#BCP2017

CHILD-BRIGHT Network

kids brain health network

3 DAYS, 2 NETWORKS, 1 COMMON GOAL

BRAIN-CHILD-PARTNERS CONFERENCE

NOVEMBER 6-8, 2017 | TORONTO, CANADA

brainchildpartners.ca

WELCOME

On behalf of the CHILD-BRIGHT and Kids Brain Health networks, welcome to the 2017 Brain-Child-Partners Conference!

Neurological conditions affect an estimated 3.6 million Canadians. Of these, as many as 850,000 are children who face life-long challenges with mobility, language, learning, socialization, and/or self-care that will impact their quality of life and create special challenges for the families of these children.

Our conference gathers all stakeholders touched by childhood neurological disabilities and, under the theme of '**Reciprocity**', we will listen, collaborate, exchange, and positively impact each other's work. We share a common goal: improving health outcomes for Canadian children at risk or impacted by brain-based disorders. Together, we can promote a better health care system, better health outcomes, and also promote the transformative impact of brain and child health research in Canada.

For the CHILD-BRIGHT Network team, this is an inaugural meeting, our first opportunity to meet many of our pan-Canadian supporters in person. We will feature our 12 new research projects, research themes, training initiatives, and engagement strategies. As a newly funded network under Canada's Strategy for Patient-Oriented Research, we also look forward to gathering our team of researchers and patients from across the country under one roof and actively engaging with all network members and supporters about our priorities. We have big plans for our five-year mandate, and can't wait to tell you more about them!

For the Kids Brain Health Network (KBHN) team, formerly NeuroDevNet, we will be meeting for the 8th consecutive year, each time with a novel focus that highlights our growth as a Network. This year's meeting will showcase cutting-edge insights into the origins and treatment of brain-based disabilities and effective strategies for family support, reflecting the priorities identified by families and other stakeholders that now shape the questions we explore as a community. Our trainees will share their latest research findings along with the programs, projects and cores that form KBHN. Join us as Kids Brain Health charts its path forwards for the next two years – and beyond.

We've designed our event programming to encourage an open and reciprocal exchange of ideas. We believe that all experts, including patients and families who are the foremost experts on the health issues that touch them, need to work together to successfully translate scientific evidence into better care and create meaningful change in the lives of patients and families.

We wish to sincerely thank our event sponsors for making this national collaborative event possible. Diversity of input is crucial and sponsors help bring us together.

Annette Majnemer OT, PhD
Director, CHILD-BRIGHT Network,
Research Institute of the McGill University Health Centre
Vice Dean Education, Faculty of Medicine, McGill University

Dan Goldowitz, PhD
Scientific Director, Kids Brain Health Network
Centre for Molecular Medicine and Therapeutics
BC Children's Research Institute
Dept Medical Genetics, University of British Columbia

OUR NETWORKS

CHILD-BRIGHT NETWORK

The CHILD-BRIGHT Network, headquartered at the Research Institute of the McGill University Health Centre (RI-MUHC), is an innovative pan-Canadian network that aims to improve life outcomes for children with brain-based developmental disabilities and their families. Using child- and family-focused approaches, we work to create novel interventions to optimize development, promote health outcomes, and deliver responsive and supportive services. Co-Directed by investigators at the BC Children's Hospital and The Hospital for Sick Children (SickKids), 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.

KIDS BRAIN HEALTH NETWORK

As the first national network in Canada focusing on brain development and neurodevelopmental disabilities, Kids Brain Health is dedicated to ensuring the best possible outcomes for affected kids and their families. Today, one out of six children worldwide lives with a life-long condition such as autism (ASD), cerebral palsy (CP), or fetal alcohol spectrum disorder (FASD).

We set out as NeuroDevNet in 2009 to study typical brain development, and identify what goes wrong - and why - in brain-based disabilities. Our aim: to meaningfully improve quality of life for children and their families through early diagnosis, effective treatment, and support for caregivers. We continue this vital work under our new banner as Kids Brain Health, bringing together leading researchers in basic and clinical sciences, and training a new generation of Canadian researchers dedicated to the same goals.

A wide range of partners and families support us in these endeavours, helping to shape our priorities and translate our findings into programs, policies and services. Together, we're moving from research to impact.

DAY 1
CHILD-BRIGHT DAY

7:00-8:30AM	**REGISTRATION** | CONFERENCE HALLWAY **BREAKFAST** | PRINCE BALLROOM FOYER
8:30-9:30AM	**WELCOME REMARKS** | PRINCE BALLROOM SOUTH
9:40-10:45AM	**THEME 1: CAN WE FIX THE BRAIN?** | PRINCE BALLROOM SOUTH
11:00-12:05PM	**THEME 2: FINDING WAYS TO IMPROVE CHILDREN'S MENTAL HEALTH** | PRINCE BALLROOM SOUTH
12:05-1:05PM	**LUNCH** | PRINCE BALLROOM FOYER
1:10-2:15PM	**THEME 3: SINK OR SWIM: CAN WE EMPOWER FAMILIES TO NAVIGATE KEY TRANSITIONS?** | PRINCE BALLROOM SOUTH
2:30-4:00PM	**YOUTH ENGAGEMENT** | ONTARIO **BRAINSTORM** | PRINCE BALLROOM SOUTH **PATIENT-ORIENTED TRAINING IN BRAIN DEVELOPMENT AND DISORDERS** | NORTH YORK **PRACTICAL APPROACHES TO SCIENCE COMMUNICATION: DIGITAL MEDIA PRODUCTION FOR THE NON-EXPERT** | DUNCAN
4:00-4:15PM	**BRIGHT REMARKS** | PRINCE BALLROOM SOUTH
4:15-6:00PM	**CHILD-BRIGHT MARKETPLACE** | CROWN
4:30-6:00PM	**TRAINEE WORKSHOP: BREAK-OUT GROUPS** | NORTH YORK, DUNCAN, VALLEYBROOK | PLEASE SEE HANDOUT

CAN WE FIX THE BRAIN?

9:40-10:45AM

All too often in Canada, and around the world, babies are born with conditions that put them at risk of brain-based developmental disabilities such as being born too early (preterm), with heart disease, or genetic conditions. Despite advances in medical care, affected newborns remain at high risk for lifelong challenges in their cognitive, physical, and social development. Based on our interactions with parents of children with these conditions, they want to ensure that their children develop as optimally as those born healthy. New evidence suggests that brain and mental health outcomes following early adversity can be improved by enhancing brain repair and recovery through novel approaches such as with brain stimulation or medicines. In this session, we will explore together whether these novel approaches to enhancing brain repair and recovery have the potential to "fix the brain".

MODERATORS: Steven Miller, Dana Geall
SPEAKER: Adam Kirton
KEY RESPONDERS: Jack Hourigan, Maryam Oskoui

FINDING WAYS TO IMPROVE CHILDREN'S MENTAL HEALTH

11:00-12:05PM

A large proportion of children with neurodevelopmental disorders also have mental health conditions that manifest through their behaviour. They may show this through aggressive behaviours toward themselves or others as well as through low motivation, disengagement, and even total withdrawal. To date, services oriented toward children with neurodevelopmental disorders identify that they are not well equipped to address these kinds of behavioural concerns; at the same time those who provide services to children with mental health issues feel equally ill-equipped to provide support to families whose children have neurodevelopmental disorders. Projects identified in this theme begin to break down the barriers between these siloes. Working together with clinicians and parent advisors, we are evaluating innovative approaches to see if they make a difference!

MODERATORS: Patrick McGrath, Frank Gavin
SPEAKER: Jennifer Crosbie
KEY RESPONDERS: Lucyna Lach, Aryeh Gitterman

SINK OR SWIM: CAN WE EMPOWER FAMILIES TO NAVIGATE KEY TRANSITIONS?

1:10-2:15PM

Families face many challenges in different health care contexts as their child grows and develops. Three CHILD-BRIGHT research projects are testing novel ways of redesigning the health care system to be more responsive to family needs through key transitions from infancy to adulthood. Coaching models together with eHealth technologies will be used to provide families and youth with personalized education and support, so that they can take charge of their health and health care. This session will highlight one study focused on supporting adolescents with developmental challenges, and will briefly summarize the other two studies with younger populations at key transitions. This research will be framed by the perspectives of parents and clinician researchers.

MODERATORS: Eyal Cohen, Crystal Chin
SPEAKER: Ariane Marelli
KEY RESPONDERS: Amy Houtrow, Kate Robson

WORKSHOP: YOUTH ENGAGEMENT

2:30-4:00PM

This session will focus on effective ways—with perhaps some mention of ineffective ways—of engaging youth as partners in research projects, on the training requirements for both youth and researchers, and on ways of sustaining and deepening such engagement. Youth and researchers from the national SPOR chronic pain network will share their experience as will youth involved in research related to brain-based disabilities.

FACILITATORS: Dolly Menna-Dack, Carley Ouellette, Kathryn Birnie

WORKSHOP: BRAINSTORM: KNOWLEDGE TRANSLATION INNOVATION INCUBATOR

2:30-4:00PM

Through this highly interactive workshop, participants will begin by defining a shared understanding of integrated knowledge translation. Participants will then discover what it means to “innovate”, and how innovations can be applied to knowledge translation science. Through creative brainstorming techniques and by building partnerships with other participants, attendees will have the opportunity to generate and expand on innovative knowledge translation project ideas. The session will conclude with concrete actions to further conceptualize the ideas discussed, and will encourage partners to participate in the Innovation Incubator funding competition to help bring a unique, innovative integrated Knowledge Translation (iKT) project to life.

FACILITATOR: Jerry Koh

WORKSHOP: PATIENT-ORIENTED TRAINING IN BRAIN DEVELOPMENT AND DISORDERS

2:30-4:00PM

This workshop is intended for all relevant stakeholder groups with an interest in the area of patient-oriented research within the context of neurodevelopmental disorders. Workshop participants from the research community can expect to gain a deeper insight into the public's understanding regarding health research, while patients and families will develop insight into the research enterprise and identify areas where they can become more actively involved. Additionally, participants will brainstorm and identify areas where there is a lack of training resources specific to pediatric brain health, and in so doing, aid in prioritizing the strategic planning of CHILD-BRIGHT's Training Core in developing training materials.

FACILITATORS: Nikola Jones and Team

WORKSHOP: PRACTICAL APPROACHES TO SCIENCE COMMUNICATION: DIGITAL MEDIA PRODUCTION FOR THE NON-EXPERT

2:30-4:00PM

This workshop is intended for trainees, researchers, and community organizers interested in developing/improving their skills in utilizing digital media platforms for presenting their research, outreach efforts, and informing the general and knowledgeable communities. In this age of YouTube videos and "3-minute thesis" competitions, the use of digital media to reach a wider audience with research-related information is becoming more necessary and even fun. We will explore practical tips and cost-effective platforms to allow, even the novice user, to reach a wider audience. We will have presentations from professionals and amateurs in the area of digital media use and production and also have the opportunity for hands-on activities to generate your own "Elevator Pitch" videos and short multimedia presentations to post for your own communities. Materials suggested: smartphone camera, laptop computer, your creativity and a big smile!

FACILITATORS: Alexandra Sebben and the KBHN Training Program

CHILD-BRIGHT MARKETPLACE

4:15-6:00PM

CHILD-BRIGHT's marketplace is a dynamic and interactive gathering where our network members, teams and programs will introduce their work and how each contributes to our collective CHILD-BRIGHT mission. The marketplace aims to create an environment conducive for members to meet each other, exchange stimulating ideas and build connections, by using a variety of formats, from interactive booths to mixed media displays e.g. posters, brochures, images and personal experiences.

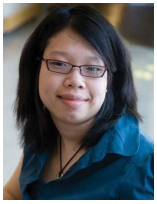
DAY 1 SPEAKERS

Kathryn Birnie

is a CIHR-funded postdoctoral fellow at the University of Toronto and the Hospital for Sick Children under the supervision of Dr. Jennifer Stinson. Dr. Birnie obtained her PhD in Clinical Psychology from Dalhousie University in 2016. She completed her predoctoral clinical internship in pediatric health psychology, and child and adolescent mental health, at the IWK Health Centre in Halifax, NS. Dr. Birnie's research and clinical expertise are primarily with children and youth experiencing pain and illness, and their families. She is currently co-leading a CIHR-funded national patient engagement project in the area of pediatric chronic pain.

Mathias Castaldo

is a student at Ryerson University, ready to graduate with a major in Psychology. Mathias has been a former client of Holland Bloorview. His experiences of living with a "disability" and his education at Ryerson have led him to work with Community Living York South as a camp counselor for their summer programs. In addition, he is currently a volunteer at Holland Bloorview where he is co-chair of the Youth Advisory Council as well as a youth leader and youth mentor. He has also advised and participated on research projects at Holland Bloorview. Furthermore, he participated in Holland Bloorview's anti-stigma campaign and will be the new Teen Lounge Host at Holland Bloorview. Mathias hopes to one day be a Special Education teacher working with other youths with "disabilities" and inspiring them to achieve their goals.



Crystal Chin

was born in Taiwan where she was diagnosed with a neuromotor condition at eight months of age. She immigrated to Canada in her late childhood where she lived in the Greater Toronto Area and received treatment and monitoring at the Hospital for Sick Children as well as Holland Bloorview Kids Rehabilitation Hospital. Through her many interactions with academic and medical sectors, she became engaged in her community, particularly around health and education issues. At Holland Bloorview Kids Rehabilitation Hospital, she previously held the role of co-chair, and public relations on the Youth Advisory Council. She is also a member of the Patient Family Advisory Council and a Foundation Ambassador.

Eyal Cohen

is a general paediatrician at the Hospital for Sick Children and an Assistant Professor in the Department of Paediatrics at the University of Toronto with cross-appointments in the Institute of Health Policy, Management and Evaluation and the Faculty of Nursing. Dr. Eyal Cohen completed his medical training at the University of Toronto in 2000. He trained in pediatrics at the Hospital for Sick Children and Children's Hospital at Westmead in Sydney, Australia and completed an MSc in health research methodology at McMaster University in 2008. His research interests focus on models of care coordination for children with complex and chronic health needs, improving the quality of inpatient care, and barriers to conducting research in vulnerable populations.

Jennifer Crosbie

is a Clinical Psychologist and Health Clinician Scientist within the Department of Psychiatry and the Clinical Lead of the Mental Health Access Program at SickKids. Dr. Crosbie is an Associate Scientist within the SickKids Research Institute, Neuroscience and Mental Health Program, and Assistant Professor at the University of Toronto. Dr. Crosbie's research and clinical work is focused on understanding the neurobiological determinants of childhood neuropsychiatric disorders, with a particular focus on attention deficit hyperactivity disorder (ADHD). Her external funding includes CIHR, the Province of Ontario Neurodevelopmental Disorders (POND) Network via the Ontario Brain Institute (OBI), and the SPOR CHILD-BRIGHT Network.

Dana Geall

is the mother of triplets Taylor, Cole and Brody, who are the inspiration behind Three to Be. Before becoming a mother, Dana was a primary school teacher with a passion for helping children to reach their full potential. When her own three children were diagnosed with Cerebral Palsy, Dana's unwavering tenacity and optimism for the discovery of treatments for neurological disorders moved her to become an advocate both for her children and all other children living with neurological disorders in Canada and around the world. Dana is passionate about developing the organization to advance research, education and therapies in this area. Dana founded Three to Be with the intention to make a difference in the lives of many children.

Frank Gavin

is the Chair of CHILD-BRIGHT's Citizen Engagement Council and a member of the Network's Steering and Executive Committees. He chaired the Family Advisory Committee at the Hospital for Sick Children (1997-2001), founded and chaired the Canadian Family Advisory Network (CFAN), and now serves as CFAN's national liaison. He recently completed two terms as a public member of the Canadian Drug Expert Committee and remains a board member of the Ontario SPOR Support Unit. Frank taught English at Centennial College in Toronto for nearly 30 years and twice chaired the department.

Aryeh Gitterman

Prior to joining the School of Child and Youth Care, Aryeh was Assistant Deputy Minister (ADM) in the Ontario Ministry of Children and Youth Services with policy responsibility for children's mental health, autism and child welfare. Prior to joining MCYS, Aryeh was ADM of the Instruction and Leadership Development Division, and the Business and Finance Division, Ontario Ministry of Education. He also worked at the Halton Board of Education, as the Head of Guidance and Special Education, and as a Curriculum Coordinator. Aryeh began his career at the Scarborough Board of Education teaching Mathematics and English.

Deborah Hirtz retired from a long career as a Program Director for Clinical Trials and Studies at the National Institute of Neurological Disorders and Stroke, NIH. She received her undergraduate degree at the University of Chicago and medical degree at Hahnemann Medical College. She is board-certified in Pediatrics and Neurology, and trained at the Children's Hospital Medical Centre and George Washington University in Washington, DC. At the NINDs, she managed a large portfolio of research involving clinical trials, seizure disorders in children, autism and other developmental disorders, cerebral palsy, and neurodevelopmental disorders of infants and children in lower and middle income countries. She has been a clinical consultant in Child Neurology for the Montgomery County Health Department, the National Children's Center, and the Children's National Medical Centre of DC. She is currently a Professor of Neuroscience and Pediatrics at the University of Vermont.

Jack Hourigan, a McGill University and Second City Alumna, is a professionally trained improviser, writer and television host with more than 20 years experience in the communications field. Jack specializes in building connection. She trains corporate leaders, staff, clinicians and individuals on how to authentically communicate with their teams, clients and audiences. She volunteers as a peer support facilitator for the Canadian Premature Babies Foundation (CPBF) and works with the #itdoesnthavetohurt pain management education initiative for kids. As a parent/patient advocate, she combines her lived experience with her communications expertise to integrate teams, bring awareness and enhance health care delivery.

Amy Houtrow, MD, PhD, MPH is Associate Professor of Physical Medicine & Rehabilitation and Pediatrics at the University of Pittsburgh. She is Vice Chair of Pediatric Rehabilitation Medicine and Quality. She completed her MD from Michigan State University, trained in Pediatrics and PM&R at Cincinnati Children's Hospital, and received her MPH from the University of Michigan and her PhD in Medical Sociology from the University of California San Francisco. Her research focuses on improving health services for children with disabilities. Clinically, she cares for children with complex disabilities and directs the Rehabilitation Institute at the Children's Hospital of Pittsburgh.

Adam Kirton is Professor of Pediatrics and Clinical Neurosciences at the University of Calgary and an attending Pediatric Neurologist at the Alberta Children's Hospital. His research focuses on applying technologies including non-invasive brain stimulation and neuroimaging to measure and modulate the response of the developing brain to early injury to generate new therapies. He is a clinician scientist and CIHR Foundation Grant Recipient. Dr. Kirton directs the Calgary Pediatric Stroke Program, Alberta Perinatal Stroke Project, ACH Pediatric Non-Invasive Brain Stimulation Laboratory and University of Calgary Noninvasive Neurostimulation Network (N3).

Jerry Koh is Director of Systems Innovation at MaRS Discovery District. He is a strategist and foresight specialist in public policy and healthcare administration. His systems change projects include innovation procurement, demand-led youth employment, urban mobility and public sector innovation.

Lucyna Lach is an Associate Professor in the School of Social Work, and an Associate Member of the Departments of Pediatrics and Neurology/ Neurosurgery in the Faculty of Medicine, McGill University. Her program of research focusses on the quality of life of children with neurodisabilities and their caregiver. She has a special interest in health-related quality of life and parenting of children with neurodevelopmental disorders. She is part of a recently funded Strategic Patient-Oriented Research (SPOR) Team entitled CHILD-BRIGHT, as co-lead of one of three themes that is evaluating five intervention/prevention approaches to supporting children with neurodisabilities and their families.

Annette Majnemer is an occupational therapist with doctoral training in the neurosciences at McGill University (MSc, PhD). She is currently a Professor at the School of Physical and Occupational Therapy, and is an Associate Member of the Departments of Pediatrics and Neurology and Neurosurgery at McGill University. Dr. Majnemer's research interests focus on the developmental, functional and quality of life outcomes of children with disabilities and their determinants. Populations of interest include preterm infants, children with congenital heart defects following open-heart surgery, children with cerebral palsy and developmental delay. She is currently lead of a patient-oriented research network called CHILD-BRIGHT that engages over 600 stakeholders in research, training, knowledge translation and citizen engagement platforms, collectively aimed at promoting brighter futures for children with disabilities.

Ariane Marelli is the Director of Cardiovascular Research and the Associate Director for Academic Affairs for Cardiology at the McGill University Health Centre. She completed her training in adult cardiology and a fellowship in pediatric cardiology at McGill University. She lectures internationally on topics related to adults with congenital heart disease. Her research interest involves the epidemiology of congenital heart disease. She is a founding member of the International Society for Adults with Congenital Cardiac Disease. She is currently the Director of the MAUDE Unit at McGill University and she joins the CHILD-BRIGHT team to contribute her expertise in transition of care from pediatric to adult health care services.

Patrick McGrath, a clinical psychologist, is Vice President Research, Innovation and Knowledge Translation for the IWK Health Centre and the Nova Scotia Health Authority and Canada Research Chair and Professor of Psychology, Pediatrics, and Psychiatry at Dalhousie University. He has a distinguished record as a researcher on innovative ways of delivering health care to families and pain in children. His research has spanned a wide range of studies on measurement and psychosocial interventions in many different types of pain in infants, children and youth. He is a co-editor of the textbook *Pain in Neonates and Infants*. His research has been recognized by being made an Officer of the Order of Canada and numerous other awards.

Dolly Menna-Dack

is a Clinical and Research Ethicist at Holland Bloorview Kids Rehabilitation Hospital and the Bloorview Research Institute. She is particularly interested in pediatric rehabilitation issues that arise in both clinical care and research with children and youth with chronic illness and disabilities. Dolly has over ten years' experience on pediatric research ethics boards, both at acute and rehabilitation hospitals. Dolly has a long-standing interest in Clinical Bioethics and completed both her undergraduate and Master's degrees in Bioethics at the University of Toronto. Prior to working in the field of Ethics, Dolly was a Youth Facilitator in the cross-organizational LIFEspan Service at Holland Bloorview and Toronto Rehab, UHN.

Maryam Oskoui

is an Assistant Professor in the Departments of Pediatrics and Neurology & Neurosurgery. She is a clinical research scholar of the FRQS with a research focus on the epidemiology of cerebral palsy (CP), and co-directs the Canadian Cerebral Palsy Registry. She serves as a member of the CHILD-BRIGHT network's Citizen Engagement Council, and is an active member of the American Academy of Neurology (AAN), serving on its Guideline Development Dissemination Implementation Subcommittee.

Steven Miller

is Head of the Division of Neurology and Centre for Brain & Mental Health at the Hospital for Sick Children, and Professor in the Department of Paediatrics, University of Toronto. He holds the Bloorview Children's Hospital Foundation Chair in Paediatric Neuroscience. Collaborating with a multidisciplinary team, his research program focuses on better understanding brain injury and development in the newborn. He and his team use advanced brain imaging and detailed long-term follow-up to understand the impact of critical illness and intensive care therapies on the developing brain. He has contributed to our understanding of brain abnormalities caused directly by preterm birth, perinatal asphyxia or indirectly by congenital heart disease.

Kate Robson

works at Sunnybrook Health Sciences Centre NICU as a Parent Coordinator and is one of the Directors of the Canadian Premature Babies Foundation in Toronto, Canada. Kate Robson's first daughter was born in 2005 at 25 weeks, weighing 500 grams. Her 2nd daughter was a slightly more robust 32-weeker born in 2007. She has spent time as a patient and as a parent in 4 different hospitals and 3 different NICUs. She now works in one of those NICUs as a Parent Coordinator, offering support to families and helping the unit deliver family centered care. Her background in Adult Education and Community Mediation, when combined with her personal experiences, helps her bring families and staff together as collaborators.

Notes

CHILD-BRIGHT
Network

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DAY 2

JOINT NETWORK DAY

7:00-8:30AM	**REGISTRATION** | CONFERENCE HALLWAY **BREAKFAST** | PRINCE BALLROOM FOYER
8:30-10:00AM	**EXPLORING THE PURPOSE AND MEANING OF PATIENT ENGAGEMENT IN PEDIATRIC NEURODISABILITY RESEARCH** | PRINCE BALLROOM SOUTH
10:15-11:30AM	**OUTCOMES THAT MATTER: ARE WE ON THE SAME PAGE?** | PRINCE BALLROOM SOUTH
11:30-12:00PM	**YOUNG RESEARCHER TALKS** | PRINCE BALLROOM SOUTH
12:00-1:00PM	**LUNCH** | PRINCE BALLROOM FOYER **MEET THE EXPERTS TRAINEE LUNCH** | NORTH YORK
1:00-2:15PM	**MAKING RESEARCH UNDERSTANDABLE: NEW CHANNELS OF COMMUNICATION** | PRINCE BALLROOM SOUTH
2:15-3:30PM	**CAN BASIC RESEARCH AND APPLIED RESEARCH BE FRIENDS?** | PRINCE BALLROOM SOUTH
3:45-5:00PM	**LISTENING TO CHILDREN'S VOICES: PROMOTING YOUNG PEOPLE'S ENGAGEMENT AND PARTICIPATION** | PRINCE BALLROOM SOUTH
5:00-7:00PM	**POSTER AND NETWORKING RECEPTION** | PRINCE BALLROOM NORTH

EXPLORING THE PURPOSE AND MEANING OF PATIENT ENGAGEMENT IN PEDIATRIC NEURODISABILITY RESEARCH

8:30-10:00AM

In this session, speakers will unpack the notion of "patient engagement" in pediatric neurodisability research and explore its potential benefits and challenges. Attendees will come away from the session with a fuller understanding of some of the issues surrounding efforts to engage patients and their families meaningfully in pediatric research. Speakers will share their experiences and reflections, encouraging dialogue and thoughtful analysis of the current state of patient engagement initiatives.

Opening comments will be presented by Jennifer Johannesen. Drawing on her experiences of parenting a child with multiple undiagnosed physical and neurodisabilities, Jennifer will present a parent's perspective on patient engagement in research, and will discuss what she considers would be helpful to children and families. Jennifer strongly advocates for brain-related research projects to extend beyond current confines, to include consideration of a person's social environment, family context and other realms typically assigned to the social sciences.

MODERATOR: Donna Thomson
SPEAKERS: Jennifer Johannesen, Evdokia Anagnostou
KEY RESPONDERS: Franco Carnevale, Julie Drury

OUTCOMES THAT MATTER: ARE WE ON THE SAME PAGE?

10:15-11:30AM

Outcome measures are tools that may be used to assess a change in particular attributes of a person over time, in areas that are thought to be meaningful in a person's life. The outcomes we measure are linked to either the effects of a particular intervention or program, or the impact of a disease or health condition, and are utilized to answer research questions. This session will provide an overview of the importance of selecting the 'right' outcomes that matter most. The tension between the different perspectives of researchers and patients will be shared, through illustration of 'outcomes that matter' for youth with a congenital heart defect and children with cerebral palsy.

MODERATOR: Annette Majnemer
SPEAKERS: Beatrice Latal, Symon Hay, Darcy Fehlings, Katie & Richard Suggitt
KEY RESPONDER: Lorraine Sunstrum-Mann

YOUNG RESEARCHER TALKS

11:30-12:00PM

During this session, students and Postdocs will give a short presentation (10 mins, 1 slide) that highlights key study findings or outcomes that have an impact on their area of research. The presenters will be selected based on abstracts and "two-sentence highlight" submissions received prior to the conference. This session will give trainees wide exposure to our conference audience and a brief introduction to their posters.

MODERATOR: Lucy Osborne

MEET THE EXPERTS TRAINEE LUNCH

12:00-1:00PM

Network and gain valuable insight from leaders in developmental neuroscience during this luncheon. Participants will discuss topics including diagnostics, interventions, genetics, and research models with our expert table hosts who guide discussion and provide personal insight into research as well as career development.

MAKING RESEARCH UNDERSTANDABLE: NEW CHANNELS OF COMMUNICATION

1:00-2:15PM

Research (both its process and its results) has often been opaque to non-researchers, sometimes, it seems, deliberately so. In this session we will learn from three people who in different roles and mainly through the use of various social media, including YouTube videos, blogs, Facebook, and Twitter, have succeeded in helping families understand research, engage in it as partners, and apply its results. And with so much misinformation and context-free information floating about, especially on social media, our experts will discuss ways of ensuring that what they convey is accurate and sufficiently nuanced while still engagingly and effectively presented.

MODERATOR: Kate Robson
SPEAKERS: Christine Chambers, Louise Kinross, Rachel Martens
KEY RESPONDER: Ann Douglas

CAN BASIC RESEARCH AND APPLIED RESEARCH BE FRIENDS?

2:15-3:30PM

This session will frame a debate on the interaction between basic research and applied research. The speakers will reflect on their experience bringing basic science discoveries to be evaluated in the clinical research domain. In our current era of patient-oriented researchers, the panel will reflect on how patients and researchers can work together most effectively to promote the translation of discoveries in the lab to better patient outcomes. This discussion will also extend to the opportunity to enhance our training programs for patient-oriented research that cross the basic-applied divide, and the opportunity to make basic research more accessible to citizens.

MODERATOR: Derek van der Kooy
SPEAKERS: Donald Mabbott, Freda Miller, Rebecca Ruddy
KEY RESPONDER: Roderick McInnes

LISTENING TO CHILDREN'S VOICES: PROMOTING YOUNG PEOPLE'S ENGAGEMENT AND PARTICIPATION

3:45-5:00PM

Children and youth are commonly considered incapable of understanding and participating in discussions and decisions that affect them. Consequently, their input is frequently discounted. We will discuss current research and practice innovations which demonstrate that the capacities of children and youth are systematically underestimated and that their exclusion from discussions and decisions that affect them can be experienced as harmful. We will also discuss strategies for promoting the engagement and participation of young people in matters that affect them.

MODERATOR: Éric Racine
SPEAKERS: Franco Carnevale, Dolly Menna-Dack

POSTER AND NETWORKING RECEPTION

5:00-7:00PM

All attendees are invited to share their research and network at our Poster and Networking Reception. Posters were selected from abstract submissions based on basic science and/or clinical studies related to neurodevelopmental disorders. Awards will be given for top presentations based on degree status (Masters, Doctoral and Post-Doctoral). We look forward to sharing and networking with trainees and investigators at this session.

DAY 2 SPEAKERS

Evdokia Anagnostou,

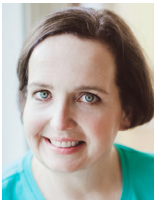
MD, is a child neurologist and senior clinician scientist at Holland Bloorview Kids Rehabilitation Hospital. Dr. Anagnostou is also the Assistant Director of Holland Bloorview's Research Institute; co-leading the Autism Research Centre (ARC). Dr. Anagnostou holds a Canada Research Chair in translational therapeutics in Autism Spectrum Disorder (ASD) and the Dr. Stuart D. Sims Chair in Autism at Holland Bloorview. Dr. Anagnostou's research focuses on translating genomic and systems biology findings into novel treatments for ASD. She is also an associate professor in the department of pediatrics at the University of Toronto, which is fully affiliated with Holland Bloorview.

Franco Carnevale

is a nurse, psychologist and clinical ethicist. He completed his undergraduate nursing degree, and three master's degrees in nursing, education, and bioethics, as well as a doctorate in counseling psychology at McGill University. He also completed a master's degree in philosophy at Université de Sherbrooke and a second doctorate in moral philosophy at Université Laval. Dr. Carnevale's primary research interests include a wide range of concerns in pediatric ethics. Dr. Carnevale is the founder and principal investigator for VOICE (i.e., Views On Interdisciplinary Childhood Ethics); a McGill-based international initiative to advance knowledge and practices relating to ethical concerns in childhood.

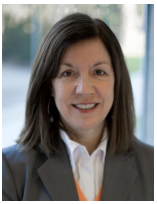
Christine Chambers

is the Canada Research Chair (Tier 1) in Children's Pain and Professor in the Departments of Pediatrics and Psychology & Neuroscience at Dalhousie University. She is based in the Centre for Pediatric Pain Research at the IWK Health Centre. She has published over 100 peer-reviewed papers on the role of developmental, psychological, and social influences on children's pain, with a current research focus on the role of families in pediatric pain and social media for knowledge mobilization. Dr. Chambers is passionate about patient and family engagement, as evidenced in the award-winning CIHR-funded #ItDoesntHaveToHurt social media initiative.



Ann Douglas

is a passionate writer, talented speaker and parenting expert. She is also the mother of four children who have each struggled with different mental health challenges. Inspired by her role as a parent and the journey of being a mental health patient herself, Ann has made it her mission to motivate others in need. An accomplished Canadian author, Ann has published numerous books about the challenges of parenting a child with mental health and neurological challenges. She hosts regular online conversations about parenting and mental health through Morneau Shepell Children's Support Solutions, the International Bipolar Foundation, and Partners for Mental Health. Ann also speaks at parenting and mental health seminars across the country.



Darcy Fehlings

is Head of the Division of Developmental Paediatrics and is a Professor in the Department of Paediatrics, at the University of Toronto. She is the inaugural holder of the Bloorview Children's Hospital Foundation Chair in Developmental Paediatrics. Dr. Fehlings is a Senior Clinician Scientist in the Bloorview Research Institute. Her research focuses on the innovation and evaluation of interventions for children with cerebral palsy. She is the lead investigator of an Ontario Brain Institute integrated neuroscience network focused on children with cerebral palsy (CP-NET) and leads the CP Discovery Project in the Canadian Kids Brain Health Networks of Centres of Excellence. She is a past President of the American Academy for Cerebral Palsy and Developmental Medicine.

Jennifer Johannesen

is a parent, patient advocate and bioethicist. Her son Owen had multiple severe disabilities all his life; when he passed away in 2010 at the age of 12, Jennifer captured her reflections of their health care experiences in her book, *No Ordinary Boy*. Through her writing and lectures, Jennifer encourages caregivers, clinicians and administrators to consider their health care experiences and encounters through a critical, reflexive lens. Jennifer also supports organizations and research teams to improve the ways in which they seek and include patient and family input. She completed an MSc in Bioethics in 2016.

Louise Kinross

is special projects manager at Holland Bloorview Kids Rehabilitation Hospital and editor of BLOOM, the hospital's blog and e-letter on parenting kids with disabilities. BLOOM promotes the idea that every child blooms in his or her own unique way. Last year the blog had readers in 181 countries. It's been picked up by the New York Times, Huffington Post and AOL Online. Louise has a 23-year-old son with a rare genetic disorder.

Beatrice Latal

is the Co-Director of the Child Development Center at the University Children's Hospital Zurich. She leads a large research group and is dedicated to teaching and faculty development. In her research, she investigates the developmental outcome of newborns and children at risk for neurodevelopmental disorders. This includes children born very prematurely, children with hypoxic-ischemic encephalopathy ("perinatal asphyxia") and children with severe congenital heart disease. Dr. Latal's main research goals are to characterize the prevalence and severity of neurodevelopmental impairments in these children, to identify the potential risk factors for impairments and to study the mechanisms involved in the etiology of brain injury.

Donald Mabbott

is a Senior Scientist and Associate Chief, Academic and Professional Practice in the Research Institute of the Hospital for Sick Children, and Associate Professor of Psychology at the University of Toronto evaluating brain/behaviour relations in normal and impaired neurodevelopment using cognitive data and quantitative MRI methods. He is currently examining neurocognitive outcomes following diagnosis and treatment with radiation for brain tumors and demonstrating that cranial radiation is associated with intellectual decline. He recently began exciting new work to find ways to foster brain repair following radiation injury in children treated for brain tumors, including using physical exercise and drugs that stimulate the growth of new brain cells.

Rachel Martens

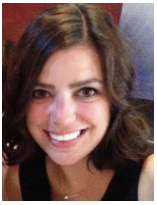
is a mom to an eleven-year-old boy born with multiple disabilities. Making hospitals and clinics her second home garnered an interest in getting involved in healthcare and research collaboration. She was the first to partner with the Rare Disease Foundation in Alberta to create a Parent 2 Parent Resource Network for families at Alberta Children's Hospital. She recently took on a position with the steering committee for the Canadian Family Advisory Network. Rachel also works with CanChild as Parent Engagement Facilitator for their program "Parents Participating in Research" seeking to create more partnerships with families and needed research.

Roderick McInnes

is the Director of the Lady Davis Institute of the Jewish General Hospital, Alva Chair in Human Genetics, Canada Research Chair in Neurogenetics, and Professor of Human Genetics and of Biochemistry at McGill University. Until 2009, he was a University Professor, the highest academic rank, at the University of Toronto. Previously, he was the Head of the Program in Developmental Biology at the Research Institute of the Hospital for Sick Children, an International Research Scholar of the Howard Hughes Medical Institute and, from 2000-2010, the inaugural Scientific Director of the Institute of Genetics of the Canadian Institutes of Health Research. He has made important contributions to the understanding of the molecular basis of retinal and eye development, the identification of genes and processes associated with inherited retinal degeneration, and to knowledge of synaptic accessory proteins that modulate the activity of ion channels in the nervous system. He is one of three coauthors of the 5th, 6th, 7th and 8th editions of the textbook Thompson and Thompson's Genetics in Medicine, for which they received the 2015 American Society of Human Genetics (ASHG) Award for Excellence in Human Genetics Education. In 2010, Dr. McInnes was the President of the ASHG. Amongst other honours, Dr. McInnes is a Fellow of the Royal Society of Canada and the Canadian Academy of Health Sciences. He was appointed to the Order of Ontario in 2008, and made a member of the Order of Canada in 2009.

Freda Miller is a Professor and Senior Scientist at the Hospital for Sick Children and the University of Toronto. She obtained her undergraduate degree at the University of Saskatchewan and her Ph.D. at the University of Calgary, and held faculty positions at the University of Alberta and the Montreal Neurological Institute at McGill prior to coming to Toronto in 2002. Her research has focused upon growth factor signaling in the developing nervous system, with a particular focus on how neurotrophic factors regulate the genesis, survival and growth of neurons. In particular, her laboratory has defined an interplay between the TrkA and p75 neurotrophin receptors that regulates the biology of developing neurons, has defined key roles for the p53 family in the brain, has identified and characterized the first dermal stem cell, and has defined how growth factors encountered in the embryonic environment regulate the self-renewal and differentiation of developing neural precursors. In recognition of this work, she has won numerous awards, and is an HHMI Senior International Research Scholar, and an elected fellow of the AAAS and of the Royal Society of Canada. In addition, this work has led to her role as a founder in two different biotechnology companies. Dr. Miller also has significant experience in administrative roles. She was previously a Councillor and Secretary for the Society for Neuroscience, President of the Canadian Association for Neuroscience, President of the International Society for Developmental Neuroscience, and is currently the Treasurer of the Society for Neuroscience.

Éric Racine is Director of the Neuroethics research unit and Full IRCM Research Professor. He is also a member of the Departments of Medicine and Social and Preventive Medicine (Bioethics Programs; Université de Montréal), an Adjunct Professor in the Department of Neurology and Neurosurgery (McGill University), and an Affiliate Member of the Biomedical Ethics Unit (McGill University). Dr. Racine's research is designed to improve the ethical aspects of quality of care, research practices and public communications in the domain of clinical and basic neuroscience. Various approaches and research methods, such as qualitative interviews, content analysis and media studies, are used to develop ethical approaches in health care and research.



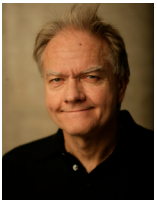
Rebecca Ruddy is a PhD student investigating the effects of cranial irradiation on neural precursor cells in a mouse model. She will be determining if metformin treatment can rescue irradiation induced deficits observed in these cell populations and in cognitive functioning. She is also studying sex-dependent effects of both cranial irradiation and metformin treatment on neural precursor cells and cognition.

Lorraine Sunstrum-Mann, Chief Executive

Officer of Grandview Children's Centre has been with the organization since 2011. Lorraine began her career as an Early Childhood Educator working with children with special needs. This work fuelled her interest in a career in nursing. Lorraine has held senior leadership roles at Lakeridge Health (Durham Region) and St. Michael's Hospital (Toronto), including Chief Nursing Executive. Lorraine holds a diploma in Early Childhood Education for the Developmentally Handicapped (Humber College), a diploma in Nursing (Durham College), a Bachelor of Arts - Health Studies (York University) and a Master of Business Administration (Heriot-Watt University). Lorraine completed the Public Sector Leadership Institute at Rotman University of Toronto in 2013. Between 2000 and 2006, Lorraine served on the Durham College and University of Ontario Institute of Technology Governing Boards including as Chair from 2004-2006. Lorraine currently sits as a Director on the Board of Sloane's House. Lorraine is a member of the Durham Child and Youth Planning Network, The Best Start Network (Durham Region), The Ontario Association of Childrens Rehabilitation Services and The Provincial Council of Maternal Child Health (Ontario). She is Chair of the Canadian Network of Child and Youth Rehabilitation (Canada), a committee of The Canadian Association of Paediatric Health Centres (Canada), and is an ex officio member of the Board of Trustees for Grandview Children's Centre.

Donna Thomson is an author and speaker on issues

relating to family caregiving, disability and aging. She is a patient and family advisor on health research and policy. Donna teaches family caregivers how to advocate for care and she blogs regularly for Troy Media and THE CAREGIVERS' LIVING ROOM www.donnathomson.com. Donna sits on the board of Kids Brain Health Network and advises on multiple committees and projects of CHILD-BRIGHT.



Derek van der Kooy received a MSc in Psychology

at the University of British Columbia, and a PhD in Anatomy, at Erasmus University in the Netherlands, and at the University of Toronto. He served as Professor in the Department of Anatomy and Cell Biology at the University of Toronto from 1991 until 2002, and then became a Professor in the Department of Molecular Genetics. His lab is the Neurobiology Research Group. The Van Der Kooy lab works on various stem cell biology and developmental biology research projects. They continue to investigate the nature of stem cells, embryonic and adult, the concept of immortal cells, and the differentiation of embryonic stem cells, capable of forming any tissue in the body, to neural stem cells. Derek received a Distinguished Scientist of the Canadian Institutes of Health Research award.

Notes

Share about the
Brain-Child-Partners Conference

#BCP2017

DAY 3

KIDS BRAIN HEALTH DAY

7:00-8:30AM	**REGISTRATION** | CONFERENCE HALLWAY **BREAKFAST** | PRINCE BALLROOM FOYER
8:30-10:00AM	**THE FRASER MUSTARD DIALOGUE: GENES VS. THE ENVIRONMENT** | PRINCE BALLROOM SOUTH
10:15-11:30AM	**DOES EARLY IDENTIFICATION LEAD TO BETTER OUTCOMES FOR CHILDREN AND FAMILIES IMPACTED BY NEURODEVELOPMENTAL DISORDERS** | PRINCE BALLROOM SOUTH
11:30-12:00PM	**BRAIN CANADA PRESENTS: TRAINEE POSTER AWARDS** | PRINCE BALLROOM SOUTH
12:00-1:00PM	**LUNCH** | PRINCE BALLROOM FOYER
1:00-2:15PM	**YOUNG RESEARCHER PRESENTATIONS: FROM DATA TO DISCOVERY TO IMPACT** | PRINCE BALLROOM SOUTH
2:15-3:30PM	**MUSIC AND THE MIND: NOVEL INTERVENTIONS TO IMPROVE BRAIN FUNCTION AND BEHAVIOUR** | PRINCE BALLROOM SOUTH
3:45-5:00PM	**RESEARCH SUCCESS STORIES: PARTNERSHIPS BETWEEN FAMILIES AND SCIENTISTS** | PRINCE BALLROOM SOUTH
5:00-5:15PM	**CLOSING REMARKS** | PRINCE BALLROOM SOUTH

THE FRASER MUSTARD DIALOGUE: GENES VS. THE ENVIRONMENT

8:30-10:00AM

This session will be a moderated discussion led by Cheryl Cytrynbaum in honour of Fraser Mustard of the role of epigenetics in neurodevelopmental disorders. Dr. Kobor will broadly outline the role of epigenetics as a mechanism by which early-life experiences can "get under the skin" to affect health and behaviour across the lifespan. To illustrate this concept, select examples of pre- and postnatal environments that sculpt the human epigenome will be highlighted. As such, a major focus of the presentation will be on the association of DNA methylation, a key epigenetic mark, with fetal alcohol spectrum disorder (FASD) in two human cohorts. Dr. Weksberg will focus on human neurodevelopmental syndromes caused by mutations in epigenetic regulators (or epigenes). This will include an explanation about how studying syndrome-specific changes in epigenetic marks can help us not only to understand how some of the clinical features arise but also for classification of genomic variants of unknown significance reported via molecular diagnostic testing. In the future, these DNA methylation marks and syndrome-specific altered epigenetic marks could be used to develop novel targeted therapies for individuals with neurodevelopmental syndromes and possibly as diagnostic predictors of FASD and other developmental disorders.

INTRODUCTION: Daniel Goldowitz
MODERATOR: Cheryl Cytrynbaum
SPEAKERS: Michael Kobor, Rosanna Weksberg

DOES EARLY IDENTIFICATION LEAD TO BETTER OUTCOMES FOR CHILDREN AND FAMILIES IMPACTED BY NEURODEVELOPMENTAL DISORDERS?

10:15-11:30AM

Early life experiences impact on the architecture of the brain, producing a foundation for all of the learning, health and behavior that follow. It is now estimated that, in the first few years of life, more than 1 million new neural connections are formed every second. At no other time in the life span is the brain more responsive to external environmental influences, which makes this period critically important for determining long-term cognitive, behavioural and socio-emotional development. Recognizing the importance of early serve and return exchanges between the caregiver and the infant, this session will explore the potential impact of early identification of children at risk of developmental delay from the perspectives of child and family health, as well as an assessment of how early identification screening tools may play a role in improving longer term socio-economic benefits.

MODERATOR: James Reynolds
SPEAKERS: Jennifer Zwicker, Chaya Kulkarni, Mary Rella

BRAIN CANADA PRESENTS: TRAINEE POSTER AWARDS

11:30-12:00PM

Awards will be given for the best trainee presentations in the poster session at the conference, followed by a celebration of the Brain Canada-Kids Brain Health partnership in support of the national training program in developmental neurosciences.

YOUNG RESEARCHER PRESENTATIONS: FROM DATA TO DISCOVERY TO IMPACT

1:00-2:15PM

The potential impact or significance of basic science research is not always clear, which can impact the understanding or appreciation of its importance. Neurodevelopmental research is heavily motivated by the goal of improving the lives of individuals and families affected by these potentially life-altering disorders. In this session, trainees will present their research, focusing on the potential impact the research may have on the communities that inspired their work. The objective of this session is to establish a broader understanding of the motivation(s) underlying and importance of much of the cutting-edge research being conducted nationally in this field.

MUSIC AND THE MIND: NOVEL INTERVENTIONS TO IMPROVE BRAIN FUNCTION AND BEHAVIOUR

2:15-3:30PM

In this panel, what we know about the neuroscience of music will be discussed and the brain connectivity that enables music to conjure up emotions and appreciation and other cognitive functions. This discussion will be expanded to how music therapy is being used in kids with neurodevelopmental disabilities to improve daily function. The invited speakers would also like to explore with the "key listeners" how creativity plays out in the world of brain development and activity, and how this may be harnessed for useful interventions.

MODERATOR: Sylvain Moreno
PANEL: Krista Hyde, Michael Thaut
KEY RESPONDERS: Patricia McKeever, Elaine Biddiss, Cheryl Peters

RESEARCH SUCCESS STORIES: PARTNERSHIPS BETWEEN FAMILIES AND SCIENTISTS

3:45-5:00PM

In this session research success stories will be presented from the vantage points of both families and researchers who have partnered to break new ground in solving medical science and healthcare issues for children with neurodevelopmental problems. The audience will then be engaged for discussion about the presentations and potential future visions for driving scientific discovery in neurodevelopmental disorders.

MODERATOR: Rosanna Weksberg
PANEL: Laura Williams, Pranesh Chakraborty, Julie Drury, Martin Holcik

DAY 3 SPEAKERS

Pranesh Chakraborty

is a physician certified by the Royal College in Medical Biochemistry and Pediatrics, with a subspecialty in Biochemical Genetics. He joined CHEO in 2003 as a clinician seeing patients with Inborn Errors of Metabolism (IEM). In 2006, he led the transition of Ontario's newborn screening program to Ottawa leading to the establishment of Newborn Screening Ontario (NSO) at CHEO. In 2008, he was instrumental in the founding of the Better Outcomes Registry and Network (BORN Ontario) at CHEO as a prescribed registry in Ontario. Finally, he is a Principal Investigator for the Canadian Inherited Metabolic Disease Research Network which recently was awarded a $1.5M CIHR Emerging Teams grant for rare disease research.

Daniel Goldowitz

received his PhD in Psychobiology at the University of California. His subsequent postdoctoral work at Harvard Children's Hospital in Boston, the Karolinska Institute in Stockholm, and the University of Utah School of Medicine in Salt Lake City was in the development of the nervous system. Using approaches that were relatively novel to the study of the brain he pioneered approaches to ascertain the function of genes in brain and behaviour. He currently holds a Tier 1 Canada Research Chair. He maintains strong NIH- , CIHR- and foundation-funded research programs in the genetics of brain development and function. Dr. Goldowitz led a successful application to be one of the federally funded NCEs, NeuroDevNet [recently rebranded as Kids Brain Health Network (KBHN)], currently in its second funding cycle with Goldowitz as the Scientific Director. More recently, Dr. Goldowitz was a part of a successful application to CIHR under Canada's Strategies for Patient-Oriented Research (SPOR) with a mandate to establish a chronic disease network focused neurodevelopmental disabilities. CHILD-BRIGHT (Child Health Innovations Limiting Disability-Brain Research Improving Growth Health Trajectories) is a national network that aims to improve life outcomes for children with brain-based developmental disabilities and their families. Within this Network, Dr. Goldowitz leads the Training Core which is tasked with developing the training program for multiple stakeholder groups (patients/families, health care providers, researchers, and policy makers).

Krista Hyde

is an Associate Professor in the Dept. of Psychology, University of Montreal and in the Faculty of Medicine, McGill University. She is a Faculty Member of world-renowned research centres in auditory cognitive neuroscience including the 'International Laboratory for Brain Music and Sound Research' and 'Center for Research on Brain Language and Music', as well as a member of leading child health initiatives such as 'NeuroDevNet' and the 'Autism Research Training Program'. As Director of the 'Auditory Brain and Cognitive Development Lab', Dr. Hyde and her team use a multi-disciplinary research approach (combining MRI brain imaging techniques of structure and function with behavioural methods) to help identify auditory-based neurobiological markers in typical development and neurodevelopmental conditions such as autism spectrum disorder. A special focus is to use music and dance as unique ways to study brain plasticity and interaction with behaviour. The ultimate goal of this research is to help refine phenotypes and to guide potential auditory-motor interventions in special populations. Dr. Hyde gratefully acknowledges funding support from sources such as NeuroDevNet, CIHR and NSERC.

Michael Kobor is a Professor of Medical Genetics at UBC and Tier 1 Canada Research Chair in Social Epigenetics. A Senior Scientist at the Centre for Molecular Medicine and Therapeutics. He serves as Theme Lead for Healthy Starts at BC Children's Hospital, an Investigator with the Kids Brain Health Network NCE, and a Senior Fellow in the Child and Brain Development Program of the Canadian Institute for Advanced Research. He completed his PhD in Medical Genetics at the University of Toronto before undertaking postdoctoral training as a Human Frontier Science Program Fellow at the University of California. Most recently Dr. Kobor's laboratory has begun investigating epigenetic variation in humans, with a particular focus on the effects of social environment on lifelong health and aging.

Chaya Kulkarni is currently the Director of Infant Mental Health Promotion (IMHP) at The Hospital for Sick Children in Toronto. Infant Mental Health Promotion is a community based coalition of individuals and professional agencies dedicated to promoting optimal mental health outcomes for infants in the first three years of life. Dr. Kulkarni provides leadership to research, professional education and public awareness activities at IMHP. In her role with IMHP, Chaya is currently leading advocacy and training initiatives in areas such as child welfare including family courts, and community based programs supporting families in their neighborhoods. She leads IMHP in the development and implementation of curricula and materials to support professionals working with families of young children.

Sylvain Moreno, PhD, Director of the Digital Health Hub and Associate Professor at the School of Interactive Arts and Technology. Dr. Moreno is a specialist in neuroscientific technologies related to digital media, rehabilitation and brain fitness solutions. Dr. Moreno has been a member of the New York Academy of Science since 2006. He is the Head of Innovation for the Kids Brain Health Network and part of the AGE-WELL NCE's innovation team. He has been the recipient of many awards from national and international organizations such as the Early Researcher Award from The Ontario Ministry of Economic Development and Innovation (2014). His work has received widespread press in various media outlets including the The New York Times and Forbes. He has authored several scientific publications and patents with real-world impacts in clinical and educational environments.

Lucy Osborne received her doctoral degree from The University of London, England and completed post-doctoral training in human genetics at the Hospital for Sick Children. She is currently a Professor in Medicine and Molecular Genetics, with a laboratory in the Medical Sciences Building. The major focus of Dr. Osborne's research is chromosome rearrangements of human chromosome 7q11.23, with the aim of understanding the molecular basis of the resulting neurodevelopmental disorders. Her lab is at the forefront of research into the deletion disorder Williams syndrome, as well as its reciprocal duplication disorder. Osborne and her team are currently using both human participants and animal models to probe the molecular and cellular bases of cognitive and behavioural aspects of these syndromes.

James Reynolds is a Professor in the Department of Biomedical and Molecular Sciences, and the Centre for Neuroscience Studies, at Queen's University. His research interests over the past 20 years have centred around studies on the effects of alcohol on the developing brain, with a focus on understanding the mechanisms of brain injury, and the resulting behavioural and cognitive deficits, that are induced by prenatal exposure to alcohol. Dr. Reynolds has been funded for interdisciplinary basic and clinical investigations into the cellular mechanisms and neurobehavioural consequences of Fetal Alcohol Spectrum Disorder (FASD), and is one of the project leaders in Kids Brain Health Network, a national Network of Centres of Excellence in developmental neuroscience. In this role, Dr. Reynolds co-ordinates multi-centre, cross-Canada projects encompassing basic science and clinical studies in FASD that involve genetics, brain imaging, neurobehavioural assessments and intervention studies.

Michael Thaut received his PhD in music with a cognate minor in movement science in 1983 and his masters in music 1980, both from Michigan State University. Since 2016 he is Professor of Music with cross appointments in Neuroscience and Rehabilitation Sciences at the University of Toronto where he directs the Music and Health Research Collaboratory (MaHRC) and the Masters/PhD programs in Music and Health Sciences. His research career has been focused on the neural and psychophysical basis of music and rhythm perception and clinical application of music and rhythm to motor, speech/language, and cognitive training in neurologic disorders. He is the founder of the evidence-based treatment system of Neurologic Music Therapy whose certificate training has been endorsed by the World Federation of Neurorehabilitation. He is President of the International Society for Clinical Neuromusicology, Vice President of the International Society for Music and Medicine, a Management Board Member of the World Federation of Neurorehabilitation, and an elected Overseas Fellow of the Royal Society of Medicine (U.K.).

Jonathan Weiss is an Associate Professor in the Department of Psychology at York University and Clinical Psychologist. He completed a predoctoral residency at Surrey Place Centre (Toronto, ON), and a postdoctoral fellowship at the Centre for Addiction and Mental Health and University of Toronto, Dept. of Psychiatry. He currently holds the federal Chair in Autism Spectrum Disorders Treatment and Care Research. His research focuses on the prevention and treatment of mental health problems in people with Autism Spectrum Disorder or intellectual disabilities. He studies the impact of stressors, such as bullying or transitions, and how cognitive behaviour therapy can help youth with Autism Spectrum Disorder who have mental health problems. Dr. Weiss conducts studies of the changing service needs and barriers to service use for individuals with Autism Spectrum Disorder and their families across the lifespan. Dr. Weiss holds the CIHR Chair in Autism Spectrum Disorders Treatment and Care Research, as well as operating funds from the Canadian Institutes of Health Research and Social Sciences and Humanities Research Council.

Rosanna Weksberg

is a Professor of Pediatrics and Molecular Genetics at The Hospital for Sick Children and the University of Toronto. She was Head, Division of Clinical and Metabolic Genetics, The Hospital for Sick Children for 11 years. Dr. Weksberg is actively involved in many University of Toronto and national initiatives in genetics and epigenetics. Her research interfaces between clinical genetics assessments on patients and molecular genetic approaches to understanding imprinting and epigenetic lesions in the development of genetic syndromes and sporadic cancers. She is currently funded by CIHR, CFI, and most recently by NIH as a co-investigator for a program to study induced pluripotent stem (iPS) cells derived from children with autism or psychosis and genomic copy number variations which will formally explore the attitudes of families to the development of iPS lines for research purposes.

Laura Williams

is the parent of an 11-year old son with a rare genetic condition, GRIN1. This diagnosis was made in December 2015 through whole exome sequencing after a 9-year search. Since the diagnosis, Laura has been connected with families across the globe who are partnering to support research to help their children. Laura is also the Director of Patient Engagement at the University Health Network (UHN). In her role, Laura provides leadership for Patient and Family Education, Patient Engagement and Partnerships, Patient Relations, Interpretation and Translation Services, Patient Experience Measurement and the Patient Portal. Over the past decade, Laura has been a champion of patient engagement in pediatric, adult and government settings, promoting the importance of embedding patient and family caregiver voices into all health care decisions. This includes policy development, organizational planning and at the point-of-care.

Jennifer Zwicker

is passionate about social policy and healthcare reform. She completed a BSc (Honours) in Physiology and Developmental Biology and a PhD in Neurophysiology at the University of Alberta. During graduate school, she was engaged in fostering innovation in informed policy development and science communication through interdisciplinary collaboration. She advocated for the important role graduates of science programs can play outside of the academic community. She currently works in health policy as a Research Associate in Calgary. Her focus is on innovation and health economics where she collaborates with stakeholders to develop health policy to foster effective and financially stable health care systems.

Patricia McKeever

is Professor Emeritus, L.S. Bloomberg Faculty of Nursing, University of Toronto and Adjunct Scientist, Bloorview Research Institute at Holland Bloorview Kids Rehabilitation Hospital. From 2007 to 2012, she held the hospital foundation's Chair in Childhood Disability Studies. Her areas of expertise include long-term care policies, chronic illness and disability, trans disciplinary scholarship, philosophy and qualitative research methods. Her research focused on disabled children's embodiment, assistive technologies, and the places where they live, attend school and/or receive care.

Notes

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KIDS BRAIN HEALTH NETWORK
PARTNERSHIP DAY

Kids Brain Health Network (KBHN) would like to invite partners and interested parties (researchers, families) to join us for a Workshop on November 9th 2017, the day after the Brain-Child-Partners conference, to explore the points of intersection between the needs of organizations that serve kids with neurodevelopmental disabilities and their families, and the knowledge being developed by KBHN researchers. We will see examples of effective partnerships that are flourishing between our investigators and a range of collaborators.

We will be there to listen and learn about your needs in screening and diagnosis, targeted treatment, support for families and other priorities that benefit children with neurodevelopmental disabilities, and explore how current and prospective Kids Brain Health researchers and organizations focused on supporting service delivery to children and families can collaborate to address unmet needs and priorities through impactful partnerships.

WORKSHOP PROGRAMMING

We need your help to understand how to best engage your organization with the country's top researchers in helping you better meet the needs of customers and clients. We realize that there is often a disconnect between what research is finding and what your organization wants to deliver. This workshop is designed to help narrow that gap.

The workshop will be facilitated by Dr. Joseph Ferenbok, Director of the Translational Research Program (TRP) at the University of Toronto.
TRP specializes in helping people, including experienced professionals, who see problems and solutions, but don't know how to move projects forward.

Our day will begin with a discussion around defining what "needs" mean to the different stakeholder present. We will then break into groups to explore the practical application of partnerships as a means to addressing needs.

Benefits to participating in the workshop:

- Better define and express your own needs
- Get feedback on your priorities from families
- Discuss how to collaborate with us moving forward

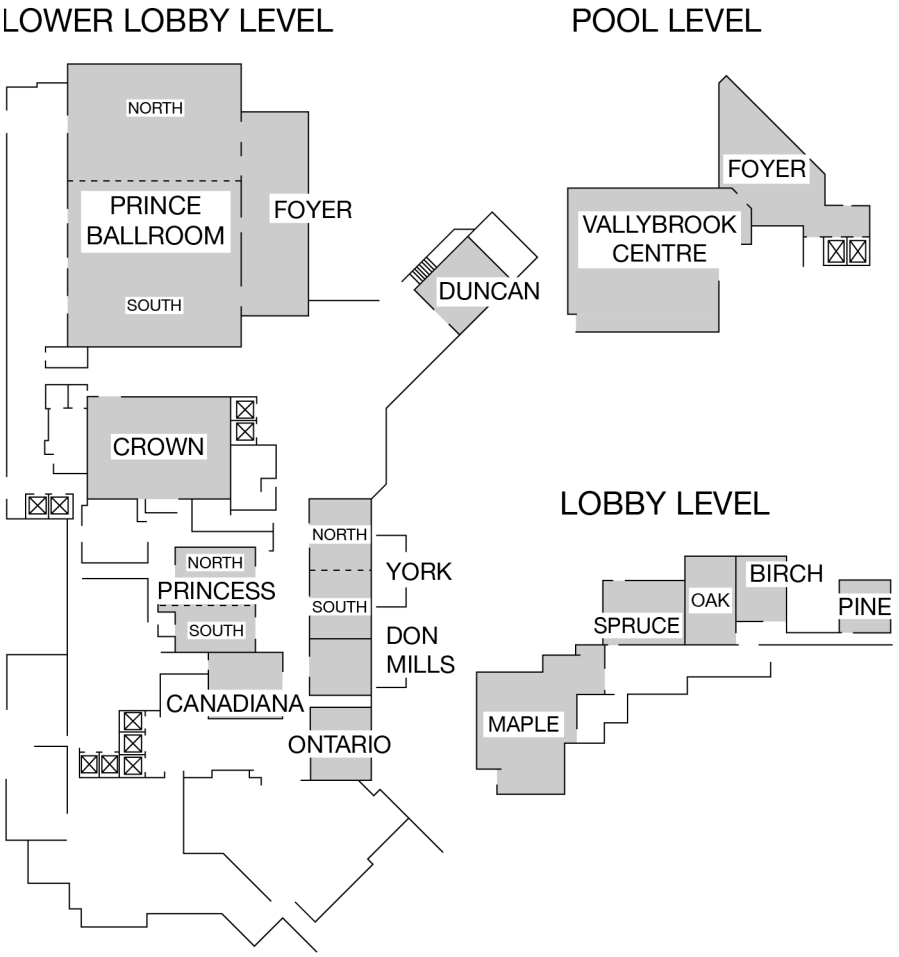
THURSDAY, NOVEMBER 9

8:00-8:15AM	**INTRODUCTION** | COLIN DEACON, VICE CHAIR, KBHN BOARD OF DIRECTORS
8:15-8:30AM	**OUTLINE OF THE DAY'S ACTIVITIES** | DR. JOSEPH FERENBOK, DIRECTOR OF THE TRANSNATIONAL RESEARCH PROGRAM, UNIVERSITY OF TORONTO
8:30-9:00AM	**PLENARY: AN INTERNATIONAL PERSPECTIVE ON TRANSFORMATIVE PARTNERSHIPS** | CATHERINE CARTY, UNESCO CHAIR PROJECT MANAGER, INSTITUTE OF TECHNOLOGY TRALEE
9:15-10:15AM	**BREAKOUT DISCUSSION: WHAT ARE OUR NEEDS?**
10:15-10:30AM	**BREAK**
10:30-11:30AM	**INNOVATIVE EXAMPLES OF ADDRESSING NEEDS THROUGH PARTNERSHIP** | CHRISTINE CHAMBERS, DALHOUSIE UNIVERSITY, IT DOESN'T HAVE TO HURT INITIATIVE/YUMMY MUMMY CLUB & JAMES REYNOLDS, DEPUTY SCIENTIFIC DIRECTOR, KBHN, FETAL ALCOHOL RESOURCE PROGRAM/CITIZEN ADVOCACY OTTAWA
11:30-12:30PM	**BUFFET / WORKING LUNCH**
12:30-1:30PM	**BREAKOUT DISCUSSION: CREATING PARTNERSHIPS**
1:30-2:00PM	**BRINGING IT ALL TOGETHER**

VENUE FLOOR PLANS

All conference programming sessions, including pre- and post-event network activities, will take place at the Westin Prince Toronto. The Westin Prince Toronto is tucked away on a picturesque 15 acres of parkland and offers an unparalleled location with the combination of inspiring scenery while still maintaining easy access to all that the city has to offer.

Visit **westinprincetoronto.com** for more information on bookings, hotel features, and Toronto tourism.



AGENDA AT-A-GLANCE | NOVEMBER 6-8

DAY 1: MONDAY

7:00-8:30AM	REGISTRATION | BREAKFAST
8:30-9:40AM	WELCOMING REMARKS
9:40-10:45AM	THEME 1: CAN WE FIX THE BRAIN?
11:00-12:05PM	THEME 2: FINDING WAYS TO IMPROVE CHILDREN'S MENTAL HEALTH
12:05-1:10PM	LUNCH
1:10-2:15PM	THEME 3: SINK OR SWIM: CAN WE EMPOWER FAMILIES TO NAVIGATE KEY TRANSITIONS?
2:30-4:00PM	WORKSHOPS: YOUTH ENGAGEMENT BRAINSTORM PATIENT-ORIENTED TRAINING PRACTICAL APPROACHES TO SCIENCE COMMUNICATION
4:00-4:15PM	BRIGHT REMARKS
4:15-6:00PM	CHILD-BRIGHT MARKETPLACE
4:30-6:00PM	KBHN PROFESSIONAL DEVELOPMENT WORKSHOPS

DAY 2: TUESDAY

7:00-8:30AM	REGISTRATION | BREAKFAST
8:30-10:00AM	EXPLORING THE PURPOSE AND MEANING OF PATIENT ENGAGEMENT IN PEDRIATRIC NEURODISABILITY RESEARCH
10:15-11:30AM	OUTCOMES THAT MATTER: ARE WE ON THE SAME PAGE?
11:30-12:00PM	YOUNG RESEARCHER TALKS
12:00-1:00PM	MEET THE EXPERTS | LUNCH
1:00-2:15PM	MAKING RESEARCH UNDERSTANDABLE: NEW CHANNELS OF COMMUNICATION
2:15-3:30PM	CAN BASIC RESEARCH & APPLIED RESEARCH BE FRIENDS?
3:45-5:00PM	LISTENING TO CHILDREN'S VOICES: PROMOTING YOUNG PEOPLE'S ENGAGEMENT AND PARTICIPATION
5:00-7:00PM	POSTER & NETWORKING RECEPTION

DAY 3: WEDNESDAY

7:00-8:30AM	REGISTRATION | BREAKFAST
8:30-10:00AM	THE FRASER MUSTARD DIALOGUE: GENES VS. THE ENVIRONMENT
10:15-11:30AM	DOES EARLY IDENTIFICATION LEAD TO BETTER OUTCOMES?
11:30-12:00PM	BRAIN CANADA PRESENTS: TRAINEE POSTER AWARDS
12:00-1:00PM	LUNCH
1:00-2:15PM	FROM DATA TO DISCOVERY TO IMPACT
2:15-3:30PM	MUSIC AND THE MIND: NOVEL INTERVENTIONS TO IMPROVE BRAIN FUNCTION AND BEHAVIOUR
3:45-5:00PM	RESEARCH SUCCESS STORIES: PARTNERSHIPS BETWEEN FAMILIES & SCIENTISTS
5:00-5:15PM	CLOSING REMARKS

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BRAIN-CHILD-PARTNERS CONFERENCE

NOVEMBER 6-8, 2017 | TORONTO, CANADA

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