

CHILD-BRIGHT
Network



Réseau
BRILLEnfant

Event Program

CHILD-BRIGHT
ANNUAL MEETING 2018





Welcome

Welcome to the CHILD-BRIGHT Annual Meeting 2018!

On behalf of the entire executive and central office team, I want to warmly welcome you to our 2018 CHILD-BRIGHT annual meeting. We are thrilled that so many of you have been able to travel to Montreal from different corners of the country to join us and we look forward to our time together.

Over the course of the next few days, we will discuss our shared mandate and brainstorm together ways to strengthen our connections among projects, programs, teams, and sites! It is our hope that by sharing on these topics, we will not only learn from each other, but also reflect on shared challenges (and solutions!) and discover ways to make CHILD-BRIGHT stronger and more sustainable in years to come.

We invite you to scroll through this document to view our full programming. You can also consult our event website, where we will consolidate any last-minute scheduling and programming changes, should they occur:

www.child-bright.ca/annual-meeting-2018
Password: Welcome

I also want to take this opportunity to express my sincere gratitude and thanks to our network funding partners—some of whom have been able to join us at this meeting—for their continued support of our work. CHILD-BRIGHT would not be possible without them.

Thanks so much to all of you for your efforts and commitment to our network’s goals and vision! Enjoy your time in Montreal.

Annette Majnemer

CHILD-BRIGHT Nominated Principal Investigator and Scientific Director
& Citizen Engagement Program Co-Lead



Share your photos online using the hashtag **#CBMeeting2018**

Take a moment at the end of each day to fill out our surveys. **See p. 17 for more details.**

Follow our work





Agenda-at-a-glance

WEDNESDAY, DECEMBER 5		THURSDAY, DECEMBER 6		FRIDAY, DECEMBER 7
7:00-8:00 a.m. Light Breakfast and Registration		7:00-8:00 a.m. Light Breakfast		7:00-8:00 a.m. Light Breakfast
8:00-8:30 a.m. Opening Remarks		8:00-9:00 a.m. All Voices Matter: Advancing Equity in Research		8:00 a.m.-12:00 p.m. CHILD-BRIGHT Policy Forum
8:30-9:15 a.m. Meet the Investigators		9:00-10:00 a.m. Learning Together: Shared Strategies and Resources Across the Network		
9:15-10:15 a.m. Can Patient-Partners Inform Investigators on How to Improve Recruitment Rates?		10:30 a.m.-noon A Roadmap Towards Brighter Futures: What Is the Best Route to Take?		
10:45 a.m.-12:15 p.m. Stakeholder Engagement: Where Are We in Our Quest for Social change?		12:00-1:00 p.m. Networking Lunch		
12:15-1:15 p.m. Networking Lunch		1:00-2:00 p.m. Health Economics group meeting		12:00-1:00 p.m. Lunch
1:15-2:45 p.m. Training for Sustainability in Patient-Oriented Research		1:00-3:00 p.m. READYorNot group meeting		
3:15-5:00 p.m. Poster Session	3:15-6:15 p.m. Citizen Engagement Council Meeting	3:15-4:15 p.m. CCENT Group Meeting	12:15-1:45 p.m. International Scientific Advisory Committee Meeting	
	Data Safety Monitoring Board Meeting	4:15-5:15 p.m. Health Economics group meeting	12:15-2:15 p.m. Patient/Family Lunch and learn	
5:00-7:00 p.m. Poster Cinq à Sept	Knowledge Translation Program Meeting	4:15-6:15 p.m. Training Group Meeting	1:45-4:45 p.m. Network Steering Committee Meeting	
7:00 p.m. Social Dinner	6:30-8:30 p.m. Research Core Program Meeting			
	Training Program Meeting			

- General Programming
- Committee and Group Meetings
- Optional Events

Detailed Event Programming

DAY 1 SPEAKERS



Kathryn Birnie

is a CIHR-funded postdoctoral fellow at the Hospital for Sick Children under the supervision of Dr. Birnie. She completed her PhD in Clinical Psychology from the University of Toronto. Dr. Birnie's research interests include child and adolescent mental health, and youth experiencing pain and illness. She is currently co-leading a CIHR-funded national patient survey on the topic of pediatric chronic pain.



Mathias Castaldo

is a student at Ryerson University. Mathias has been a volunteer at the Hospital for Sick Children since 2015. He is currently a member of the Youth Council as well as a member of the Education Team. He has participated in various programs, including the Youth Council's "Disability Awareness" program, and has been involved in various community projects. He is currently a member of the Youth Council as well as a member of the Education Team.



Crystal Chiu

is a student at the University of Toronto. She is currently a member of the Youth Council as well as a member of the Education Team. She has participated in various programs, including the Youth Council's "Disability Awareness" program, and has been involved in various community projects. She is currently a member of the Youth Council as well as a member of the Education Team.



Eyal Cohen

is a student at the University of Toronto. He is currently a member of the Youth Council as well as a member of the Education Team. He has participated in various programs, including the Youth Council's "Disability Awareness" program, and has been involved in various community projects. He is currently a member of the Youth Council as well as a member of the Education Team.



Jennifer Crosbie

is a Clinical Psychologist and the Clinical Scientist within the Department of Psychiatry and the Clinical Scientist of the Mental Health Access Program at SickKids. Dr. Crosbie is an Assistant Professor at the University of Toronto. She is currently a member of the Youth Council as well as a member of the Education Team.



Dana Geall

is the mother of two children. She is currently a member of the Youth Council as well as a member of the Education Team. She has participated in various programs, including the Youth Council's "Disability Awareness" program, and has been involved in various community projects. She is currently a member of the Youth Council as well as a member of the Education Team.



Get ready!

Throughout the meeting, we will ask you for your opinion! You can use your phone, tablet or laptop to respond. You don't need to download anything.

You can participate by sending a text message or visiting the URL from any web browser. The presenter will provide the URL and text number during the session.

DAY 1 - WEDNESDAY, DECEMBER 5

7:00-8:00 a.m.

Foyer 1

LIGHT BREAKFAST AND REGISTRATION

8:00-8:30 a.m.

Rose-Fuchsia Room

General Programming

OPENING REMARKS

Nancy Mason MacLellan, Lucy Lach, and Frank Gavin

ALSO AVAILABLE ONLINE

www.child-bright.ca/annual-meeting-2018
(Password: Welcome)



8:30-9:15 a.m.

Rose-Fuchsia Room

General Programming

MEET THE INVESTIGATORS

Steven Miller, Anne Synnes, Don Mabbott, Darcy Fehlings, Adam Kirton, Patricia Birch, Astrid Guttmann, Hal Siden, Patrick McGrath, Lucy Lach, Keiko Shikako-Thomas, Jennifer Crosbie, Julia Orkin, Maureen O'Donnell, and Ariane Marelli

The research being conducted by CHILD-BRIGHT investigators has the potential to change the lives of those living with brain-based developmental disabilities and their families. At this session, an investigator from each CHILD-BRIGHT project will tell us about the story behind their research question and give us a brief update on their project.

Objectives:

1. To put a face to the name of an investigator from each project.
2. To understand the motivation behind their research and get a brief update on their project.
3. To promote the poster session presentations.

9:15-10:15 a.m.

Rose-Fuchsia Room

General Programming

CAN PATIENT-PARTNERS INFORM INVESTIGATORS ON HOW TO IMPROVE RECRUITMENT RATES?

Lucy Lach (moderator), Ali Martens, Lori Seller and Barb Galuppi

Many study-eligible participants choose not to participate in research, and they might decline because of issues with the protocol, participating would be inconvenient, or other reasons. Researchers aim to recruit participants as efficiently and sensitively as possible, but could an open discussion about recruitment practices lead to higher recruitment rates and more satisfied participants?

Objectives:

1. Learn strategies from the patients themselves about what to do to improve recruitment.
2. Learn how researchers and administrators approach recruitment.
3. Assess whether there is a gap that can be closed between the needs of the patients and the strategies of the researchers.

10:15-10:45 a.m.

Foyers 1 & 2

BREAK

10:45 a.m.-12:15 p.m.

Rose-Fuchsia Room

General Programming

STAKEHOLDER ENGAGEMENT: WHERE ARE WE IN OUR QUEST FOR SOCIAL CHANGE?

Jonathan Weiss, Connie Putterman, and Keiko Shikako-Thomas

In this session, we will present the current state of stakeholder engagement at CHILD-BRIGHT and how it is currently being measured. We will work together to revisit our engagement strategies and find common solutions to improve the way we engage with stakeholders and measure its outcomes.

Objectives:

1. To present different perspectives on stakeholder engagement from an invited guest.
2. To describe our findings and current status of stakeholder engagement in the CHILD-BRIGHT Network.
3. To establish the role of the Knowledge Translation Program in developing the measurement tool and analyzing stakeholder engagement in the network.
4. To identify our strengths, gaps, and discuss solutions to improve stakeholder engagement.
5. To have CHILD-BRIGHT members share what they have done with regards to stakeholder engagement, and discuss what can be done differently.

12:15-1:15 p.m.

Foyers 1 & 2

NETWORKING LUNCH



1:15 p.m-2:45 p.m.

Rose-Fuchsia Room

General Programming

TRAINING FOR SUSTAINABILITY IN PATIENT-ORIENTED RESEARCH*Kent Cadogan-Loftsgard, Amy Outschoorn, Leah Getchell, Caroline Wong, Tracy Jirikowic, and Katherine Bevans*

Through a co-building approach, patient engagement is proving to be critical to the research process. Patient-partners' strong initial enthusiasm for involvement in research can wane due to extended timelines or lack of effective communication by team leaders. How does the research project team meaningfully and practically sustain patient engagement once participants are recruited or involved? What critical role can the Training Program play to facilitate this process?

Objectives:

1. To explore recurring issues that commonly impede or promote sustainable patient engagement.
2. To share practical lessons learned relative to patient engagement strategies.
3. To appreciate the structures or mechanisms needed to support successful patient engagement.
4. To delineate specific training resources that can inform effective and meaningful patient engagement, or identify unmet needs.

2:45-3:15 p.m.

Foyers 1 & 2

NETWORKING BREAK

3:15-4:15 p.m.

Zibo Room

Closed Meeting

CCENT GROUP MEETING

This is a closed group meeting organized by Arpita Parmar.

3:15-5:00 p.m.

Foyer 1

General Programming

POSTER SESSION

All meeting attendees including patients, families, trainees, staff, and faculty, are invited to attend our Poster Session (3:15-5:00 p.m.) and our Poster cinq à sept (5:00-7:00 p.m.). This session is an ideal opportunity for multidisciplinary health professionals, researchers, and patients/families to illustrate the extensive ongoing and innovative activities within their projects and initiatives that are focused on childhood brain-based developmental disabilities. We are excited to invite CHILD-BRIGHT members and all other meeting attendees to showcase their ongoing research work. The aim of this poster session is to share progress updates of their work over the previous year and to further strengthen connections between all members.

3:15-6:15 p.m.

Cyan Room

Closed Meeting

CITIZEN ENGAGEMENT COUNCIL MEETING

This is a closed committee meeting.

3:15-6:15 p.m.

Orange Room

Closed Meeting

DATA SAFETY MONITORING BOARD MEETING

This is a closed committee meeting.

3:15-6:15 p.m.

Indigo Room

Closed Meeting

KNOWLEDGE TRANSLATION PROGRAM MEETING

This is a closed committee meeting.

4:15-5:15 p.m.

Violet Creative Lounge

Closed Meeting

HEALTH ECONOMICS MEETING

This is a closed group meeting organized by Brittany Finlay.

4:15-6:15 p.m.

Zibo Room

Closed Meeting

TRAINING GROUP MEETING

This is a closed group meeting organized by Pierre Zwiegers.



5:00-7:00 p.m.

Foyer 1

General Programming

POSTER *CINQ À SEPT*

In Quebec, a *cinq à sept* brings together friends and colleagues around a specific event, in a setting where wine, beer, and cocktails are served alongside finger foods and hors d'oeuvres. It's akin to a wine and cheese, or a slightly more formal happy hour. It's an ideal venue for multidisciplinary health professionals, researchers, and patients/families to gather and converse about the extensive and innovative activities going on within their projects.

6:30-8:30 p.m.

Cyan Room

Closed Meeting

RESEARCH CORE PROGRAM MEETING

This is a closed committee meeting.

6:30-8:30 p.m.

Indigo Room

Closed Meeting

TRAINING PROGRAM MEETING

This is a closed committee meeting.

7:00 p.m.

Zibo Restaurant

Registration Required

CHILD-BRIGHT SOCIAL DINNER

All who registered are invited to gather at the restaurant at 7:00 p.m.!

7:00-8:00 a.m.

Foyer 1

LIGHT BREAKFAST

8:00-9:00 a.m.

Rose-Fuchsia Room

General Programming

ALL VOICES MATTER: ADVANCING EQUITY IN RESEARCH

Frank Gavin (moderator), Lucy Lach (moderator), Brenda Elias, Pam Naponse-Corbiere, Brenda Johnson, David Nicholas, Nancy Poole, Aline Bogossian, Maryam Oskoui, Kate Robson, Jill Hanley, Laura Pacheco, and Dolly Menna-Dack

This session will focus on “how” rather than “why” we should be engaging populations who have often not been included adequately or at all as subjects or as partners in research related to children with disabilities. Among the populations we will be considering are parents and children with intellectual disabilities, Indigenous people, people who live with financial hardship, and immigrant and refugee families. Each facilitated round-table group will focus on one population for 30 minutes. Participants can then choose to stay with the same population for another 30 minutes or move to a different table to discuss engagement with a different population. Together, we will identify barriers and ways to overcome them.

Objectives:

1. To reinvigorate commitment to expanding the patient-partner demographic.
2. To generate a set of actions for engagement based on dialogue at each table.

Tables and Topics:

1. Indigenous People (Brenda Elias)
2. Indigenous People (Pam Naponse-Corbiere and Brenda Johnson)
3. Children and youth with intellectual disabilities (David Nicholas)
4. LGBTQ2S (Nancy Poole)
5. Fathers (Aline Bogossian)
6. Children and youth with rare disorders and their families (Maryam Oskoui)
7. Parents of severely disabled children (to be announced)
8. Parents living with income insecurity (Kate Robson)
9. Newcomers whose first language is not English (Jill Hanley)
10. Parents with intellectual disabilities (Laura Pacheco)
11. Youth who use communication devices and/or live with multiple diagnoses (Dolly Meena-Dack)



9:00-10:00 a.m.

Rose-Fuchsia Room

General Programming

LEARNING TOGETHER: SHARED STRATEGIES AND RESOURCES ACROSS THE NETWORK

Eyal Cohen (moderator), Adam Kirton (moderator), Patrick Berrigan, Wendy Ungar, Jennifer Zwicker, Nora Fayed, Rick Watts, Maryna Yaskina, Tanya Voth, Lawrence Richer, Jan Willem Gorter, Andrea Cross, Donna Thomson, Julia Orkin, Aryeh Gitterman, Connie Putterman, Pierre Zwieggers, Josée Della Rocca, Valerie Frost, and Michael Shevell

CHILD-BRIGHT members are developing expertise and resources for their project that could be useful for your project. One of the main benefits of working in a network is the opportunity to share this expertise and these resources across the network, so that the network becomes greater than the sum of its parts. This is a one hour session that attendees will split between 2 tables to learn about their peers' resources or strategies that could be integrated into future research activities.

Objective:

The objective of this session is for network members to learn about 2 resources or strategies developed by a CHILD-BRIGHT peer that could be integrated in a future research project.

Tables and Topics:

1. Measuring health and non-health resource use and costs for economic evaluation (Patrick Berrigan, Wendy Ungar, and Jennifer Zwicker)
2. Optimizing patient-reported outcome and experience measures for clinicians and patient stakeholders (Nora Fayed)
3. How the Data Coordinating Centre can help you (Rick Watts and Maryna Laskina)
4. Secondary Data Use (Tanya Voth and Lawrence Richer)
5. Engaging the Public in Research on Twitter: practical pointers (Jan Willem Gorter)
6. Family engagement in research in the digital age: Exploring how family-researcher partnerships are fostered through online Facebook groups (Andrea Cross and Donna Thomson)
7. Collaboration and Co-design – Family Advisory Groups for Research and Clinical Care (Julia Orkin)
8. Using CHILD-BRIGHT's iKT Tracking Tool to document and improve engagement strategies (Aryeh Gitterman and Connie Putterman)
9. Resources available through CHILD-BRIGHT's Training Program (Pierre Zwieggers)
10. How to keep donors and foundations engaged in research: Perspectives from foundation representatives (Josée Della Rocca and Valerie Frost)
11. Fundraising for your research: How to develop and strengthen relationships with foundations (Michael Shevell)

10:00-10:30 a.m.

Foyers 1 & 2

BREAK

10:30 a.m-noon

Rose-Fuchsia Room

General Programming

A ROADMAP TOWARDS BRIGHTER FUTURES: WHAT IS THE BEST ROUTE TO TAKE?

Annette Majnemer, Michael Shevell, and Kate Robson

This session will provide a capsule summary of the key accomplishments thus far by CHILD-BRIGHT across the various programs and services. As a collective community, we will consider the ways that being part of this network provides added value to our individual members, to the research projects, and ultimately to children with brain-based developmental disabilities and their families. Together we will explore ways to maximize the benefit of CHILD-BRIGHT membership for all stakeholders, and we will co-build a sustainability plan so as to ensure that the network continues to support our collective vision beyond 2021. Our network is now well established, and as we look forward, we will need to prioritize particular areas to ensure that we achieve brighter futures for children with developmental disabilities and their families.

Objectives:

1. To summarize the key successes of CHILD-BRIGHT over the first two years as a SPOR network.
2. To determine what the value added is for members to be part of this network, and discuss how best to maximize this benefit.
3. To co-build a sustainability plan.
4. To collectively prioritize the areas to improve upon in our network's programs and processes, including enhancing the level of citizen engagement.

Noon-1:00 p.m.

Foyers 1 & 2

NETWORKING LUNCH

12:15-1:45 p.m.

Cyan Room

Closed Meeting

INTERNATIONAL SCIENTIFIC ADVISORY COMMITTEE MEETING

This is a closed committee meeting

12:15-2:15 p.m.

Indigo Room

Registration Required

PATIENT/PARENT LUNCH AND LEARN

All who registered are invited to gather in the Indigo Room at 12:15 p.m.!

1:00-2:00 p.m.

Violet Creative Lounge

Closed Meeting

HEALTH ECONOMICS MEETING

This is a closed group meeting organized by Brittany Finlay.

1:00-3:00 p.m.

Zibo Room

Closed Meeting

READYORNOT MEETING

This is a closed group meeting organized by Alicia Via-Dufresne Ley.

1:45-4:45 p.m.

Orange Room

Closed Meeting

NETWORK STEERING COMMITTEE MEETING

This is a closed committee meeting.



7:00-8:00 a.m.

Foyer 1

LIGHT BREAKFAST

8:00 a.m.-noon

Orange Room

Registration Required

POLICY FORUM

Aryeh Gitterman (moderator), Alexander Bezzina, Mary Ann McColl, Anne Fuller, and Bruce Rodrigues

This session will connect policymakers from across Canada with patient-partners, service providers, and researchers. This multi-stakeholder group will jointly tackle important issues related to the care of children and youth with neurodevelopmental disabilities. Leading up to the Forum, each invited policymaker will be tasked with defining a major gap between government policy and care delivery. These prioritized areas will be presented to forum attendees for input as well as developing a potential plan of action to address the identified gaps.

Objectives:

1. Develop a mutual understanding of the individual and collective roles that researchers, policy makers, and patient-partners can and do play in shaping policy (e.g. advocacy, dissemination of knowledge, communication of findings, creation of policy, seeking information).
2. Develop a plan of action to address the gaps identified by policymakers.
3. Practically demonstrate how research and ideas translate into public policy.
4. Provide the opportunity for both patient-partners and researchers to communicate with policymakers.

Noon-1:00 p.m.

Orange Room

LUNCH

All who registered for the Policy Forum are invited to gather in the Orange Room at noon!



Your Voice Matters

At the end of our annual meeting, please take a moment to share your comments with us.

Your feedback will continue to steer our work and will help us better customize future meetings, objectives, and programming to meet the needs of all members of our network.

Annual Meeting (Dec. 5 & 6)

bit.ly/CBMeeting_Survey



Policy Forum - December 7

bit.ly/PolicyForum_Survey



Thank you!



Speakers & Contributors

BRAIN-CHILD-PARTNERS CONFERENCE
NOVEMBER 6-8, 2017 | TORONTO, CANADA

PATRICK BERRIGAN

Research Coordinator,
Health Economics



DAY 2

9:00 a.m.

“CHILD-BRIGHT plays an important role in generating new knowledge that can be helpful to families living with neurodevelopmental disorders and other disabilities. CHILD-BRIGHT allows patients, families, health care providers, and researchers to work together and gain insights from each other.”

I work in the field of health economics as a Research Associate at the University of Calgary and CHILD-BRIGHT Health Economics Research Coordinator. My goal is to help assess the cost associated with new treatments, because treatments are only useful if the health care system can afford to implement them.”

KATHERINE BEVANS

POR Community Partner



DAY 1

1:15 p.m.

“As an Associate Professor at the Temple University College of Public Health, Department of Rehabilitation Sciences, I believe that engaging youth and caregivers as true collaborators in research is essential for ensuring that research has meaningful effects on people’s lives. We developed Family Youth Researcher Education (FYREworks), a set of interactive, web-based training modules and resources that prepare youth and collaborating researchers to establish, maintain, and operate research partnerships. The FYREworks training material provides a basic introduction to partnership-based research principles and empowers youth and caregivers to share their unique perspectives and expertise with multi-stakeholder research teams. FYREworks may be useful as a supplement to CHILD-BRIGHT’s patient-oriented research training.”

ALEXANDER BEZZINA

Policy Expert



Policy Forum

“For the past 35 years, I have been deeply committed to the improvement of the lives of vulnerable people. From 1983 to 1999, I worked directly with clients in the non-profit sector. I then joined the Ontario Public Service where I held senior executive positions in several social policy ministries. In March 2012 I was appointed Deputy Minister of Children and Youth Services, and from 2016 until my retirement in 2018 I was the Deputy Minister of Citizenship and Immigration. Throughout my career of policy development and service delivery, I ensured that people and their needs remained front and centre, and that evidence and research were cornerstones of my advice to government. By sharing my experiences of successful collaboration between policy makers and researchers, I hope to add value to CHILD-BRIGHT’s vision and mission.”

PATRICIA BIRCH

CHILD-BRIGHT Research
Project Team Member



DAY 1

8:30 a.m.

“I am the Project Research Manager for the IMAGINE project. IMAGINE is one of the CHILD-BRIGHT Network research projects and gives formal support to the participant-centred research and care that is central to my philosophy as a nurse and researcher. Within the realm of genome sequencing, there is no testing decision that is ‘right’ for everyone. What matters is that health care consumers reach decisions that are consistent with their own values, and that full communication with families—to the extent that they choose—respects their autonomy, builds on their strengths, and supports their decision-making. Our team is working with our study’s participants to learn how best to include them, communicate the research process, and advocate for them.”

Community Engagement Partner



DAY 2 8:00 a.m.

“CHILD-BRIGHT signifies hope, community, and a space of unity for people with different types of expertise and mutual interests. Together, we are working in meaningful and creative ways.

I am a trained social worker and social science researcher working at l’Université de Montréal. For over 10 years, I have had the privilege of working on different research projects that focus on families of children with neurodisabilities, and have learned that dads are an underrepresented population both in pediatric settings and in parenting research. This means that very little is known about their experiences and how to best engage and support them. I am very excited to have these conversations and think about father-inclusive practice!”

CHILD-BRIGHT Committee Member and Patient-Partner



DAY 1 1:15 p.m.

“Positive experiences during my formative years as a pediatric chronic asthma and congenital cerebral palsy patient, treated at British Columbia’s Children’s Hospital, were my initial inspiration to pursue my diverse health professional background as a health communications producer and clinical educator. Working with CHILD-BRIGHT represents another welcome opportunity to apply my qualifications in support of our constant efforts to improve the design and delivery of patient-centered care and patient-oriented research. As a part of the Training Committee, my primary role is to help drive the network’s overall vision of enhancing capacity in the area of patient-oriented research.”

CHILD-BRIGHT Principal Investigator



Program Committee
DAY 2 9:00 a.m.

“CHILD-BRIGHT is a community of patients, their families, clinicians, and researchers who all come together to try to improve the lives of children with brain-based developmental disabilities.

As a pediatrician, researcher for SickKids, and the co-lead of the BRIGHT Futures theme at CHILD-BRIGHT, I am helping guide project teams within the network who are looking at ways to redesign health care systems and services to be more responsive to family needs. I am also helping lead the Coached, Coordinated, Enhanced Neonatal Transition (CCENT) project within that theme, which is focused on coaching and care coordination during the time of transition out of the neonatal intensive care unit.”

CHILD-BRIGHT Principal Investigator



DAY 1 8:30 a.m.

“The Mega Team project aims to create and investigate a novel video game-based cognitive intervention that may be beneficial for children with a range of brain-based disorders.

CHILD-BRIGHT is an opportunity to interact with and learn from researchers, clinicians, patients, families, and community partners.

Feedback and collaboration with children, youth and their families with lived experience is vital to creating an engaging and useful intervention. The families’ contribution is equally crucial in determining meaningful outcomes.”

CHILD-BRIGHT Collaborator

CHILD-BRIGHT Funding Partner Representative

Community Engagement Partner

CHILD-BRIGHT Research Project Team Member



DAY 2 9:00 a.m.

DAY 2 9:00 a.m.

DAY 2 8:00 a.m.

DAY 2 9:00 a.m.

“Researchers and citizens bring complementary knowledge and expertise to a research project and by working together we can improve the research process and outcomes. An important first step to citizen engagement is to develop authentic and meaningful partnerships.

As a facilitator for the Learning Together roundtable discussion, I will share how an online Facebook Group ‘Parents Partnering in Research’ has helped researchers and families build a trusted community to support meaningful engagement throughout the research process.”

“Philanthropy is behind numerous innovative projects, research discoveries, and programs that bring social change to our communities. The CHILD-BRIGHT Network is a perfect example of a project that approaches health care challenges in novel and collaborative ways. As the Director of Partnerships at the Montreal Children’s Hospital Foundation, I am privileged to be involved and to contribute through the support of our donors. It gives me a great sense of pride to know that ultimately, the lives of children and their families, and the quality of care and services offered to them, will be improved thanks to this groundbreaking research.”

“CHILD-BRIGHT is about dignity realized through courtesy, recognition, acceptance, generosity, presence, love, advocacy, levelling and empowerment. It is also about children’s rights grounded in human dignity, autonomy, equality, and solidarity. All children are deemed invaluable, capable and deserving of respect, and CHILD-BRIGHT helps advance understanding, interactions and practices that promote positive participation, opportunity, non-discrimination, and the wellbeing of children. As Associate Professor at the University of Manitoba, Max Rady College of Medicine, I am also working towards these goals. Through “Translating to the Community: A social epigenetic study of FASD” and the “Looking after each other: A dignity promotion partnership for those impacted by FASD”, we are collectively advancing the dignity and rights of children.”

“CHILD-BRIGHT is about connecting with like-minded people who share the common pursuit of improving the daily lives of children with neurodisabilities and their families. It’s about giving researchers, patients and service providers a way to interact and work together to meet new challenges with new solutions.

As a child-health researcher, I am concerned with the measures we use to determine whether care is working for children and their families. Children and families have, in the past, not been involved in developing or selecting the measures that are so important to telling their stories. I’d like to work with like-minded people who want to tackle that problem and solve it.”

CHILD-BRIGHT
Principal Investigator



DAY 1 8:30 a.m.

“I am Head of the Division of Developmental Paediatrics and a Professor in the Department of Paediatrics at the University of Toronto. I am also a Senior Clinician Scientist in the Bloorview Research Institute. My research focuses on the innovation and evaluation of interventions for children with cerebral palsy.

I feel citizen engagement in research is critically important across all aspects to help ensure that the research is impactful and meaningful, and that the findings get incorporated into the real world.”

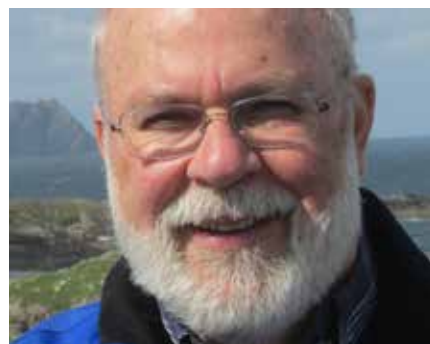
CHILD-BRIGHT Funding
Partner Representative



DAY 2 9:00 a.m.

“Philanthropy is behind numerous innovative projects, research discoveries and programs that bring social change to our communities. The CHILD-BRIGHT Network is a perfect example of a project that approaches health care challenges in novel and collaborative ways. As Director of Stewardship and Donors relations at the Montreal Children’s Hospital Foundation, I am part of a fundraising team that is privileged to be involved in CHILD-BRIGHT and contribute to the network through the support of our donors. It gives us a great sense of pride to know that ultimately, the lives of children and their families, and the quality of care and services offered to them will be improved thanks to this groundbreaking research.”

CHILD-BRIGHT
Citizen Engagement Director



Program Committee
DAY 2 8:00 a.m.

“CHILD-BRIGHT has been a gift, especially in terms of the people I have gotten to know in so many parts of the network. It is also an opportunity for all of us to make a whole series of distinct but related advances that will be significant for children and families, even when seemingly small. And by bringing together a variety of children, youth, families, and a range of researchers (young and old) in the ways we have, I hope and believe we can permanently change—in good and necessary ways—the culture of health research related to children and the future we will all inhabit.”

SPOR Community Partner



DAY 1 1:15 p.m.

“I’m so happy to be here at the CHILD-BRIGHT annual meeting representing a sister SPOR chronic disease network, Can-SOLVE CKD (focussed on chronic kidney disease).

I came to Can-SOLVE CKD as a Patient Engagement and Training Facilitator about 3 years ago, and also as a patient partner; my mom had kidney disease and I was also at the time working for a provincial kidney research group in Ontario. My mom was a professional storyteller and now, I have this amazing job where I get to help kidney patients tell their stories to enhance research—divine intervention, I think so!”

CHILD-BRIGHT
Committee Member



Policy Forum

“My interest in the intersection of policy and research dates to my time at the Ontario Ministry of Education. Understanding research was very helpful in finding common ground among the many people and organizations who had an interest in education policy. During my time at the Ministry of Children and Youth, I was responsible for policies related to children and youth with special needs, and children on the spectrum. Researchers and their work were very helpful in navigating the landscape of special needs and ASD program development. I hope that CHILD-BRIGHT can continue to forge strong bonds between these two ‘worlds.’”

CHILD-BRIGHT
Principal Investigator



DAY 2 9:00 a.m.

“As the Co-Principal Investigator for the READYorNot™ Brain-Based Disabilities Moving Ahead with Transition of Care from Adolescence to Adulthood project, my research focuses on improving the health and well-being of youth with disabilities and their families, with a special interest in transition from pediatric to adult healthcare.

In my clinical work, I am committed to the family-centred model of care. In our CHILD-BRIGHT transition project, we are developing and evaluating an e-health application in partnership with patients and families, with the goal of helping prepare youth to take charge of their health. I am inspired by the rich and valuable insights of the youth and families involved in our project, as we work together on sorting the pieces of the transition puzzle!”

CHILD-BRIGHT
Principal Investigator



DAY 1 8:30 a.m.

“As a CHILD-BRIGHT Steering Committee member and co-lead of a project exploring prenatal opioid exposure and implications for child development, I am grateful to CHILD-BRIGHT for supporting participatory action research to better understand the incidence of prenatal opioid exposure in First Nation communities in Southern Ontario, its impact on communities, and the strengths that exist to address it.

In partnership with the Community Wellness Development Team, First Nations communities and community leaders, the Institute for Clinical Evaluative Sciences, and the University of Ontario Institute of Technology, we look forward to further engaging with the broader CHILD-BRIGHT community about next steps for this.”

Community Engagement
Partner



DAY 2 8:00 a.m.

“I am an Associate Professor at the McGill School of Social Work, where I teach on issues of social policy, migration, and community organizing.

My research focuses on access to social rights (health, labour, housing) for precarious status migrants.

I am also co-founder of the Immigrant Workers Centre, where I have been actively involved for nearly 20 years.”

CHILD-BRIGHT Committee Member and Patient-Partner



Program Committee

“CHILD-BRIGHT for me is all about helping children (and their families!) have a better quality of life.

As a patient-partner, and someone with lived experience in some of the issues that the network is researching, I get to use what I know best, my experience, to be a (rather loud) voice for patients at different levels of the CHILD-BRIGHT Network, and wherever else I seem to go.”

POR Community Partner



DAY 1 1:15 p.m.

“Engagement is important to understand priorities that matter for families and children who are recipients of health care and related services, and to support participation in research. We are engaging a network of community stakeholders that include individual self-advocates, parents, health professionals, researchers and community organization administrators, and members in research capacity building. At PCORI, our goal is to identify research priorities and meaningful outcomes to study linkages between social participation in communities and health and well-being.

As an Associate professor at the University of Washington, I hope to share experiences and lessons learned from our project engaging this matrix of stakeholders locally and nationally.”

CHILD-BRIGHT Principal Investigator



DAY 1 8:30 a.m.

DAY 2 9:00 a.m.

“CHILD-BRIGHT is an example of national networking in the truest sense of the word; bringing together many relevant voices to make real progress toward better outcomes for children with disabilities and their families.

In my work as a pediatric neurologist and clinician scientist at the Alberta Children’s Hospital, I provide opportunities for children with disabilities to try new ways by which they might realize new opportunities to steepen their developmental trajectories. We are conducting a novel, patient-centered, goal-directed, peer-supported trial to see if non-invasive brain stimulation can enhance the natural ability of young brains to learn new skills.”

CHILD-BRIGHT Principal Investigator



DAY 1 8:30 a.m.

“Citizen engagement is important for research as it ensures that the research questions asked are relevant to patient populations. The personal experiences and perspective of patients, families, and caregivers provide invaluable feedback that will guide the development and progress of a study as well as interpreting results.

I am the ABPP Program Head, Neurosciences & Mental Health at The Hospital for Sick Children Research Institute. As a psychologist, I provide services to children with brain tumours and their families. My research focuses on fostering brain repair and cognitive recovery following acquired brain injury in children. Using brain imaging and psychological tests I study the impact of brain injury on how the brain grows and develops in childhood.”

CHILD-BRIGHT Nominated
Principal Investigator &
Scientific Director

DAY 2

10:30 a.m.

“I feel privileged to have the opportunity to co-lead the CHILD-BRIGHT Network together with our Executive team, and under the direction of our dedicated patient-partners.

In my role as CHILD-BRIGHT Nominated Principal Investigator and Scientific Director, and in my functions as Citizen Engagement Program Co-Lead, I am learning a great deal about patient-oriented research, and gaining valuable insight into the different perspectives of our network members, on this topic.

I am proud of all that we are accomplishing together for children with disabilities and their families.”

CHILD-BRIGHT
Communications Manager

Program Committee

“In my functions as Communications Manager, I have the unique opportunity to collaborate with all members of our network; I help share knowledge about patient-oriented research, help promote our work to new audiences, and help raise the visibility of CHILD-BRIGHT as an up-and-coming Canadian leader in the field of patient-oriented research.

As the mother of a child with epilepsy, I am excited to see so many great minds, from many different fields of expertise, gathering around the important cause of helping children with brain-based developmental disabilities. I’m honoured to contribute to this effort by helping put in place solid and sustainable communication bridges between these people, pathways of communication that I believe are critical to our long-term success.”

CHILD-BRIGHT
Principal Investigator

DAY 1

8:30 a.m.

“The CHILD-BRIGHT network has provided a unique opportunity to develop and test a digital intervention to improve the transition of care journey. I am leading the development of the MyREADY Transition App in collaboration with 360Medlink, McMaster University (Jan Willem Gorter), University of Toronto, University Hospital Health Network (Khush Amaria and Adrienne Kovacs) and Ronen Rozenblum (Brigham and Women’s Hospital) along with our research teams. This intervention will be deployed in an RCT across Canada. We have directly engaged patients, their caregivers, and families as partners in research through a Patient and Family Advisory Council that has directly informed the design and testing of the intervention.”

CHILD-BRIGHT
Patient-Partner

DAY 1

9:15 a.m.

“CHILD-BRIGHT to me is an opportunity to get involved on a national level in pediatric health care research. It is a beacon of hope for me as a mom. The idea of research being done in our own country—research that will help future families who are dealing with struggles similar to ours—is huge for me.

As a volunteer member of multiple parent advisory committees through both the health and human services branches of the Alberta Government, I get to share the relevant bits and pieces of our story as well as shed light on what new legislation or policies will mean for families.

I enjoy my roles on these committees and love to be involved in discussions regarding issues that impact our everyday life.”

SPOR Representative



DAY 1

8:00 a.m.

“Having been with the Canadian Institutes of Health Research for over 18 years, I have managed funding initiatives across the spectrum of health research.

My current responsibilities as Manager of Major Initiatives in the Research, Knowledge Translation and Ethics Portfolio at CIHR include the management and oversight of Canada’s Strategy for Patient-Oriented Research, the Drug Safety and Effectiveness Network, as well as the implementation of CIHR’s Patient and Citizen Engagement Strategies.”

CHILD-BRIGHT
Principal Investigator



DAY 1

8:30 a.m.

“I am a clinical child psychologist and have devoted my life to making my research make a difference in the lives of children and families. CHILD-BRIGHT—and more specifically my work with the Strongest Families Neurodevelopmental project—has been an opportunity to meet a critical need for interventions by making mental health care available to children with neurodevelopmental disabilities in the privacy and comfort of their own homes.

CHILD-BRIGHT is changing the face of health care. I am proud to be part of it.”

Policy Expert



Policy Forum

“I am a Professor in the departments of Rehabilitation Therapy and Public Health Sciences at Queen’s University; Associate Director at the Centre for Health Services & Policy Research; and Academic Lead for the Canadian Disability Policy Alliance. I am the author of Disability & Social Policy in Canada (2nd ed., 2006), Introduction to Disability (1998), Emerging Models of Chronic Disease Management (2006), and Inter-Professional Primary Health Care (2009). My latest book, Appreciative Disability Studies, is due to be released in March 2019. I have also authored several books in occupational therapy: the Canadian Occupational Performance Measure (5th ed., 2014), Spirituality and Occupational Therapy (2nd ed., 2011), Theoretical Basis of Occupational Therapy (3rd ed., 2015), and Interventions, Effects and Outcomes in Occupational Therapy (2010).”

CHILD-BRIGHT
Committee Member



DAY 2

8:00 a.m.

“CHILD-BRIGHT is an innovative and dedicated community filled with passion for generating new knowledge that will impact the lives of kids and their families.

I am so pleased to be working with CHILD-BRIGHT to create a National Youth Advisory Panel (NYAP).

Youth with brain-based neurodevelopmental disabilities have a wealth of knowledge that they are waiting to share. CHILD-BRIGHT has taken the time to ensure that youth have a mechanism that they can shape to provide input into the network.”

CHILD-BRIGHT Scientific Co-Director & Principal Investigator



DAY 1 8:30 a.m.

“As a patient-oriented research network dedicated to improving the outcomes of children with brain-based developmental disabilities and their families, CHILD-BRIGHT is enabling me and my team to listen to parents’ hopes and dreams. I am confident that the engagement of families in the research process will make our research more impactful in supporting children with brain-based developmental disabilities.

I work with Alan Cooper and the engaged Research Committee to ensure that our pan-Canadian portfolio of research is as impactful as possible towards the goal of improving the lives of children with brain based developmental disabilities and their families.”

CHILD-BRIGHT Research Project Team Member



DAY 2 8:00 a.m.

“My name is Pam Naponse-Corbiere. I am from a small community in Northern Ontario- Atikameksheng Anishnawbek and am a proud Ojibway Anishnabe kwe (woman), mother of two beautiful daughters, and married for 25 years to my wonderful husband and best friend. Working for our First Nation communities and organizations for over 20 years in health, community development, governance, and social work has been a rewarding and challenging experience. It is important that when working with First Nation families/communities, we remember that respect, sharing, and communication is a good practise. Our culture guides our practises, our lifestyles, and our families growth. Working face-to-face, visiting communities; listening to our Elders, participating in community events has been an enlightening and rewarding experience. Meegwetch (thank you).”

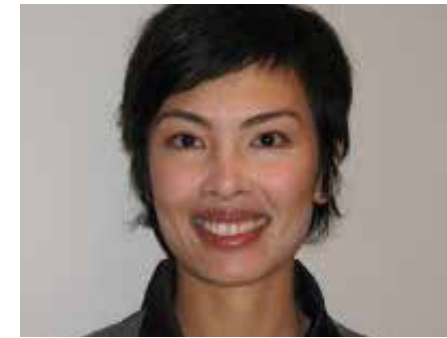
Community Engagement Partner



DAY 2 8:00 a.m.

“As a Professor in the Faculty of Social Work at the University of Calgary (Edmonton Division), my research addresses quality of life, employment support and transition in disability, family support, parenting, family-centred care, chronic illness, and neurodevelopmental disabilities, with a focus on autism spectrum disorder. I appreciate CHILD-BRIGHT’s contribution to practice advancement, its aims of seeking greater opportunity and quality of life for children and families, and its ongoing role in informing future research initiatives. I also contribute to this effort in my work as founder of the Vocational Abilities Innovation Lab in the Faculty of Social Work, which seeds studies in developmental disabilities and employment, and through my work building employment opportunities and job readiness for people with developmental disabilities.”

CHILD-BRIGHT Operations Director



Program Committee

“As the Operations Director, I oversee the administrative functions (from preparing budgets to organizing gatherings) that support the network’s day-to-day activities.

I joined CHILD-BRIGHT because I believe in early intervention to optimize a child’s potential to grow and thrive, so that they can integrate in social roles and activities and can contribute to their communities to the degree that they wish to. We all benefit when patients and their families are empowered to participate and take charge of their health.”

CHILD-BRIGHT
Principal Investigator



DAY 1

8:30 a.m.

"In my role as Executive Director of Child Health BC, and as a developmental pediatrician serving children with cerebral palsy and their families, children and families have taught me that without their partnership, clinical planning is impossible and/or meaningless. In my role as a provincial health administrator and contributor to provincial child health policy, authentic engagement with our province's youth has truly inspired me and opened my eyes to the art of the possible. As an academic working in a university setting, including in our CHILD-BRIGHT research, I have seen and benefited from the gracious insights of our parent partners whose contributions have truly changed our directions on many fronts."

CHILD-BRIGHT
Principal Investigator



DAY 1

8:30 a.m.

DAY 2

9:00 a.m.

"CHILD-BRIGHT gives us an opportunity to truly engage in a collaborative way to improve the lives of the children and families we care for. Through CHILD-BRIGHT, we have been able to completely redefine how care has been provided for those children most at risk transitioning from the neonatal intensive care unit to home, and through that first year of life. We have heard time and time again that its like falling off a cliff—finally we can do something about it. We can walk alongside our patients and allow them to thrive, succeed and enjoy that important time in their lives as a family. It is a privilege and an honour to be able to support these families and to be a part of this network."

CHILD-BRIGHT Investigator
& Committee Member



DAY 2

8:00 a.m.

"I am a pediatric neurologist, a member of the Citizen Engagement Council, and an investigator in the READYorNot clinical trial. I am also an Associate Professor in the Departments of Pediatrics and Neurology and Neurosurgery at McGill University, recipient of a Clinical research scholar junior 2 award from the FRQ-S, and Associate Member of the Department of Epidemiology and Biostatistics at McGill University. I am a member of the Guideline Development Dissemination Implementation subcommittee of the American Academy of Neurology, contributing to evidence-based practice guidelines in the field of Neurology. I co-direct the Canadian Cerebral Palsy Registry, am Chair of the Canadian Neuromuscular Disease Registry spinal muscular atrophy working group, and am active in clinical trials in neuromotor disorders."

CHILD-BRIGHT Committee
Member & Patient-Partner



DAY 1

1:15 p.m.

"As the parent of premature twins and Board Director at the Canadian Premature Babies Foundation, it is an honour to sit on the CHILD-BRIGHT Training Committee. With my role as the Director, Continuing Professional Development at the College of Family Physicians of Canada and experience as a parent, my goal is to support with bringing patients, families, health care providers and researchers together through research, education and advocacy. I am looking forward to an engaging conference, thank you for attending!"

LAURA PACHECO

Community Engagement
Partner



DAY 2 8:00 a.m.

“I have been working with children and families for over 15 years within the community, hospital and in rehabilitation centers. I also have personal experience with a lifelong disability.

In my functions as Round Table Facilitator at the Centre Intégré universitaire de santé et de service sociaux de l’ouest de l’île de Montréal, I value the link between personal experiences, knowledge, professional practice, and research in order to improve the quality of life of children and their families—this is also at the heart of the CHILD-BRIGHT initiative.

I am currently involved in several research projects that aim to improve services to parents with an intellectual disability and promote healthy starts for children.”

NANCY POOLE

CHILD-BRIGHT Committee
Member and Sex & Gender
Champion



DAY 2 8:00 a.m.

“In my work at the Centre of Excellence for Women’s Health we try to involve researchers, service providers, policy analysts and girls and women with health concerns in all research we do. All are citizens, and all are important to designing and delivering health interventions that work! I have long been involved in ensuring that the voices of girls and women are heard in efforts to prevent Fetal Alcohol Spectrum Disorder and to support all individuals with that disability. Bringing an understanding of sex and gender influences on health for girls, boys and gender diverse individuals, and promoting gender equity is an important goal for research funders and governments in Canada now too!”

CONNIE PUTTERMAN

CHILD-BRIGHT Knowledge
Translation Program Co-Lead



DAY 1 10:45 a.m.

“Its important that families/citizen stakeholders have a ‘place’ in research, to ensure that the insights that families can bring to research are inspiring and meaningful to the community of researchers, and to ensure that parent and family stakeholders are shaping the future direction of research. Families want to be part of the process that helps to build relationships between research, research practice, and public benefit. The key is to find ways of doing so that fit research models but also break down barriers at the same time. I bring a unique perspective to the KT core team and KT committee. I view our activities with an appreciation and respect for the research process but at the same time I am excited to provide insights that link research to impact. The KT core team reflects the values of shared commitment to one another and the community we represent.”

LAWRENCE RICHER

Lead,
Data Coordinating Centre



DAY 2 9:00 a.m.

“I’m the academic lead for the Data Coordinating Centre at the Women and Children’s Health Research Institute (WCHRI) in Edmonton, Alberta. Our team provides data-related support services to the CHILD-BRIGHT research projects and programs.

I have broad interest in improving the access and use of health information to improve patient care through research and process improvement. Through the Maternal, Infant, Child, and Youth Research Network (MICYRN), KidsCAN Clinical Trials for Children initiative, and CHILD-BRIGHT Network I lead efforts to improve standards in research data management among maternal and health research institutes in Canada.”

KATE ROBSON

CHILD-BRIGHT Committee Member and Patient-Partner



DAY 2	8:00 a.m.
DAY 2	10:30 a.m.

“CHILD-BRIGHT is the promise of a space in which relationships are nurtured, and where connections are created between researchers, parents, children, health care practitioners, and community partners. These types of relationships, and citizen engagement, allow for good health care to happen. I have spent time as a patient and as a parent in 4 different hospitals and 3 different NICUs. I worked in one of those NICUs as a Family Support Specialist, offering support to families and helping the unit deliver family centred care. I now manage projects in a neonatal follow up clinic, working to promote family wellbeing and community partnerships. My background in adult education and community mediation, combined with my personal experiences, helps me bring families and staff together as collaborators.”

BRUCE RODRIGUES

Policy Expert



Policy Forum

“I work to be a leading voice in Ontario’s education system. Before joining the ministry, I was the CEO of Ontario’s Education Quality and Accountability Office where I led a new strategic plan for the organization and worked to modernize the provincial assessment program. I held several senior leadership roles including as Director of Education of the Toronto Catholic District School Board. I also served as President of the Ontario Catholic Supervisory Officers’ Association.”

I am a seasoned educator and have spent 33 years in the classroom as a secondary school teacher. I also held positions of vice-principal, principal and superintendent before becoming director. I am committed and passionate about putting students at the heart of my work to ensure their success.”

MICHAEL SHEVELL

CHILD-BRIGHT Committee Member



DAY 2	9:00 a.m.
DAY 2	10:30 a.m.

“I have the best job in the world as Chair of the Department of Pediatrics at McGill and Physician-in-Chief at the Montreal Children’s Hospital because I get to be funny, I get to help, and I get to make a difference where it really counts. I value the opportunity that CHILD-BRIGHT provides to work with patients and families addressing issues that are of importance to them.”

At CHILD-BRIGHT, I am addressing the topic of sustainability beyond the current five-year funding period, to help ensure that we can continue our work and help as many families as possible moving forward.”

KEIKO SHIKAKO-THOMAS

CHILD-BRIGHT KT Co-Lead & Principal Investigator



DAY 1	8:30 a.m.
DAY 1	10:45 a.m.

“CHILD-BRIGHT is an amazing community, an opportunity to better understand how we can work together with children, youth, and their families towards meaningful outcomes, and a chance to make research more relevant, timely, innovative, and transformative for all involved.”

As an occupational therapist, I hope my research within CHILD-BRIGHT can contribute to help children with disabilities and their families engage in activities that are meaningful for them, that are fun and can keep them healthy! I am also working towards similar goals in my functions as Canada Research Chair in Childhood Disability: Participation and Knowledge Translation, as the Knowledge Translation Program Co-Lead, and Jooyay Project Principal Investigator.”

CHILD-BRIGHT
Principal Investigator



DAY 1

8:30 a.m.

“My work as the Medical Director of Canuck Place Children’s Hospice, as an Investigator (BC Children’s Hospital), as a Clinical Professor of Pediatrics (University of British Columbia), and as a principal investigator for CHILD-BRIGHT has allowed me to combine clinical and research endeavours highly integrated with families and their experiences.

I have learned the most from the children and families that I help provide care to clinically, and this has driven my research programs. It is a great experience to be a member of CHILD-BRIGHT where the focus is on family-engaged research.”

CHILD-BRIGHT
Principal Investigator



DAY 1

8:30 a.m.

“As a neonatologist at the BC Women’s Hospital, I have witnessed the progress made in terms of improving the rate of survival of children born very prematurely, and see many of these babies now living with brain-based disabilities. It is time to improve their futures.

New research shows we can improve language and cognitive abilities and that parent-based interventions are most effective. I believe that existing resources in Canadian neonatal follow-up programs can provide effective, affordable and sustainable parent-based interventions, that parent voices can help us communicate about outcomes and disabilities, and that the Canadian Neonatal Follow-Up Network (CNFUN) database can tell us whether we are making a difference.”

CHILD-BRIGHT Committee
Member & Patient-Partner



DAY 2

9:00 a.m.

“I work hard to bring the lens of lived experience to CHILD-BRIGHT research and I’m encouraged by the productive working relationships being built between families and researchers across the network.

As a family leader engaged in research, I hope to do my part in building a cohort of future engaged youth, parents and researchers skilled in patient-oriented research.

CHILD-BRIGHT working methods and research is already making a positive difference in the lives of Canadian children with disabilities and their families. I know that as we evolve, so too will our impact.”

Program Officer,
Data Coordinating Centre



DAY 2

9:00 a.m.

“I’m the administrative lead for the Data Coordinating Centre at the Women and Children’s Health Research Institute (WCHRI) in Edmonton, Alberta. Our team provides data-related support services to the CHILD-BRIGHT research projects and programs.

Our function within CHILD-BRIGHT is to provide a service, however, we also see ourselves as a partner and collaborator within the network, aiming to support research excellence, build capacity in children’s health research, address the unique health needs of children, and innovate with our stakeholders to increase the impact and reach of children’s health research!”

Co-Lead,
Health Economics Platform



DAY 2 9:00 a.m.

“CHILD-BRIGHT is a unique opportunity to understand the value and cost-effectiveness of new treatments and services for children with developmental disabilities, as well as the impact of the condition on the quality of life of children and family members.

Working closely with network teams, our health economics research will generate vital evidence to support funding and access to new treatments that will improve the lives of children, their caregivers, and family members.”

Team Lead Clinical
Research Informatics, Data
Coordinating Centre



DAY 2 9:00 a.m.

“I’m the research informatics team lead for the Data Coordinating Centre at the Women and Children’s Health Research Institute (WCHRI) in Edmonton, Alberta. Our team provides data-related support services to the CHILD-BRIGHT research projects and programs.

My team helps the CHILD-BRIGHT Network use a system called REDCap to build and maintain study databases. We have an open door policy and are always happy to help network staff and research teams – this may involve working with teams to implement their data collection forms or surveys in REDCap, providing ongoing data monitoring and reporting support, or just being available to provide advice as the study progresses!”

CHILD-BRIGHT Knowledge
Translation Program Co-Lead



DAY 1 10:45 a.m.

“Citizen engagement is important first and foremost to ensure our efforts are meaningful and result in evidence that improves the lives of those we serve, and secondly, to build enthusiasm and support for scientific pursuits; it is a critical process for creating a positive and constructive relationship between research, practice, and the public. As CHILD-BRIGHT’s Knowledge Translation Program Co-Lead, and Associate Professor in the Department of Psychology at York University, I am passionate about research that, when applied, improves the lives of people with disabilities and their families. My work on mental health and developmental disability underscores the importance of interdisciplinary and multisectoral solutions, and at its heart, the need to receive guidance from our stakeholders in an ongoing way.”

Community Engagement
Partner



DAY 1 1:15 p.m.

“As Executive Manager of the Centre of Excellence on Partnership with Patients and the Public, I oversee the strategic, financial and resource operations of the centre. The CEPPP’s mission is to make partnership with patients and the public a science, a culture, and the new standard to improve the health and the health care experience of all citizens. It also aims to support organizations across the health care spectrum to develop strategies and implement partnerships. I have been a project manager in health research since 2011 and was the former Communications Project Manager for CIHR’s Institute of Circulatory and Respiratory Health. My experience includes working with patient partners, researchers, and health care professionals to co-build networks, plan, implement and evaluate partnership, and transform science and practices through consensus building.”

Biostatistician,
Data Coordinating Centre



DAY 2

9:00 a.m.

“Children’s Health Research Institute (WCHRI) in Edmonton, Alberta. Our team provides data-related support services to the CHILD-BRIGHT research projects and programs.

I work closely with the CHILD-BRIGHT research study teams to help them identify statistical methods best suited to answering their specific research questions. I provide methodological insight into the study design and protocol development, develop safety reports, analyze data, interpret results, and assist with manuscript preparation. I’m keen to help study teams incorporate the best possible statistical principles up front to ensure clear conclusions and high-quality results!”

Co-Lead,
Health Economics Platform



DAY 2

9:00 a.m.

“CHILD-BRIGHT is a essential network connecting and engaging a community of children youth and their families. Citizen engagement is essential to increase the relevance of research and improve its translation into policy and practice, contribute to more effective health services and products, and improve the quality of life of youth and their families.

The health economics team is working collaboratively projects and stakeholders in CHILD-BRIGHT. With broad interests in the impact of health and social policy on health outcomes, the health economics team utilizes economic evaluation and policy analysis to assess interventions and inform policy around allocation of funding, services and supports for children and youth with developmental disabilities and their families.”

CHILD-BRIGHT
Training Coordinator



DAY 2

9:00 a.m.

“To me, CHILD-BRIGHT signifies the democratization of the research process. It is an opportunity to pursue novel research projects that have been developed in response to stakeholder input, and by virtue of this process, may ultimately enhance the uptake and dissemination of research findings.

As the CHILD-BRIGHT Training Coordinator, my role is to help build capacity for patient-oriented research throughout the network by actualizing priorities developed by the Training Program Committee. Through developing training initiatives that engage with multiple stakeholder groups, we aim to enhance patient engagement throughout the research process.”



Venue Floorplan



For any questions or requests to make your stay more enjoyable, visit us at the registration table or email us at admin@child-bright.ca.





Poster Session

PROJECT - PRESENTER(S)	POSTER #
MATCH - Davide Marini	1
Metformin in CP - Darcy Fehlings	2
Parent-EPIQ - Anne Synnes	3,4,6
SPORT - Adam Kirton	5
IMAGINE - Colleen Giumond, Nicole Liang	7,8
INAS - Serene Kerpan	9
PIUO - Sharan Sahota	10
Strongest Families - Karen Turner	11
Jooay - Keiko Shikako-Thomas	13
MEGA TEAM - Victoria Lishak	14
CCENT - Arpita Parmar	15
BRIGHT Coaching - Tatiana Ogourtsova	16
READYorNot - Sonya Strohm, Alicia Via-Dufresne Ley	17,18
Bringing understanding of sex and gender into health research, practice and policy - Nancy Poole	12
Disability Data Project: Navigating Disability Supports and Services Across Canada - Brittany Finlay	19
Enabling Visions and Growing Expectations (ENVISAGE): An international parent-researcher partnership to support best starts for parents of children with disabilities - Andrea Cross	20
Building capacity for families as partners in research: A Family Engagement in Research Certificate Program - Andrea Cross	21
Guideline Development for Rehabilitation in Arthrogyrosis: Collaboration with youth, parents, and clinicians - Caroline Elfassy	22

Consult the Poster Abstract Booklet for more details

A photograph of a family walking on a beach, holding hands. The child is in the center, wearing a white t-shirt with striped and polka-dot sleeves. The background is a bright, hazy beach scene. The text "Thank you to our financial partners" is overlaid in white, centered on the image.

Thank you to our
financial partners



CHILD-BRIGHT is made possible thanks to a five-year grant by the Canadian Institutes of Health Research (CIHR) under Canada's Strategy for Patient-Oriented Research (SPOR), and 27 generous funding partners from public and private sectors across Canada.

PLATINUM PARTNERS (\$1M +)



GOLD PARTNERS (\$500,000 TO \$999,000)



SILVER PARTNERS (\$100,000 TO \$499,000)



BRONZE PARTNERS (\$1 TO \$99,999)



