are created and communicated, and how we incorporate and engage families. She is grateful daily to have been afforded continuous opportunities to create, foster, and grow relationships with professionals, fellow parents and caregivers.



Agnew is an active member of volunteer organizations such as CP-Net, CHILD-BRIGHT Citizen Engagement Committee, PONDA, the AACPDM Community Council and is a director on the board of directors for Easter Seals Ontario.

In addition to her role with Gluckstein Lawyers, Agnew is also a school board trustee with the HCDSB in her second term, where she is also the chair of the Special Education Advisory Committee.

Expanding the world of possibility

The talk covers Dr. Jan Andrysek's journey within the BRI over the last 20+ years, and how the institute has grown and expanded, and the research program alongside it.

Dr. Jan Andrysek, senior scientist, Bloorview Research Institute and associate professor, University of Toronto, Institute of Biomedical Engineering

Dr. Jan Andrysek is a senior scientist at BRI and an associate professor at the University of Toronto's Institute of Biomedical Engineering. His research focuses on developing assistive technologies, with a focus on prosthetic and orthotic limb design and fabrication, wearables for rehab, and tools to measure mobility and physical activity. He also studies the global impact of prosthetic rehabilitation.



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Elevating the family voice in research

The impact of client and family engagement in research

At the heart of all research studies and projects at the Bloorview Research Institute lies our clients and families. From the initial research concept to the completion of a study, scientists and researchers work hand-in-hand with their clients and families every step of the way.

Here is what some of our families and researchers had to say:

“ I would never do a project now without them [Family Leaders]. It's been the best thing ever.
– *BRI researcher*

“ If I can be a player in making system change and more opportunities exist for the kids in healthcare, then I think I'm getting a lot out of it.
– *Family leader*

“ As a family member who has been engaged in research, I'm learning about the world that my daughter is in – it's a huge benefit.
– *Family leader*

“ I will say that external to Holland Bloorview, it's a rare moment when a colleague really gets it (family engagement in research), and sees the value. They are willing, and they think it's important, but they don't take that next step.
– *BRI researcher*

“ [The family leader] changed our entire research question. We would never have thought of that.
– *BRI researcher*

“ Research for families represents HOPE.
– *Family leader*

Student/Trainee Presentations

Each year, the Bloorview Research Institute welcomes over 100 graduate and doctoral students, otherwise known as trainees, from universities across Canada and beyond to study alongside some of the world's leading scientists and gain first-hand knowledge on the latest advancements in childhood disability research. The BRI symposium is one of several events where these trainees can showcase their research to a broad audience.

This year's presenters are:

- 1. Towards developing a digital workflow for transradial prostheses**
Presenter: Calvin Ngan
Authors: Calvin Ngan and Jan Andrysek
- 2. Gamified Assessment: Extracting and characterizing reach performance in children with cerebral palsy using data collected from Bootle Blast, a movement tracking video game**
Presenter: Sorsha Asady
Authors: Sorsha Asady, Elaine Biddiss, Ajmal Khan, Soowan Choi
- 3. Applying an implementation science framework to pediatric autism assessment: Facilitators and barriers in Ontario**
Presenter: Zahra Wakif
Authors: Zahra Wakif, Lisa Kanigsberg, Genevieve Ferguson, Melanie Penner; Project ECHO AuDIO Team
- 4. Development and Validation of a Textile-Based Prosthetic Socket Pressure Sensing System**
Presenter: Thierry Dugas
Authors: Thierry Dugas and Jan Andrysek
- 5. Analysis to Examine Phenotypic and Physiological Correlates to Irritability in Autism**
Presenter: Sara Alatrash
Authors: Sara Alatrash, Tithi Paul, Brendan Andrade, Suneeta Monga, Jessica Brian, Evdokia Anagnostou, Melanie Penner, Atena Roshan Fekr, Azadeh Kushki
- 6. Exoskeleton-assisted physiotherapy: feasibility and outcomes associated with usage in school and outpatient settings for children with cerebral palsy**
Presenter: Stefanie Bradley
Authors: Stefanie Bradley, Virginia Wright, Anne Kawamura, Tom Chau
- 7. Engaging Clinicians and Youth in the Development of a Novel Multidomain Assessment and Rehabilitation Tool for Concussion**
Presenter: Josh Shore, Danielle DuPlessis, Brian Xiao
Authors: Josh Shore, Danielle DuPlessis, Brian Xiao, Andrew Lovell, Pavreet Gill, Emily Lam, Fanny Hotze, Ajmal Khan, Stephanie McFarland, Andrea Hickling, Kylie Mallory, Michael Hutchinson, F. Virginia Wright, Nick Reed, Sarah Munce, Elaine Biddiss, Shannon Scratch.
- 8. Home-based transcranial direct current stimulation to promote self-regulation in children with autism spectrum disorder (ASD)**
Presenter: Norna Abbo
Authors: Norna Abbo, Trina Mitchell, Evdokia Anagnostou, Brendan Andrade, Deryk Beal

Poster Sessions – Nov. 7 and 8

At the Bloorview Research Institute, scientists, researchers and trainees are co-creating transformative, equity-driven research with clients and families to enable healthy futures for children and youth living with developmental differences and disabilities, and their families in Canada and worldwide.

Please stop by and have a chat with our presenters to learn more about their incredible research.

- 1. Exploring the employment experiences of young adults with multiple minoritized identities: A qualitative study focusing on race and non-apparent disabilities**
Authors: Dr. Sally Lindsay, Natanela Dain, Shaelynn Hsu
Presenter: Dr. Sally Lindsay
Authors: Narges Abdeahad, Sally Lindsay
Presenter: Narges Abdeahad
- 2. Experiences and factors affecting poverty among families raising a child with a disability: A scoping review**
Authors: Dr. Sally Lindsay, Sarah Leo, Janice Phonepraseuth, Lily Cao
Presenter: Janice Phonepraseuth
- 3. A systematic review of racial health inequities among children and youth with physical disabilities**
Authors: Dr. Sally Lindsay, Janice Phonepraseuth, Sarah Leo
Presenter: Sarah Leo
- 4. What Do Today's Parents Want and Need from Healthcare Services?: Developing a New Measure of Family-Centred Service**
Authors: Madhu Pinto, Gillian King, Kinga Pozniak, Elizabeth Chambers, Rachel Martens, Sarah Wellman-Earl, Olaf Kraus de Camargo, Dayle McCauley, Rachel Teplicky, and Peter Rosenbaum
Presenter: Gillian King
- 5. The role of race and ethnicity in leisure participation among children and youth with disabilities: A systematic review**
Authors: Rushmita Alam, Narges Abdeahad, Sally Lindsay
Presenter: Rushmita Alam
- 6. Developing and Testing a New Feedback-based Therapy Exercise Game Using Design Thinking**
Authors: Marina Petrevska, F. Virginia Wright, Selvi Sert, Elaine Biddiss
Presenter: Marina Petrevska
- 7. Psychopharmacology in children with genetic disorders of epigenetic and chromatin regulation: clinical description and analysis of potential biomarkers**
Authors: Sophia Lenz, Sarah J. Goodman, Ajilan Sivaloganathan, Cheryl Cytrynbaum, Jesiqua Rapley, Emma Canning, Rosanna Weksberg, Danielle Baribeau
Presenter: Sophia Lenz
- 8. Learning about family experiences in accessing an autism diagnosis in Northern Ontario: Preliminary findings**
Authors: Carly Cermak, Jesiqua Rapley, Melissa Penner
Presenters: Carly Cermak, Jesiqua Rapley
- 9. Exploring the clothing experiences of children and youth with physical disabilities A Scoping Review**
Authors: Rushmita Alam, Narges Abdeahad, Sally Lindsay
Presenter: Rushmita Alam

Poster Sessions – Nov. 7 and 8

- 10. Comparative Analysis of Phenotypic and Genotypic Characteristics in Regressive and Non-Regressive Autism**
Authors: Seyed Hassan Tonekaboni, Alana laboni, Brett Trost, Zsuzsa Lindenmaier, Azadeh Kushki, Elizabeth Kelley, Jessica Jones, Muhammed Ayub, Stelios Georgiades, Robert Nicolson, Elim Chan, Andrada Cretu, Jessica Brian and Evdokia Anagnostou
Presenter: Seyed Hassan Tonekaboni
- 11. Effectiveness of clinician supported, parent-mediated participation promoting interventions for children with physical disabilities: A Systematic Review**
Authors: Testani, D.A, Simon, T., King, G., Munce, S., Shearer, H.M, Fehlings, D.
Presenter: Daniela Testani
- 12. Creation of a smart template library for digital transradial prosthetic socket design**
Authors: Vishal Pendse, C.C. Ngan, Jan Andrysek
Presenter: Vishal Pendse
- 13. A retrospective assessment of a multidisciplinary intensive inpatient rehabilitation program for children with Spinal Muscular Atrophy**
Authors: Christina Ippolito, Lathushikka Canthiya, Andrea Hoffman, Laura McAdam
Presenter: Christina Ippolito
- 14. Qualitative perspectives of a school-based physiotherapist team about the use of an overground powered exoskeleton in a primary school setting for children with cerebral palsy**
Authors: Ledycnarf Holanda, Stefanie S. Bradley, F. Virginia Wright
Presenter: Ledycnarf Holanda
- 15. The Teach-ABI Professional Development Module: A Mixed Method Analysis Of Change In Open-Ended Case Study Responses**
Authors: Danielle DuPlessis, Sara Marshall, Willow Barton, Mary Desrocher, Shannon Scratch
Presenter: Danielle DuPlessis
- 16. Identity Negotiations of Multiply Marginalized Youth with Disabilities**
Authors: Van Slothouber, Sally Lindsay
Presenter: Van Slothouber
- 17. Utilization of Emergency Department Services among Children with Neurodevelopmental Diagnoses: A Scoping Review**
Authors: Humna Siddiqui, Alyssa Henderson, Iveta Lewis, Melanie Penner
Presenter: Humna Siddiqui
- 18. A Scoping Review of Disabled Students' Schoolyard Experiences**
Authors: Amanda Chan, Élyse Comeau, Sally Lindsay, Tim Ross
Presenter: Amanda Chan
- 19. Early Detection and Intervention of Cerebral Palsy (EDIT-CP): A Knowledge Implementation Project**
Authors: Bisman Mangat, Lauren Switzer, Sophie Lam-Damji, Liz Cambridge, Darcy Fehlings
Presenter: Bisman Mangat
- 20. A single patient trial of Fluoxetine in KCNC1 related disorder**
Authors: Christina Tsetsos, Evdokia Anagnostou, Gregory Costain, Elise Heon, Ajoy Vincent, Jacob Vorstman, Carolina Gorodetsky, Jim Dowling, Mark Bedford, Kimberly Amburgey, Danielle Baribeau
Presenter: Christina Tsetsos

Poster Sessions – Nov. 7 and 8

21. **The Autism Occupational Therapy Coach Program: Promoting Neurodiversity Affirming Practices**
Authors: Christine Provvidenza, Ashleigh Townley, Sarah Holman, Moira Peña, Jaden Chong, Shauna Kingsnorth
Presenters: Moira Peña, Jaden Chong
22. **We Are Sexual Too: A Partnership to Support the Intimate Citizenship of Youth With Disabilities Across Canada**
Authors: Amy McPherson, Shauna Kingsnorth, Jonathan Leef, Ann Fudge Schormans, Shaniff Esmail, Alan Santinele Martino, Hilary Brown, Loree Erickson, Emily Cox, Heather Cobb, Jessica Wood & Madison Giles
Presenter: Amy McPherson
23. **We Are Sexual Too: Co-creating resources for youth, with youth**
Authors: Emily Cox, Gavi Engel-Yan, Cameron Stewart, Emily Mazur, Alexandra Rego, Francis Routledge, Christine Provvidenza, & Amy McPherson
Presenter: Emily Cox
24. **Navigating Digital Communication: Co-Creating a Survey on Computer-Mediated Communication (CMC) in Adolescents with Acquired Brain Injury (ABI)**
Authors: Lisa Kakonge, Hannah Boamah, Jessica Tomarchio
Presenters: Lisa Kakonge, Hannah Boamah, Jessica Tomarchio
25. **Context-Driven Evaluation and Iterative Development of Bootle Blast**
Authors: Selvi Sert, Daniela Chan-Viquez, Marina Petrevska, Ilana Naiman, Ajmal Khan Elaine Biddiss
Presenter: Selvi Sert
26. **Interim Feasibility Analysis of Metformin for Motor and Cognitive Improvement in Children with Cerebral Palsy: A Feasibility Study**
Authors: Eisha Amjad, Lauren Switzer, Cynthia B. de Medeiros, Amber Makino, Jenna Doig, Cecilia Lee, Donald J. Mabbott, Darcy Fehlings
Presenter: Eisha Amjad
27. **Validation of Dry Textile EEG Electrodes for Brain-Computer Interface Applications**
Authors: Yuan Dou, Jason Leung, Tom Chau
Presenter: Yuan Dou
28. **3D Printing Method for Upper-Limb Diagnostic Sockets**
Authors: K. Meng, C.C. Ngan, H. Sivasambu and J. Andrysek
Presenter: Katrina Meng
29. **Transforming Therapies with Insights into Cortical Neural Dynamics: Unveiling Distinct Signatures of Action Observation, Imitation, and Execution in Children with Cerebral Palsy and Hemiplegia**
Authors: Niloufaralsadat Hashemi, Deryk Beal, Tom Chau
Presenter: Niloufaralsadat Hashemi
30. **Access to virtual interdisciplinary pediatric concussion services within the Persistent Concussion Clinic: A retrospective chart review**
Authors: Roshan Ahmad, Michaela Harper, Andrea Hickling, Alexa Irvin, Pavreet Gill, Shannon Scratch, Kylie Mallory
Presenter: Kylie Mallory

Poster Sessions – Nov. 7 and 8

31. **Predicting Adaptive Function in Neurodevelopment Conditions Using Computer Vision Readouts of Motor Activity**
Authors: Fatima Karim, Andre Telfer & Evdokia Anagnostou
Presenter: Fatima Karim
32. **A Comprehensive Characterization of the Extensive Needs Service Pilot Program Participants**
Author: Bisola Olaseni
Presenter: Bisola Olaseni
33. **Development of a Music-Based Wearable Biofeedback System to Improve Lower Limb Amputee Gait Symmetry**
Authors: Adolfo Sebastian Silva, Jan Andrysek
Presenter: Adolfo Sebastian Siva
34. **Cognition and Executive Function in Aging Autistic Adults**
Authors: Azra Delpak, Evdokia Anagnostou
Presenter: Azra Delpak
35. **Funding equitable access to 'start-early' employment supports for youth with disabilities: A cost-benefit model**
Authors: Laura Bowman, Carolyn McDougall, René Doucet, Brendon Pooran, Jeannette Campbell
Presenter: Laura Bowman, Carolyn McDougall
36. **Assessing Player Engagement Across Difficulty Adjustment Methods in a Video Game for Teaching Music-Making to Children with Diverse Abilities**
Authors: Michael S. W. Lam, Alexander Hodge, Elaine Biddiss
Presenter: Michael S. W. Lam
37. **A Pilot Evaluation of the Novel Infant Social ABCs Caregiver-Mediated Intervention**
Authors: Dowds, E., Zwaigenbaum, L., & Brian, J.A.
Presenter: Erin Dowds
38. **Phenotypic and Sociodemographic Correlates of Cognitive-Adaptive Functioning Discrepancy in Neurodivergent Children Using A Machine Learning Approach.**
Authors: Eric Wan, POND group, Dr. Azadeh Kushki
Presenter: Eric Wan
39. **Does baseline expressive language ability predict early intervention outcomes? Evidence from the Social ABCs**
Authors: Daoud, S., Bernardi, K., Brian, J
Presenter: Sara Daoud & Kate Bernardi
40. **A Virtual Dental Office Experience for Children with Autism – A Randomized Controlled Trial**
Authors: Tithi Paul, Molly Friedman, Annie Dupuis, Harshit Bokadia, Melanie Penner, Azadeh Kushki
Presenter: Tithi Paul
41. **Teaching Educators about Acquired Brain Injury (TeachABI): Through Hospital to School Transition**
Authors: Christine Muscat, Sara Marshall, Shannon Scratch
Presenter: Christine Muscat
42. **A transdiagnostic and data-driven approach for characterizing rich-club development in neurodivergence.**
Authors: Marlee Vandewouw, Azadeh Kushki, Jennifer Crosbie, Russell J. Schachar, Stelios Georgiades, Robert Nicolson, Elizabeth Kelley, Muhammad Ayub, Jessica Jones, Paul Arnold, Jason Lerch, Margot Taylor, Evdokia Anagnostou
Presenter: Marlee Vandewouw

Notable Awards

Dr. John Whittaker Memorial Cerebral Palsy Award

The Dr. John Whittaker Memorial Cerebral Palsy Award rewards outstanding contributions to research, service, or product developments that improve the quality of life of children and youth with cerebral palsy or other developmental disabilities. The award was created by Dr. Whittaker's family and friends in recognition of his dedication to improving the quality of life of children with cerebral palsy and other developmental disabilities.

This year's Whittaker award is awarded to **Dr. Virginia Wright**.



Congratulations, Dr. Wright!

Emerging Research Leadership Award

Dr. Melanie Penner, a senior clinician scientist and developmental pediatrician, has been awarded the Emerging Research Leadership Award by the University of Toronto's Department of Paediatrics and the Hospital for Sick Children this year. The award recognizes the outstanding achievements and progress in research by a physician during the first 10 years after their initial appointment to the faculty of an academic health sciences centre.



Congratulations, Dr. Penner!

Academic Scholar Award

Dr. Danielle Baribeau, a clinician scientist and psychiatrist, has been awarded the Academic Scholars Award from the University of Toronto's Department of Psychiatry.



The department grants the merit-based awards to support the professional development of early- to mid-career faculty members in their progression towards attaining academic promotion.

Congratulations, Dr. Baribeau!

American Academy for Cerebral Palsy and Developmental Medicine Lifetime Achievement Award

Dr. Darcy Fehlings, a senior clinician scientist and developmental pediatrician, has been awarded the Lifetime Achievement Award by the American Academy for Cerebral Palsy and Developmental Medicine. This award recognizes the outstanding significance to the field of medicine and for the benefit of individuals with cerebral palsy and other child-onset disabilities.



Congratulations, Dr. Fehlings!

Announcements

Academic Promotion

Congratulations to **Dr. Shannon Scratch**, a clinician scientist at the Bloorview Research Institute and clinical neurologist at Holland Bloorview. She has received a well-deserved promotion to associate professor at the University of Toronto's Temerty Faculty of Medicine. As head of the of the NOVEL (Neurorehab Outcomes via Education & Learning) Lab, Dr. Scratch and her team is leading the way in developing new treatment approaches and pathways for people who have experienced concussion or acquired brain injury.



Congratulations, Dr. Scratch!

Associate Chief of Faculty and IDEAA Advancement

Congratulations to **Dr. Elaine Biddiss** on being named associate chief of faculty and IDEAA advancement. The senior scientist and head of the PEARL Lab is leading BRI's strategy priority in advancing research practices through an IDEAA – inclusion, diversity, anti-racism, accessibility – lens and supporting diverse learners in research endeavours.



Congratulations, Dr. Biddiss!

Inaugural EMBARK scientist

Dr. De-Lawrence Lamptey is the BRI's inaugural EMBARK (Empowering Black Academics, Researchers and Knowledge creators) scientist. His research focus is on the intersectionality of childhood disability and racial identity/ethnicity across Canada. Through his research, Dr. Lamptey aims to better understand the unique experiences of racialized or ethnically diverse children and youth with disabilities and their families.



New scientist hires

Dr. Jacob Ellegood

Dr. Jacob Ellegood has been named BRI's new neuroimaging scientist. He is leading a program of research and will build up the research institute's reputation in MRI research and childhood disability and developmental differences with a focus on precision health and equity.



Dr. Sarah Munce

Dr. Sarah Munce is the research institute's new implementation scientist. Her top priority is build an implementation science program that forges strong links between research and clinical teams, bringing research findings into care, policy and practice at all levels.



Graduate student awards

The BRI congratulates the 2024-25 Graduate Student Scholarship Award recipients:

The **Kimel Family Graduate Student Scholarship in Pediatric Rehabilitation** winners are:

Katrina Meng,
Second year,
Master of Applied
Science, Institute
of Biomedical
Engineering,
University of
Toronto



Project (under the supervision of Dr. Jan Andrysek): Parametric and Image-based Digital Upper-Limb Prosthesis Design Workflow

Vishal Pendse,
Third year, PhD
in biomedical
engineering,
University of
Toronto



Project (under the supervision of Dr. Jan Andrysek): Partial automation of upper-limb prosthesis socket design using machine learning.

The **Kimel Family Graduate Student Scholarships in Pediatric Disability Research** winners are:

Thierry Dugas,
Second year,
Master of
Applied Science
in Biomedical
Engineering,
University of
Toronto



Project (under the supervision of Dr. Jan Andrysek): Development and Validation of a Textile-Based Prosthetic Socket Pressure Sensing System

Amanda Chan,
Second year, PhD
in rehabilitation
sciences at the
University of
Toronto



Project (under the supervision of Dr. Timothy Ross): Redefining Recess: A Study of Autistic Students' Schoolyard Experiences

Michael Lam, First year, Master of Applied Science in clinical engineering, University of Toronto



Project (under the supervision of Dr. Elaine Biddiss): Measuring Player Engagement Across Difficulty Adjustment Methods in a Video Game for Teaching Music-Making to Children with Diverse Abilities

The **Whipper Watson Graduate Research Scholarship** winner is:

Humna Siddiqui, First year, Master of Science in the Institute of Medical Science, University of Toronto



Project (under supervision of Dr. Melanie Penner): Evaluating the effectiveness of the ENS pilot in Ontario in reducing utilization of emergency department services among children with extensive behavioural needs

Thank you for supporting BRI

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About Bloorview Research Institute

The Bloorview Research Institute (BRI) is embedded within Holland Bloorview Kids Rehabilitation Hospital, Canada's largest pediatric rehabilitation hospital that is fully affiliated with the University of Toronto. It has ranked amongst Canada's top 40 research hospitals for more than a decade. The institute is the only university-affiliated research institute in Canada dedicated to pediatric disability and one of very few in the world.

The BRI brings together teams of top researchers and trainees from a wide array of disciplines including physicians, psychologists, allied health professionals, engineers, neuroscientists, sociologists and even urban planners. Together, they work collaboratively with the community to co-design and conduct transformative, clinically relevant research focused on childhood-onset disability, injury and developmental diversity.

The research institute is guided by its four key priorities as part of its strategic priorities: to advance research practices through an inclusive, diverse, equitable, anti-racist and accessible lens, to fuel precision health, to empower a thriving research community and to enable transformational impact. Learn more: www.hollandbloorview.ca/BRI

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About Holland Bloorview Kids Rehabilitation Hospital

Holland Bloorview Kids Rehabilitation Hospital believes in creating a world where all youth and children belong. We are the only children's rehabilitation hospital in Canada focused on combining world-class care, transformational research, and academic leadership in the field of child and youth rehabilitation and disability. We are a top 40 Canadian research hospital that is fully affiliated with the University of Toronto. Providing both inpatient and outpatient services, Holland Bloorview is renowned for its expertise in co-creating with clients and families to provide exceptional care and is the only organization to ever achieve 100 per cent in three 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. Together we dream big. Together we champion a world of possibility.

For more information or to donate, please visit hollandbloorview.ca or connect on Twitter, Facebook, Instagram, LinkedIn and the parent-blog BLOOM.

Disclaimer: the program details in this booklet may not reflect any last-minute changes to the event. Please scan this QR code for the latest event details.

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The web and PDF versions of the impact report are accessible for screen readers and other accessible technologies.