

## 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



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.”*

## 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 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.”*

## Community Engagement Partner



DAY 2

8:00 a.m.

*“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 Research Project Team Member



DAY 2

9:00 a.m.

*“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

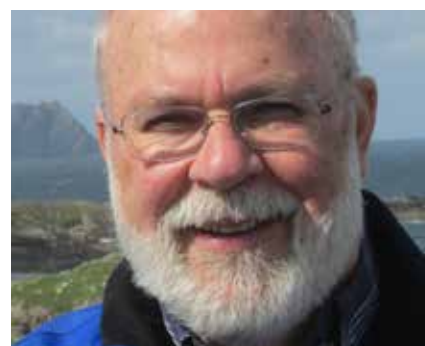


DAY 2

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."*



## STEVEN MILLER

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."*

## PAM NAPONSE-CORBIERE

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)."*

## DAVID NICHOLAS

Community Engagement  
Partner



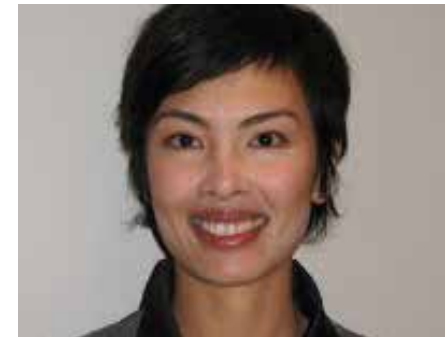
DAY 2

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."*

## TO NHU NGUYEN

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.”*