

2018-19 Report to Community

Fiscal year ended
March 31, 2019



Empowering Connections



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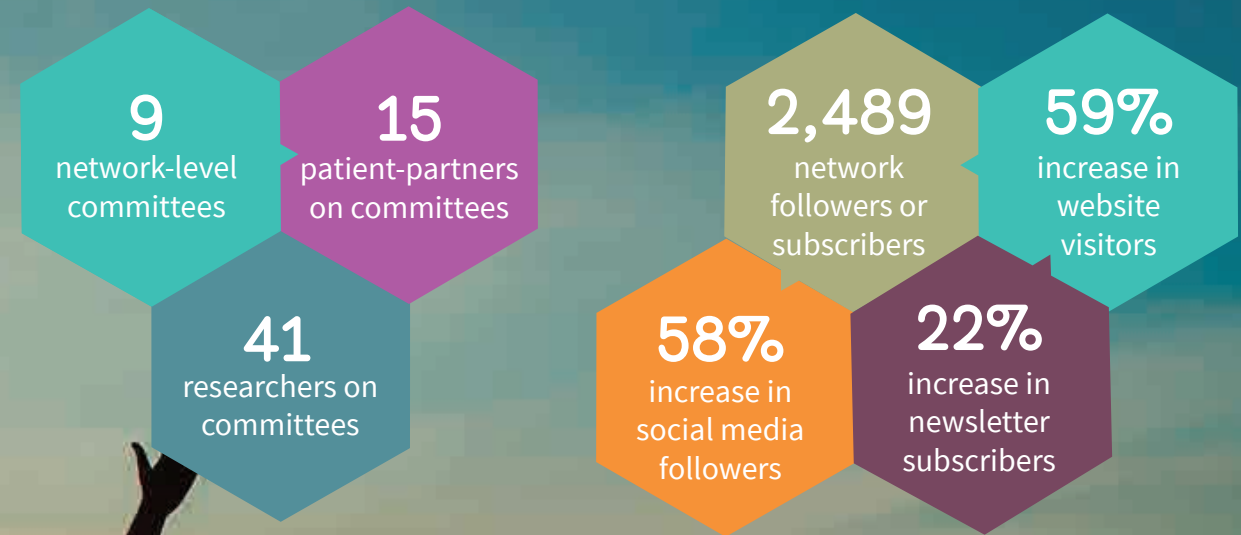
About CHILD-BRIGHT

Who we are

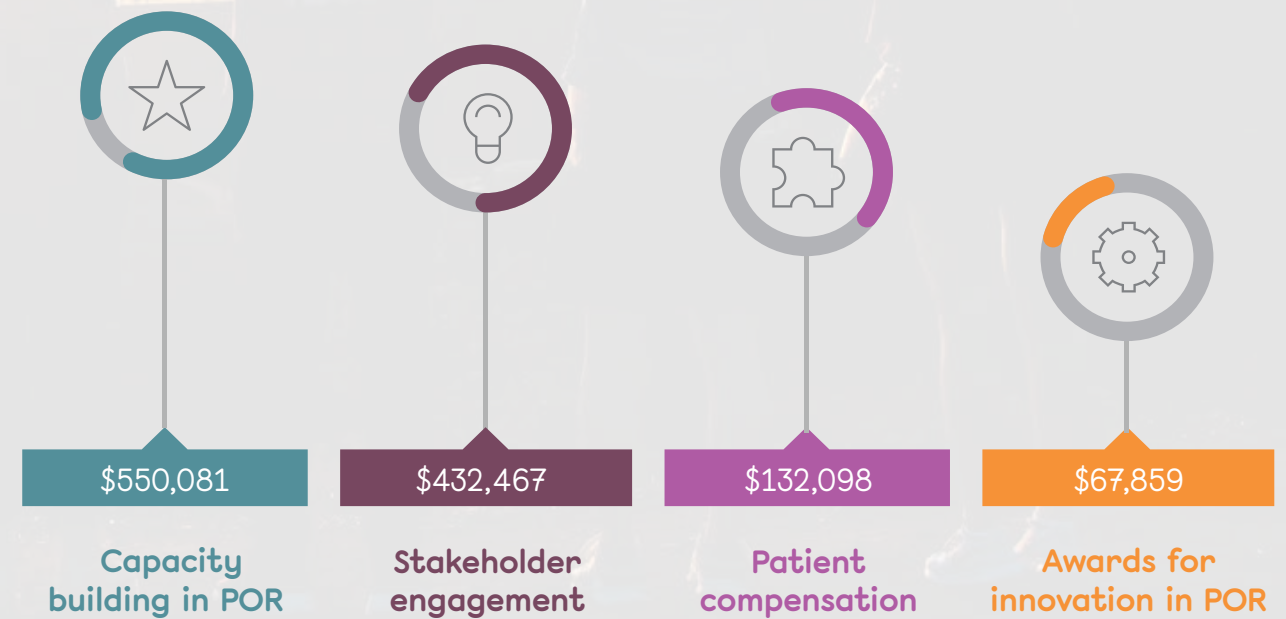
The CHILD-BRIGHT Network, headquartered at the Research Institute of the McGill University Health Centre (RI-MUHC), is an innovative pan-Canadian network that aims to improve life outcomes for children with brain-based developmental disabilities and their families. Using family and child-focused approaches, 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 28 generous funding partners from public and private sectors across Canada.



Our network at a glance



A glimpse at financial investments to support patient engagement



Message from Annette Majnemer

CHILD-BRIGHT Network Director

Dear CHILD-BRIGHT community,

Each year, I look forward to sharing our progress with you... this year especially because, as a network, we are celebrating the connections we have forged, and continue to forge! Connections have been crucial to our progress towards building a community that supports patient-oriented research (POR), and connections make CHILD-BRIGHT stronger than the sum of all its elements. By joining forces, we have not only established a new infrastructure for ourselves but are fostering new attitudes, new practices, new ways of thinking, and are finding transformative solutions to existing problems. We are leading a movement for change in Canada, and slowly starting to influence global partners. It has been a fruitful year thanks to these connections, and I am thrilled to share a few of our accomplishments here with you.

We diversified our patient partnerships

This year, we launched our new National Youth Advisory Panel (NYAP) and we doubled the number of children and youth who help steer our work. Our NYAP members bring a crucial perspective to our work and are already hard at work advising research teams on ways to engage youth and communicate findings to youth and policy makers. We invite you to meet these new youth members on p. 12. By reading the updates from all the research teams on pages 26 to 51, you will also meet many other youth and patient-partners and learn how they are crucial to helping advance our research work.

We are also happy to share that we launched our new Prenatal Opioid Exposure and Neonatal Abstinence Syndrome research project this year (more on p. 36). First Nation communities now make up 20% of our community and patient partnerships and these new members are helping develop training initiatives and educate CHILD-BRIGHT members about issues of importance when working in partnership with Indigenous Peoples (more on p. 61).

We combined efforts across research teams

Connections among CHILD-BRIGHT researchers continue to flourish. Investigators and study teams across the network continue to work collaboratively to navigate institutional and jurisdictional regulations, and enable multi-site recruitment across the country for our projects. Eleven of our 13 projects are now recruiting participants and collecting data.

Teams also gathered with network members in December for our 2018 CHILD-BRIGHT Annual Meeting. In total, 117 members of all our programs and project teams, including 17 patient-partners, came together to discuss our shared mandate and brainstorm ways to strengthen our connections! More on this on p. 56.

We started mapping out a policy-influencing system

As part of our efforts to enhance connections with policy makers, and to educate our members about the interplay between research and policy, we held a CHILD-BRIGHT Policy Forum in Montreal this year (more on p. 63). We are also developing a CHILD-BRIGHT Policy Hub, a new initiative that will help identify the potential policy impact of projects, conduct policy analyses, and create an evidence-based response unit for childhood disability. In March, we were also grateful to receive the visit of the Honourable Ginette Petitpas Taylor, federal Minister of Health. Together, with 13 of our network members from all stakeholder groups, we discussed issues of importance to our members.

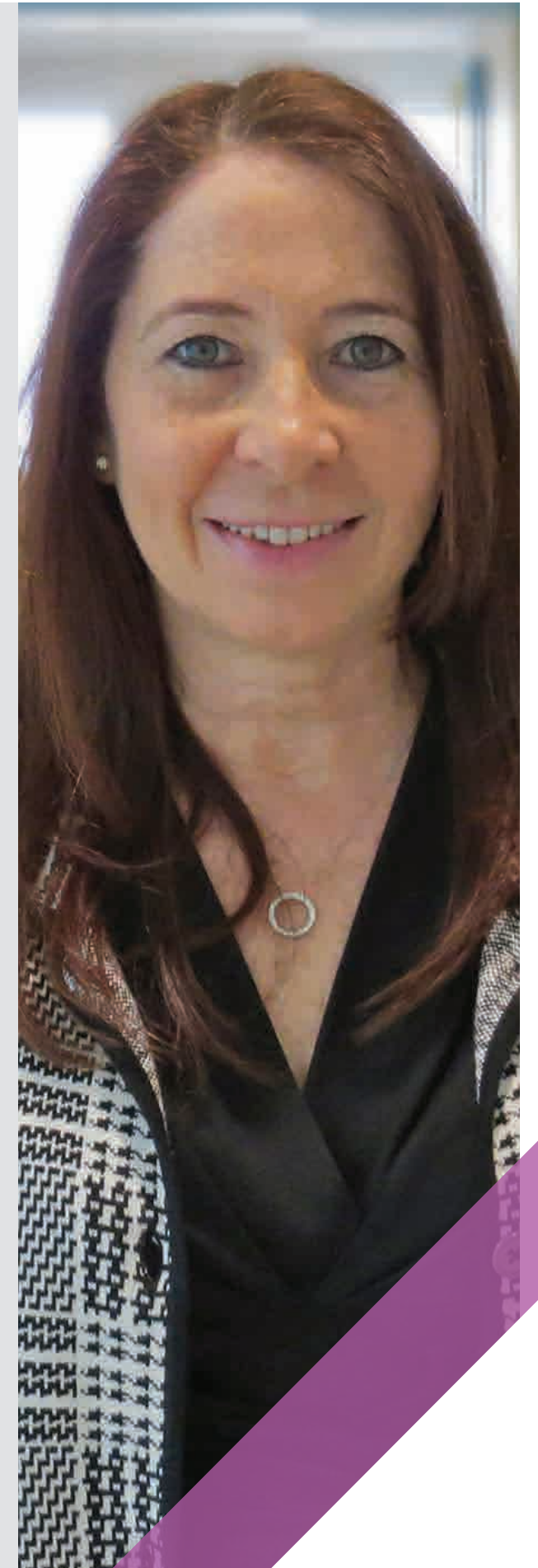
We continue to build capacity in patient-oriented research and CHILD-BRIGHT

Via our many webinars (see p. 68), our 2018 CHILD-BRIGHT Summer Learning Series, and various collaborations with fellow SPOR and industry partners, we continue to offer training opportunities to help educate trainees, researchers and patient-partners in skills required to better engage patients as partners in the research process. In partnership with the BC SUPPORT Unit and UBC's Faculty of Medicine, we created and launched an online Patient-oriented Research Repository (PoRR) designed to match and connect students with POR projects teams.

All these accomplishments, and many more, are made possible thanks to these strong bonds that we have established. They provide CHILD-BRIGHT with a strong foundation and will be key to helping us become a movement for change in Canada in years to come. Thank you all for your commitment on behalf of children with disabilities and their families.

Gratefully,

Annette Majnemer



Message from Frank Gavin

CHILD-BRIGHT Director of Citizen Engagement

Dear CHILD-BRIGHT Network Members,

This letter is part of our third Report to Community, a title that assumes the existence of a particular community.

But is there such a community—a CHILD-BRIGHT community? And, if so, does it include all who want or need to belong to it? These are questions we ask ourselves with increasing frequency and some urgency because we understand that helping to create an ever-more inclusive community is essential to CHILD-BRIGHT’s mission—a term I would not have used a year ago—and its eventual success.

In one session at our annual meeting in December 2018 everyone participated in small-group discussions about the barriers that impede the participation in our network of specific populations (such as recent immigrants, people who live in or near poverty, young people and parents with intellectual disabilities, and people who live with severe mobility difficulties) and about ways to overcome these barriers. Talking about inclusion, however, is not the same as being inclusive, so our efforts now must be to act on what we said and heard we need to do. And it may not be as difficult as we sometimes think. At the meeting, one parent who came with her child with very complex needs from northern Alberta said, “we’re actually not that hard to reach.”

One area in which we have made real gains is youth engagement. In last year’s letter we announced the formation of a National Youth Advisory Panel, and I’m pleased to tell all that it’s up and running, with members eager to support youth-partners in research projects and already advising researchers on effective ways to engage youth. They have already grown increasingly diverse in terms of geography and language and are represented on the Citizen Engagement Council (CEC) by their chair, Mathias Castaldo.

The CEC itself has continued to review and refine the network’s compensation and reimbursement guidelines—in large part to facilitate the participation of a wider range of parent and youth partners. Receiving compensation twice rather than once a year and timely reimbursement for travel expenses to attend network events makes an enabling difference for some parents and youth. Council members from the CEC have also been advising network research projects on matters ranging from the recruitment of study participants to the roles of patient-partners on research teams.

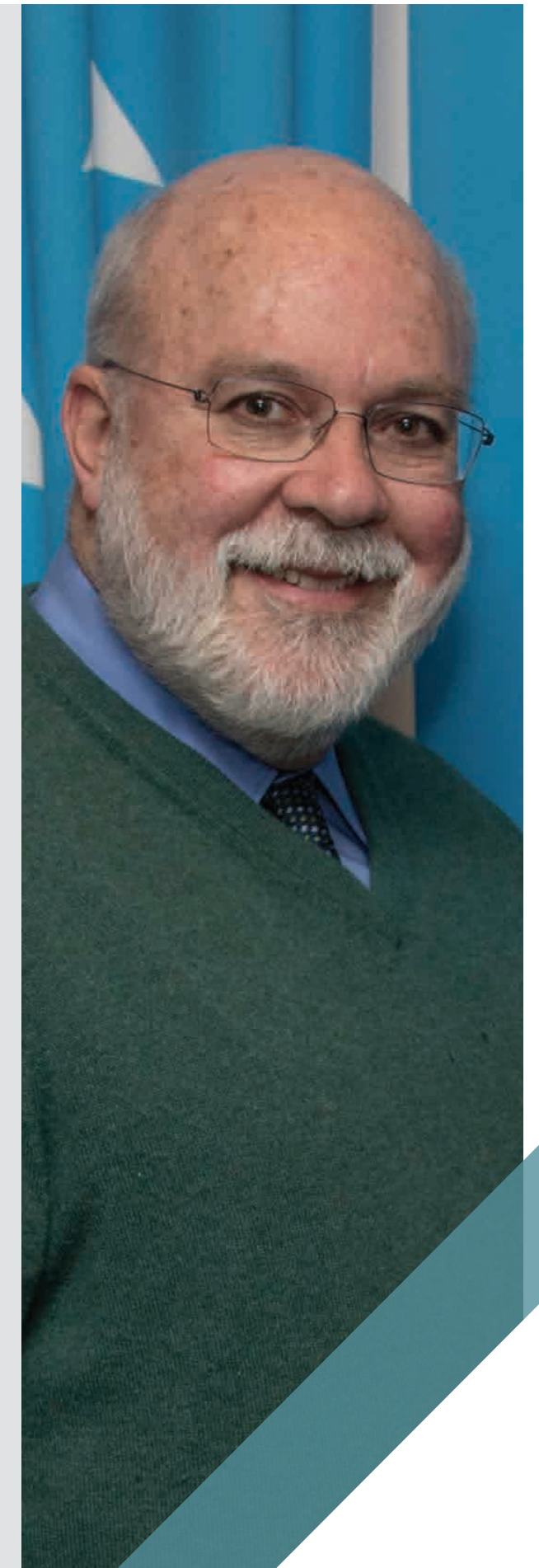
In last year’s letter I noted the hiring of a parent peer-mentor, Susan Cosgrove. Several months after Susan started, she left for a full-time position elsewhere, so we reflected on her experience and helpful advice and made some changes to the role, now very capably being performed by Carrie Costello. The emphasis now is to connect with, listen to, and (if appropriate) support parent partners so they continue to participate as—or grow to become— full and equal members of research teams. We also want to help them feel part of and contribute to the wider network community. We’ve learned this doesn’t happen simply as a result of good intentions: the community needs to be consulted, heard, and built step-by-step.

Elsewhere in this Report are accounts of our newest research project, which is being led by a number of First Nations in Ontario. The project is not only enlarging the CHILD-BRIGHT community but also helping us envision the community we can become—one that enables and nourishes partnerships between individuals and between groups once unknown to one another and that makes permeable the borders of once separate worlds.

Many of us in CHILD-BRIGHT have begun to talk of transforming the network into a movement, but perhaps that’s just another way of saying we’re trying to create a genuine and vibrant—and therefore sometimes cantankerous but more often harmonious—community.

We hope you will consider joining us,

Frank Gavin



Message from Mathias Castaldo

CHILD-BRIGHT National Youth Advisory Panel Chair

My name is Mathias Castaldo, I currently live in Toronto where I attend OISE (University of Toronto). I am studying for my Masters of Education in Developmental Psychology and Education, and work as a youth facilitator as part of Holland Bloorview Kids Rehabilitation Hospital's employment team. I hope to one day be a teacher and work with students with disabilities.

As Chair of the National Youth Advisory Panel (NYAP) at CHILD-BRIGHT, I am happy to report that the NYAP had a busy first year.

Initially, four members of the NYAP came together in the summer of 2018 at Holland Bloorview Kids Rehabilitation Hospital for a training session (see p. 57). Soon after, two more youth joined the NYAP and we met once a month via teleconferences. Throughout these meetings, we had the opportunity to connect with researchers, consult on research projects such as the Metformin project, and connect with members of CHILD-BRIGHT's Citizen Engagement Committee and Knowledge Translation Committee.

The NYAP, being a pan-Canadian virtual research advisory committee, has provided members with an opportunity to connect with other youth with lived experience of brain-based disabilities. In addition, the NYAP has provided members with a valuable learning experience, such as learning about various research methods and different research studies of interest to us.

It has been beneficial that we hold our meetings via teleconference. We come to a consensus on the best day to hold a meeting to ensure that the majority of the members can attend the meeting. Meeting via teleconference is also much more accessible versus having to meet in person.

Furthermore, it has been beneficial having a translator since some members speak English while others speak French. The Citizen Engagement Coordinator, working with the administrative support staff, provide all documents (e.g. meeting agenda and materials), and translations so all members can participate fully in either language that is easier for them.

The friendly and inviting environment the NYAP has created makes it easy to ask questions and provide input into what is being discussed. We also take votes on major decisions involving NYAP activities, allowing each member to give their opinion freely and without judgement.

The panel will soon accept external fee-for-service consultation requests from research projects focused on children and youth with brain-based developmental disabilities. We are working with Holland Bloorview Kids Rehabilitation Hospital in the construction of this service – more details on our progress to come!

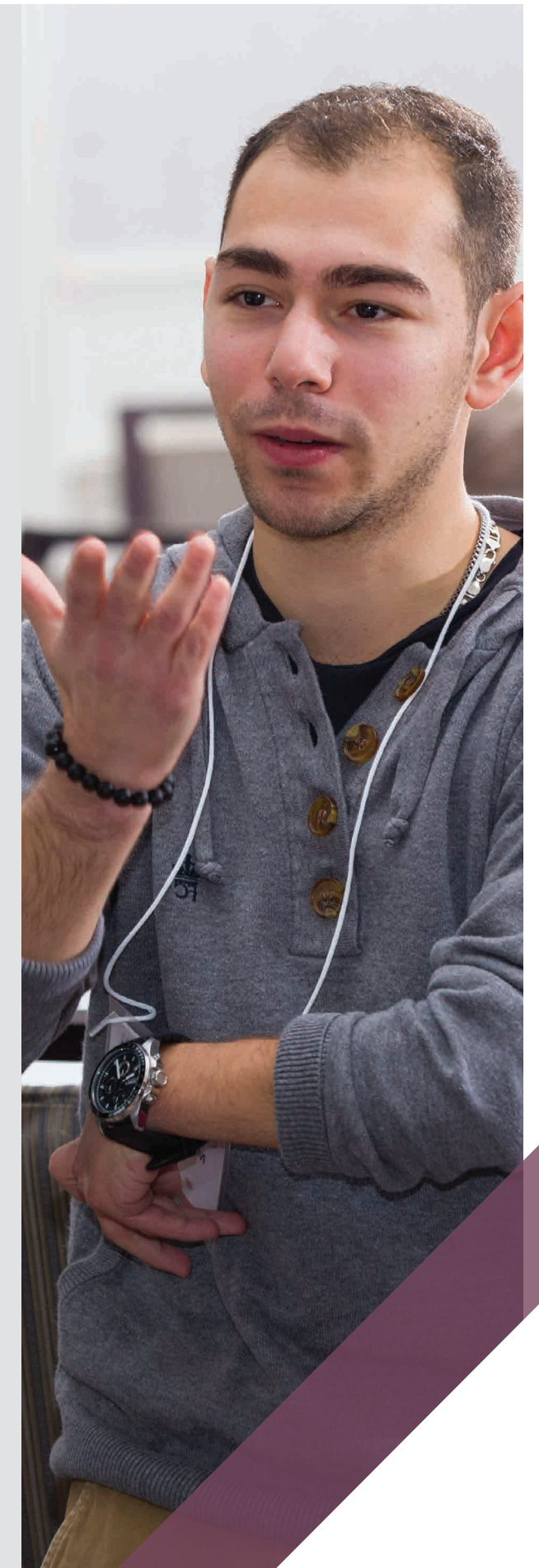
Some of our members have joined the Knowledge Translation Committee while others have joined the Policy Hub at CHILD-BRIGHT.

We also hope to connect with other youth to share and learn from their experiences of being a youth-partner on projects.

Lastly, we will soon be publishing our eight tips for researchers to consider when engaging youth members in research, which we hope will help not only the CHILD-BRIGHT community, but other researchers looking to connect with young people with a lived experience with a brain-based developmental disability.

Our work is just starting and we hope to recruit more members from across Canada – we are currently looking to recruit youth out west (e.g. British Columbia) and east (e.g. New Brunswick, Nova Scotia) so let us know if you are interested!

Thank you,
Mathias Castaldo



Meet our youth panel members

Our National Youth Advisory Panel (NYAP) members had a busy first year; they met monthly via teleconferences, gathered in Toronto for their first training session (more on p. 57) and developed a tip sheet to support the engagement of youth patient-partners, which will be made available to CHILD-BRIGHT researchers and associated consultants later in 2019. The NYAP is also working on constructing a fee-for-service structure for external researchers seeking the lived experience of youth. Meet them below!



MATHIAS CASTALDO
(TORONTO)

Mathias is pursuing a Master's degree in Developmental Psychology and Education. He enjoys reading, traveling, and running. Mathias hopes to learn how the NYAP will be able to advise on improving research methods so that it will have a positive impact on young people's lives.



MIKE SAMETZ
(CALGARY)

Mike studies business at the University of Calgary, and is a road and track cyclist on the Para-Cycling National Team. He won bronze at the Rio Paralympics and Gold at the World Championships in 2017-2018. His hope for the NYAP is to ensure research studies have a positive influence and impact on all patients.



MAYA PAJEVIC
(CALGARY)

Maya is completing a Bachelor's degree in Sociology at Mount Royal University. She enjoys traveling, photography, and thrill-seeking activities. She hopes that the NYAP can help shift research to become 'best practice' and improve health care for those who need the services.



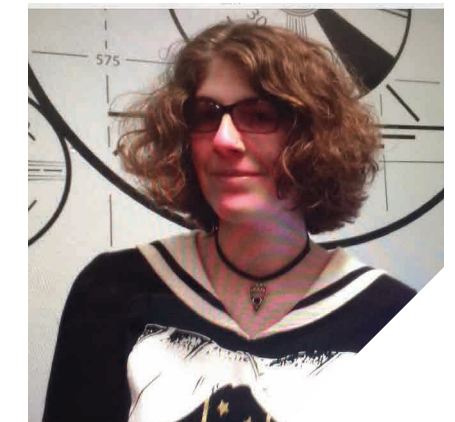
HANS DUPUIS
(MONTREAL)

Hans works at Air Canada and has acted as a mentor at Action Main d'Oeuvre, helping people with autism get ready for the workforce. He enjoys graphic novels, live-action role play, and Cosplay conventions. His goal is to help others with brain-based disabilities or autism, and to learn from other NYAP members.



LOGAN WONG
(TORONTO)

Logan is completing a Bachelor of Social Work at Ryerson University, enjoys sports and volunteering, and hopes to bring youth voices to conversations about research. Logan hopes that by working as a team, the NYAP can make research proposals more accessible to the youth population.



ÉLISE ROBERT-HUET
(MONTREAL)

Élise is an administrative assistant at l'Arche Canada and often appears on French television and radio to discuss topics of her life. She enjoys cinema, visual arts, and literature. Her hope for the NYAP is to provide equal opportunity for all Canadians to participate on the panel.



Citizen Engagement Program



We aim to meaningfully and effectively engage as many people as possible touched by brain-based developmental disabilities in our work. Dynamism is growing thanks to what we are learning from new and more experienced network members and from our experience working together. Here are a few highlights:

Meeting the Honourable Ginette Petitpas Taylor

In March 2019, CHILD-BRIGHT members, including patient-partners, researchers, a trainee, a funding partner, and central team members, hosted the Honourable Ginette Petitpas Taylor, Minister of Health at our Montreal office. It was a chance for our members to discuss issues of importance to our population, such as how to influence policy, with the Minister.

[Read more about our work to influence policy \(see p. 63\)](#)

Addressing the complications of compensation

We are committed to patient-partner compensation and reimbursement and therefore refine our guidelines yearly to ensure they address the realities of parents of children with complex needs and of youth partners. This last year, our Citizen Engagement Council proposed the following changes to our guidelines, which have been applied:

- We now compensate patient-partners twice yearly, rather than once yearly
- We added a provision that details the reimbursement of childcare expenses
- We now compensate patient-partners for extra tasks undertaken for the network.

CHILD-BRIGHT's Patient-Partner Compensation Guidelines are available on our website.

Assembling (and growing!) our community

This year, relationships between CHILD-BRIGHT leaders and First Nations researchers led to connections with First Nations communities and the launch of a new research project. Network members, including 20 patient-partners and new First Nations partners, gathered at our 2018 Annual Meeting in December. Parents and youth also took part in CIHR's SPOR Summit in November, where CHILD-BRIGHT took the lead in organizing a panel session where patient-partners from all SPOR networks addressed engagement.

[Read more about our partnership with First Nation communities \(see p. 61\)](#)

[Read more about our 2018 Annual Meeting \(see p. 56\)](#)

Training Program



We develop training and mentoring opportunities to help foster a culture of patient-oriented research that will positively affect health research in Canada and improve outcomes for patients and their families. This year, we are proud to have trained more than 370 participants through a number of online and in-person activities. Some of our initiatives include:

Summer Learning Series

In 2018, we launched the Summer Learning Series, a collection of 4 webinars open to all CHILD-BRIGHT stakeholder groups in which we explored the concept of patient-oriented research, the drivers or inhibitors of effective engagement, and demonstrated how patient engagement can be incorporated into a research project.

[Read more about our Summer Learning Series webinars \(see p. 69\)](#)

Summer Studentship Training Program

As part of our ongoing efforts to train the next generation of researchers, we supported 9 trainees in our Summer Studentship Training Program. These trainees were embedded within 8 of our research project teams and learned the central tenets of patient-oriented research through practical experience and an online learning modality.

Supporting old and new partnerships and connections

Partnerships and new connections help us enhance training resources available to Canadians. This year, we continued to develop our relationship with representatives from each of Canada's SPOR Networks in Chronic Disease. These interactions helped inform the launch of the 2018 Training Innovation Fund, which resulted in new partnerships being established with groups developing unique POR training outputs.

[Read about our 2018 Training Innovation Fund \(see p. 59\)](#)

Looking ahead to translating knowledge to action

This year the Training Program hosted the Policy Forum which connected policy experts from across Canada with 34 CHILD-BRIGHT members. At the forum, we discussed how to best mobilize our research findings towards implementation and policy change.

[Read more about the Policy Forum \(see p. 63\)](#)

Knowledge Translation Program



We are developing and implementing strategies to effectively translate the results of our research findings to families, health care professionals and society at large.

Fostering old and new connections

We welcomed Cat Lau (Knowledge Translation Coordinator) and Roberta Cardoso (Research Associate) to the Knowledge Translation Program and Committee this year. They contribute to the logistics and evaluation of our initiatives from measuring stakeholder engagement within the network to engaging policy makers. Our committee has continued to help provide opportunities for research teams to engage different stakeholders, inform policy, and disseminate their research to a broad audience.

[Read more about our work to influence policy \(see p. 63\)](#)

Evaluating engagement and knowledge translation activities

We are measuring the impact of stakeholder engagement using a collection of tools based on findings from our rapid review. At our 2018 Annual Meeting, we presented preliminary results to network members and this provided everyone with the opportunity to evaluate how much we've already achieved and where we can focus to improve engagement going forward. We also presented our newly developed, integrated Knowledge Translation Tracking Tool, which is meant to assist CHILD-BRIGHT researchers increase the impact of their KT activities. This was positively received and inspired meaningful discussion with different stakeholders on its value for research projects.

[See an overview of our network engagement and membership stats \(see p. 4\)](#)

New initiatives to engage vulnerable populations

We are examining strategies to engage hard-to-reach populations and expecting to publish our findings in a review article this year. In addition, a project is currently underway focusing on low-income families to gain insight on how to engage these families as partners in research.

Research Program



We progressed significantly this year. Many projects transitioned from single-site to multi-site projects, and 11 project teams are now recruiting participants and collecting data. Here are a few other highlights:

Launched a 13th research project

Back in 2017, we responded to a request from First Nation communities in southern Ontario to help better support families who have a child with opioid withdrawal. This led to the launch of our *Prenatal Opioid Exposure and Neonatal Abstinence Syndrome* project this year, which joins our BRIGHT Beginnings theme.

[Read more about this new research project and team \(see p. 36\)](#)

[Read more about our partnership with First Nation communities \(see p. 61\)](#)

Built network demographic forms

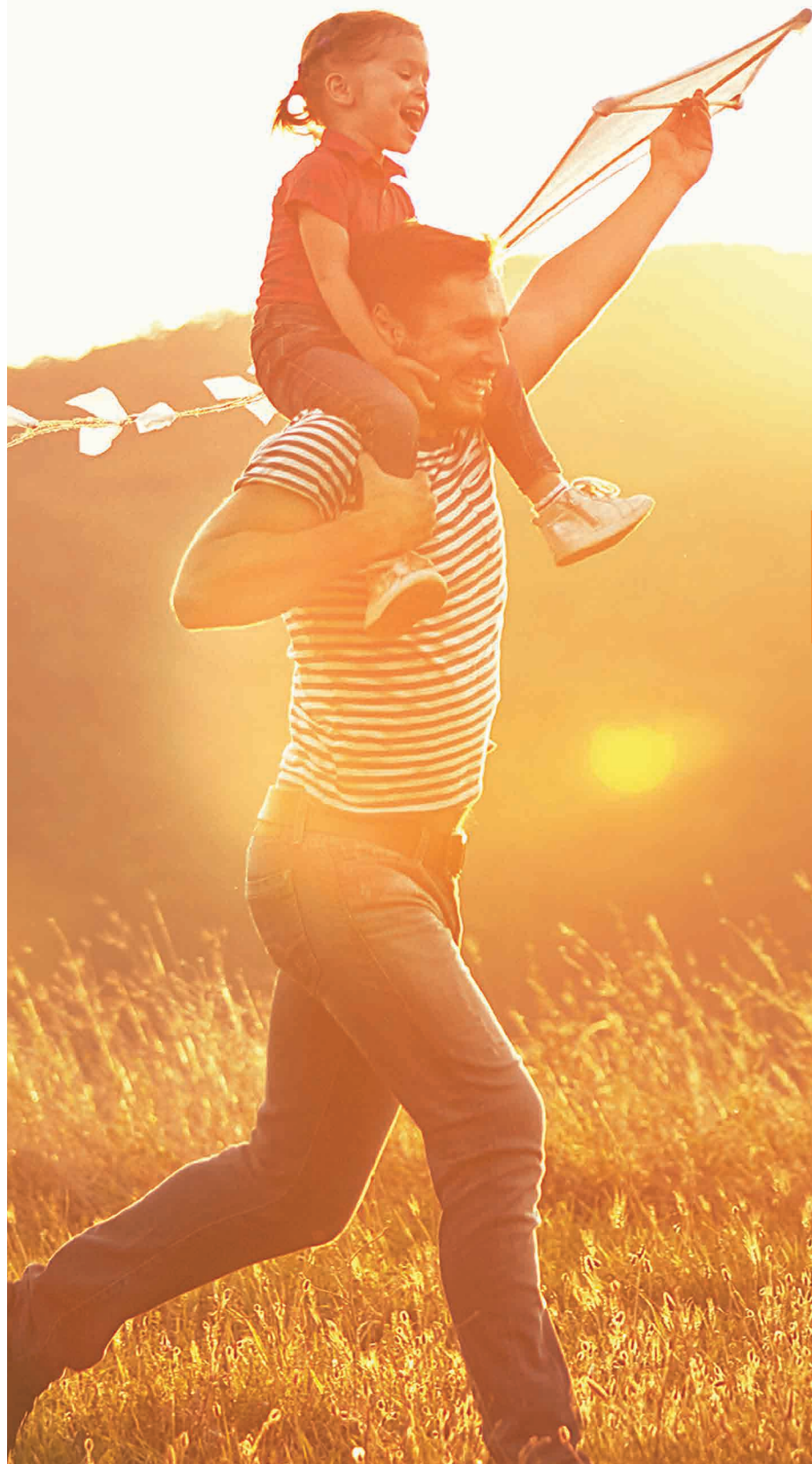
To improve our understanding of the impact of brain-based developmental disabilities on children and families in Canada, we need to collect information uniformly across all projects. For this, in collaboration with patient-partners, we finalized forms that all projects are using to collect demographic information. Patient-partners helped ensure that we collect only information that's really needed and make it as easy as possible for families to provide it. Patient-partners also suggested that we provide families with an opportunity to share information that is not typically asked in forms, such as stories of resilience or how they've helped other parents.

Collaborating to develop a data reuse strategy

In partnership with the Data Coordinating Centre and PolicyWise for Children & Families, a not-for-profit organization committed to using evidence to improve the well-being of children and families, we are starting to consider how CHILD-BRIGHT may be able to advance future research in Canada by putting in place strategies to use data collected to answer one question to answer further questions. By reusing previously collected data to answer new research questions, we can save time and money, and accelerate the discovery of new findings.

[Read also how our investigators are advancing sex- and gender-based analyses \(see p. 64\)](#)

Research at a glance



Our research themes



BRIGHT Beginnings

(6 research projects)

Early intervention is key in minimizing developmental problems that children may face. Over the past decade, experimental studies have identified fetal, neonatal, and early childhood rehabilitation practices that optimize brain and developmental outcomes. CHILD-BRIGHT's six research projects under the BRIGHT Beginnings theme focus on bringing these experimental advances to human clinical studies to minimize brain injury and restore brain function. Knowing how these therapies influence brain development will allow our team to identify the most effective practices to promote resilience, improve the child's physical and mental health, and enhance overall well-being.



BRIGHT Supports

(4 research projects)

The BRIGHT Supports theme will transform outcomes by integrating mental health support into the care of children and youth with brain-based developmental disabilities who experience behavioural difficulties. Novel information technologies as well as medical interventions are being evaluated in children with a wide range of developmental disabilities. Health promotion strategies that foster fitness and social participation are also being developed. The four BRIGHT Supports projects will fill a critical gap by offering family centred 'help-giving' practices to support parents in their role as caregivers.



BRIGHT Futures

(3 research projects)

Under the BRIGHT Futures theme, we will redesign key parts of the health care system to be more responsive to the needs of families as their children develop. We are focusing on key transition periods: discharge from the neonatal intensive care unit, the transition from preschool to school, and the transition into the adult health care system. Our intent is to produce policy-relevant, cost-effective innovations that will transform real-world service delivery to patients and families throughout their growth trajectories. This transformation will both improve children's physical and mental health and empower their families.

The steps of research

75

Patient-Partners

26

Principal Investigators

126

Collaborating Investigators

49

Staff Members

23

Trainees

8

Support Team Members

STEP 1: STUDY DESIGN AND PROJECT DEVELOPMENT

Researchers and patient-partners work collaboratively to develop protocols for patient-oriented research projects.

STEP 2: REGULATORY AND ETHICS APPROVAL

Since all our projects involve human participants, they require approvals from research ethics boards. These approvals ensure that participants are treated fairly and that studies follow appropriate procedures.

STEP 3: PARTICIPANT RECRUITMENT AND ENROLLMENT

Each project team must recruit and enroll a predetermined number of participants in their project. At CHILD-BRIGHT, patient-partners co-design recruitment material and suggest strategies to reach more potential participants.

STEP 4: STUDY INTERVENTION AND DATA ANALYSIS

After participants are enrolled, they take part in the carefully designed project. Sometimes, a small-scale, pilot project is conducted before moving to a large-scale project. A number of CHILD-BRIGHT projects completed pilot projects after which they incorporated additional feedback from youth and parent partners into the protocol.

STEP 5: KNOWLEDGE TRANSLATION

We need to ensure that information about our research and research findings is communicated to all knowledge users. At CHILD-BRIGHT, we are doing this by engaging stakeholders in ongoing KT activities (see p. 18), and by planning end-of-study KT activities designed with researchers, clinicians, and families in mind.



A BRIGTH Beginnings Research Project

MATernal hyperoxygenation in Congenital Heart Disease (MATCH)

We're testing if giving mothers supplemental oxygen in the 3rd trimester will improve the brain development of their baby with heart disease.

PRINCIPAL INVESTIGATORS



Mike Seed
(SickKids)



Steven Miller
(SickKids)

PROJECT UPDATE

In the MATCH trial, we are asking whether supplemental oxygen inhalation will improve brain development in fetal congenital heart disease. First, we are investigating the effects of acute maternal hyperoxygenation on fetal cerebral oxygen delivery in different forms of congenital heart disease. To date, 23 pregnant moms have participated in this phase of the trial.

Second, we are investigating the effects of chronic maternal hyperoxygenation in fetuses with congenital heart disease by providing moms with supplemental oxygen throughout their third trimester. To date, 5 moms have participated in this phase of the trial, in which we measure the growth of the baby's brain and their neurodevelopment at 1.5 years of age. Carrying an oxygen tank throughout your third trimester requires lifestyle changes, but moms have reported that it is tolerable and that participating in the study reduces some of the anxiety associated with this diagnosis.

We look forward to continued progress on the above phases of our trial before testing this intervention in a larger population.



Celebrating connections

CONNECTING ACROSS DISCIPLINES

Children with congenital heart disease (CHD) are at a high risk to experience brain injuries and develop cognitive, behavioural, or learning delays. Therefore, to support these children, we must work across medical and research disciplines, and with parents. This interdisciplinary approach is a hallmark of MATCH and the Cardiac Neurodevelopment (CND) Program at SickKids.

MATCH is co-led by a cardiologist and a neurologist, setting the stage for effective cross-disciplinary cooperation. MATCH is also one of many studies drawing on the expertise of the SickKids CND Program.

The CND Program's focus is to ensure that children with CHD thrive in their development through collaborations across neurology, cardiology, cardiac intensive care, psychology, and neonatal follow-up teams. The program actively monitors neonates born with CHD—who are at increased risk of brain-based disabilities—through brain MRI scans and neurology assessments before and after cardiac surgery. In addition, these children are followed to 18 months of age through the Neonatal Follow-Up Program to assess their motor skills, social development, language, and learning ability to determine if they are developing on target.

The CND Program is particularly excited to be working on the MATCH trial because it offers a chance to intervene and potentially help babies with CHD before they are born, which is a critical period for brain development. And our team at MATCH believes strongly that combining efforts across fields of expertise helps children achieve the best health outcomes possible.





A BRIGTH Beginnings Research Project

Parent-Centred Evidence-Based Care for Premature Graduates (Parent-EPIQ)

PROJECT UPDATE

The Parent-EPIQ project is working on three related studies to improve the lives of children born preterm and their families, all focused on what is important to families.

Firstly, using a series of surveys, we are capturing parent voices to identify what matters most to parents of very preterm children. After obtaining ethics approvals for four different surveys and focus groups across Canada, we now have results from approximately 500 families.

Secondly, to help children born preterm improve their cognitive and language abilities, we have introduced evidence-based targeted interventions at 11 Neonatal Follow-Up Programs across Canada that are affordable, feasible and parent approved. Promoting reading, talking and singing to children is one strategy that has been used at several sites. We have partnered with several public libraries and researchers and speech language pathologists to do this.

Thirdly, we have collected the information and published a report in December 2018 that details the survival rate, well-being and challenges of 5,316 Canadian children born preterm between 2009 and 2015. This is valuable up-to-date Canadian information for parents and health care providers. Our goal will be to use what we learn from the surveys to ensure that our annual reports provide the information that parents want.

Our team's visibility is growing, both nationally and internationally. We hosted our annual EPIQ conference where over 200 neonatal health care providers and parents learned about Parent-EPIQ and presented at the 2018 CHILD-BRIGHT Annual Conference. We are making great progress, are generating awareness, and are thrilled by the enthusiasm of all involved!

We want to improve the development of children born premature by giving their parents meaningful information and putting in place proven interventions.

PRINCIPAL INVESTIGATORS



Anne Synnes
(BC Women's Hospital)



Prakeshkumar Shah
(Mount Sinai Hospital)



Celebrating connections

CONNECTING WITH OTHER RESEARCH TEAMS

Back in 2016, when CHILD-BRIGHT was formed, our Parent-EPIQ team and the CHILD-BRIGHT CCENT team (see p. 46) immediately connected. Both our teams share the common goal of helping families and young infants who needed extra medical care as babies to meet their developmental potential and well-being. Both our studies also use the Canadian Neonatal Follow-Up Network (CNFUN) infrastructure.

At Parent-EPIQ, we are managed by the CNFUN steering committee and use CNFUN sites to partner with parents: to capture their opinions about important outcomes, to create teams for the 11 sites where we are introducing interventions to improve language and thinking abilities of children born preterm, to collect information about their children, and to publish the results of our work.

CCENT will be using CNFUN sites to evaluate the effectiveness of a coach and navigator system to support parents of high-risk infants compared to usual care. In turn, CCENT will share the information they gather relating to the needs of parents of children seen in neonatal follow-up programs with CNFUN who will disseminate the results to Neonatal Follow-up Programs across Canada.



(Members gather for the CNFUN Parent-EPIQ Annual Meeting in Toronto in 2019)

“Clinicians and researchers decide the categories of neurodevelopmental impairment. Parents categorize their children differently. Measured outcomes influence life and death decisions.”

Annie Janvier, neonatologist and parent representative



Enhancing Brain Repair with Metformin (Metformin in CP)

PROJECT UPDATE

We are conducting the first clinical trial in the world that is testing whether metformin and physiotherapy can improve motor and cognitive skills in children with cerebral palsy. This past year, we worked closely with regulators to take the necessary precautions that help ensure the safety of the children with complex medical needs in our project.

After obtaining regulatory approval from Health Canada to launch the trial, we obtained conditional approvals from both the Holland Bloorview and SickKids Research Ethics Boards. Both boards put forward recommendations which we implemented. We then re-applied to Health Canada for approval of those changes. Our significant progress will allow us to initiate recruitment in the coming months.

This year, we also successfully negotiated contracts with the pharmaceutical companies producing our metformin study tablets and ensured robust study monitoring by an external provider.

Lastly, we welcomed three developmental paediatricians to serve as study physicians to conduct study procedures and assess side effects, should they occur. We anticipate beginning enrollment as early as Fall 2019.



(Darcy Fehlings and Donald Mabbott presenting about the project at the 2018 CHILD-BRIGHT Annual Meeting)

We are evaluating whether metformin combined with physiotherapy enhances motor and cognitive skills in children with cerebral palsy.

PRINCIPAL INVESTIGATORS



Darcy Fehlings
(Holland Bloorview Kids Rehabilitation Hospital)



Donald Mabbott
(SickKids)



Celebrating connections

FORMALIZING CONNECTIONS

This past year, we announced the creation of our Stakeholder Engagement Committee (SEC). This committee consists of 5 stakeholders with a wide range of lived experience in the cerebral palsy community, including three individuals diagnosed with cerebral palsy and two parents of children diagnosed with cerebral palsy.

The SEC was formed to provide a platform for collaboration, input, and guidance from various stakeholders specific to our research study. SEC members bring insights from previous involvement with cerebral palsy research including participating in pediatric research, serving on research advisory committees, helping to secure funds for basic and clinical cerebral palsy research, and being involved in health journalism.

Our first SEC meeting was held at Holland Bloorview Kids Rehabilitation Hospital in February and included all 5 members and the research teams from Holland Bloorview and SickKids. It served as an opportunity to familiarize the members with the study design, aims and objectives.

The committee members provided meaningful input that we integrated into the study design. For example, the SEC advised on how we can better communicate eligibility criteria to families to ensure their understanding as well as expanding on how the study pills can be administered (i.e. crushed via gastrostomy tube). This initial committee meeting marked what we're certain will be a fruitful collaboration between the research team, stakeholders, and the greater cerebral palsy community.

We look forward to continued collaboration and input from these uniquely qualified individuals.



“I am an active member of the disabled community and often use my journalism to advocate for and further the understanding of what it is like to live with a disability. When Dr. Darcy Fehlings invited me to join the Metformin for CP trial Stakeholder Engagement Committee, I was all too happy to accept and bring my experience to the table.”

Jessica Geboers, SEC Member



A BRIGHT Beginnings Research Project

Stimulation for Perinatal Stroke Optimizing Recovery Trajectory (SPORT)

PROJECT UPDATE

This past year, our SPORT team welcomed participants to summer camps at all 3 of our study sites: Calgary, Edmonton, and Toronto. At these camps, participants receive our non-invasive brain stimulation intervention to achieve new motor function goals while also building their confidence and making new friends. In total, 37 participants have enrolled in our project, keeping us on track to achieve our goal of more than 80 participants, making our project the largest such rehabilitation trial ever done in children worldwide!

We are also very proud to share that all of the families enrolled in the summer camps have attended subsequent testing and brain imaging appointments over the 6 months following the camp. This is a wonderful testament to the commitment of our families and team and is helping us build a rich data set of clinical imaging and brain physiology outcomes that will help us understand how young brains recover from early injury.

We enjoy consistently receiving positive feedback from parents and SPORT campers, with many asking: “Can we come back next summer?”

We are conducting a clinical trial to test whether non-invasive brain stimulation improves function in children with cerebral palsy.

PRINCIPAL INVESTIGATOR



Adam Kirton
(University of Calgary)



(Researchers and participants having fun at SPORT camp!)



Celebrating connections

CONNECTING WITH THE MEDIA & PUBLIC

We strive to be close to our public, and have started building connections with the media to help share news of our work.

For example, our SPORT camp in Edmonton was featured in the Edmonton Journal and on Global News in the summer 2018. This helped to give visibility to our project. It was also a wonderful forum to help educate the general public not only about perinatal stroke, but also about how non-invasive brain stimulation can change the brain. Additionally, the media coverage highlighted CHILD-BRIGHT’s mission to help children with brain-based developmental disabilities, giving visibility to our pan-Canadian network.

In September, in partnership with Children’s Healthcare Canada, we also presented a webinar titled ‘A Tale of Research & Clinical Collaboration: The SPORT Trial’, that highlighted our team’s clinical-research partnership.

We really enjoy working closely with the media and public!



“Brandon was sooooo excited today that he could open his palm and keep his thumb out!!! That’s a big improvement for him. He talked my ear off the whole way home. Says he wants to keep the cast on for week 2 and wants the camp to last a month. Thank you and the whole team for all your efforts for these kids.”

Brandon’s parent

“Thank you everybody for being so nice to me at camp last summer. I really feel that my right arm has gotten stronger from the therapy that you guys provided. I loved getting to know kids that are like me. Camp was a lot of fun because of the activities that you guys planned for us. Thank you for this awesome summer!”

Spencer (camp participant)





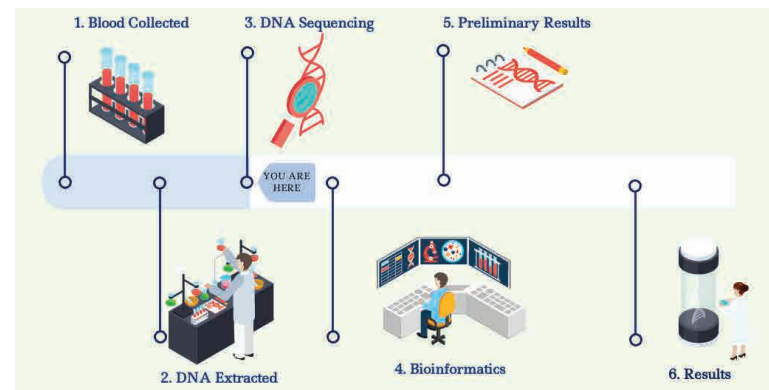
Diagnosis Using Integrated Metabolomics And Genomics In Neurodevelopment (IMAGINE)

PROJECT UPDATE

Our goal is to help as many project participants as possible learn the cause of the atypical cerebral palsy (CP) that affects children in their family. We began this project suspecting that between one-third and half of children with atypical CP actually have an undiagnosed genetic condition causing their symptoms. Atypical CP refers to a neurodevelopmental condition that cannot be attributed to a birth injury or a similar well-defined cause. We are providing whole genome sequencing and metabolomics (analyzing the body's genetic instructions and pathways) to find the genetic changes ('variants') in 100 children. Finding a genetic cause can end families' diagnostic odysseys, remove feelings of guilt and blame, can provide understanding and expectations for the future, and can provide guidance regarding recurrence risks for family members. In some children, it will suggest a change in management, or in rare cases, it may lead to treatment.

In this last year, we provided results to 49 families. Just over half of these children have a firm or likely diagnosis and 10% have uncertain results requiring further investigation.

Our testing is extensive and families often wait more than 6 months for results. Parents shared that this long waiting period can result in some unease. In partnership, we implemented a FedEx-inspired automated and individualized timeline called "POP-Up" to keep parents apprised of the status of the testing.



(A sample of our interactive POP-Up tool)

We are using advanced genomics and metabolomics to ask whether children's cerebral palsy can be caused by genetic and metabolomic conditions.

PRINCIPAL INVESTIGATORS



Jan Friedman
(University of British Columbia)



Clara van Karnebeek
(University of British Columbia)



Celebrating connections

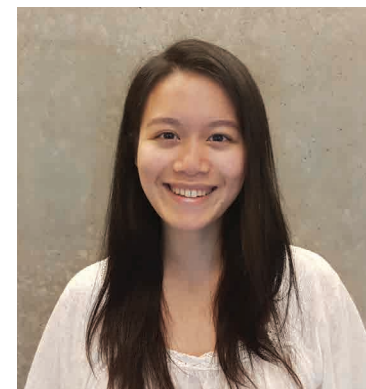
CONNECTING WITH SUMMER TRAINEES

We are grateful for our collaboration with yearly Summer Studentship awardees, who join our team and are paired with a parent to both learn about patient-oriented research and develop a parent-recommended patient-oriented project.

During our first summer, Elisa Lau developed plain language study material in English, then oversaw its translation into 5 other languages, to meet the needs of families whose first language is not English.

Our second Summer Studentship awardee, Nicole Liang, worked with our parent-partner team to develop, test, and implement our interactive POP-Up tool. Nicole also presented the project at the 2018 CHILD-BRIGHT Annual Meeting in Montreal, and at the American Society of Human Genetics meetings, in San Diego.

We can't wait to see the result of this summer's collaboration between studentship awardee Julia Handra and the parent in our team. This year, they are tackling the problem of what happens after results are provided to families. Our parents identified this as a time when many families would like to receive additional support.



(Left to right: Elisa Lau and Nicole Liang)

Did you know that only 5% of applicants are admitted into a genetic counselling program in university (making it more competitive than med school). We are proud that Nicole Liang, shown to the left, will be pursuing her Masters in Genetic Counselling at the University of Toronto in the fall, bringing with her a strong background in patient-oriented research.





A BRIGTH Beginnings Research Project

Prenatal Opioid Exposure and Neonatal Abstinence Syndrome

We have an opioid crisis in Canada. We are working with 13 First Nations to better understand the impact of prenatal opioid exposure on children, families and caregivers, and communities.

PRINCIPAL INVESTIGATORS



Jennifer Walker (ICES)



Astrid Guttman (ICES)



Serene Kerpan (Ontario Tech University)

PROJECT UPDATE

By working closely with First Nation communities, we strive to better understand the impact of prenatal opioid exposure.

Neonatal abstinence syndrome is a withdrawal syndrome observed in the babies of individuals who either used opioids or were treated for opioid dependence during pregnancy. Prenatal opioid exposure has risen substantially over the past two decades and can have lasting health impacts for infants and children, including potential long-term neurodevelopmental impairments.

In our first year, we worked to secure the necessary ethics approvals to launch our research project. We also reached out to 33 Ontario First Nations to attend a community-based engagement session to learn more about our project and the people leading it, and to invite them to participate. To date, 13 communities have signed research agreements and come on board, each approved by Chief and Council.

After extensive involvement of—and engagement with—our community partners, we are now poised to start collecting data for our project.



Celebrating connections

CONNECTING WITH FIRST NATION COMMUNITIES

We are proud that the project came from a need identified by First Nation communities in Ontario, who reached out to us in 2017 with concerns about the health of their school-aged children. First Nation members guide our team's work. From inception, First Nation community partners have helped inform and shape all aspects of the project. They:

- Champion the project, and help onboard and engage the appropriate stakeholders and decision makers
- Act as delegates at community engagement sessions
- Identify and invite focus group and interview participants, as well as community advisory group members
- Review project materials, adapt research methods, and select data elements.

They help ensure our processes are community- and culturally-appropriate and recommend new approaches when necessary. For example, to address privacy and confidentiality concerns from community members, community partners suggested we provide communities with the option to create dedicated focus groups for people with lived experience, so members could gather more privately. They also proposed asking focus group questions recognizing the gifts and strengths of children with prenatal opioid exposure.

The involvement and engagement of First Nation community partners and advisory groups have been critical to our success!

(Right: Artwork by Maxine Wesley, Ginoogaming First Nation artist and master craftswoman)



This project upholds the First Nations principles of ownership, control, access, and possession (OCAP®), and employs Indigenous data governance principles that support ethical and collaborative partnerships.



A BRIGHT Supports Research Project

Optimizing the Management of Pain and Irritability in Children with Severe Neurological Impairment (PIUO)

We are testing a systematic approach to manage pain in children with severe brain-based developmental disabilities and limited ability to communicate.

PRINCIPAL INVESTIGATORS



Hal Siden
(BC Children's Hospital & University of British Columbia)



Tim Oberlander
(BC Children's Hospital & University of British Columbia)

PROJECT UPDATE

This year, we launched our recruitment at 4 sites in Canada: BC Children's Hospital in Vancouver, Alberta Children's Hospital in Calgary, SickKids in Toronto, and CHEO in Ottawa.

From our first 4 participants, we have already learned a great deal. For example, we better understand the previous workup that they received, which gives us clearer insight into the experiences and care that future participants may also have received. Our work with these participants also reinforced our commitment to improving how the pain management needs of children with severe neurological impairment are evaluated. This must be done in a more focussed and thorough way, which is what we aim to achieve with our systematic approach.

New this year, our study team added community visits to our research strategy, to better understand what is being offered at community clinics. From this, we learned that access to health care services is very important, equally as important as the attention given to the children's specific health care needs.

We look forward to welcoming more participants in our clinic spaces across our 4 sites as our work continues.



(BC Team. From left: Sharan Sahota, Research Assistant, Anne-Mette Hermansen, Research Coordinator, Colleen Pawliuk, Research Librarian, Hal Siden, PI, Gail Andrews, Study Nurse, Ashley Wilson, Study Nurse)



Celebrating connections

CONNECTING WITH COMMUNITY GROUPS

If our study is successful, we hope to ultimately be able to create a set of clinical guidelines for assessing and treating pain and irritability in children with severe neurological impairments.

In order to create such a tool, we need real feedback from the community as to whether our study procedures translate to a service delivery setting.

In partnership with the Centre for Child Development in Surrey, BC and the University Hospital of Northern British Columbia, we have begun this exploration. As we educate our community partners on our study, our community partners in turn identify members of their organizations who could benefit from knowing about our research.

Our community partners have put great effort into giving us opportunities to engage with their staff as well as their broader membership, including families. This has given us access to excellent feedback as to what works and what doesn't when implementing a clinical pathway for pain management in children.



"This study helped by acknowledging that pain has been an ongoing issue since my son was born. The study helps medical teams to better understand the unexplained pain within your child. This is very valuable, especially when the child is non-verbal and cannot express how or where it hurts."

Parent



A BRIGHT Supports Research Project

Strongest Families™ Neurodevelopmental Program (Strongest Families™ ND)

PROJECT UPDATE

The Strongest Families Neurodevelopmental Program is asking whether emotional and behavioural regulation can be improved in children with neurodisabilities by using parenting programs that include online education, telephone support, parent-to-parent connections, and resource information.

Our main focus this year has been completing the adaptation of the Strongest Families Neurodevelopmental Program for parents of children with disabilities. Together with our parent-partners, and inspired by the Strongest Families parenting program for typically developing children, we've named this program "Parents Empowering Neurodiverse Kids."

As part of our work this year, we uploaded content to the online platform, tested functionality of the online program, finalized the study procedures and protocol, and received the necessary approvals to begin testing the effectiveness of our program across Canada.

We also completed a study on the experiences of Parent Advisors and researchers with respect to the involvement of parent-partners in research. We presented preliminary results at a conference in Halifax in October 2018, and are preparing a report for publication in the near future.

We are developing an online education program to help parents of children with disabilities.

PRINCIPAL INVESTIGATORS



Patrick McGrath
(IWK Health Centre and Nova Scotia Health Authority)



Lucyna Lach
(McGill University Health Centre)



(Left to right: Study Coordinator Karen Turner, Co-Principal Investigators Lucyna Lach and Patrick McGrath, and Parent Advisors Donna Thomson, Kathleen O'Grady, and Samadhi Mora Severino)



Celebrating connections

CONNECTING WITH PARENTS

Our most beneficial collaboration is with the members of our Parent Advisory Committee, who generously share their expertise as we develop our program and test it nationwide.

Their impact is significant. For example, parents on this committee identified the need to carefully plan how we inform participants of their ineligibility to take part in the study, when applicable. As researchers, we strive to anticipate the experiences of study participants and be mindful in our messaging, however, there is no substitute for the perspectives offered by those with lived experience. Parents are the ones who are able to tell us what research feels like and were best able to help us revise our communications accordingly. Parents also provided important feedback on our video scripts and character development, to ensure that we accurately represent children with disabilities, and families of diverse cultural backgrounds.

By providing feedback on program content, critiquing development of the animated videos, representing the project at conferences and public events, and fostering connections for study recruitment, the voices of our Parent Advisors have been interwoven into all aspects of the project.



(Left to right: Parent Advisor Jenny Tyler, and Strongest Families Institute Coaches Katryna McGuire and Breanna Pottie)



"Parenting a child with needs can be lonely. You sometimes feel you have tapped your usual circle of support. By working with the team at Strongest Families, I feel that my circle has grown bigger. I am stronger in my parenting and own care."

Jenny Tyler, Parent Advisor



A BRIGHT Supports Research Project

Jooay App: Promoting Participation in Leisure

We created Jooay to provide families with easy access to information about appropriate leisure activities in communities across Canada.

PRINCIPAL INVESTIGATOR



Keiko
Shikako-Thomas
(McGill University)

PROJECT UPDATE

We are providing information about accessible leisure activities to people with disabilities in communities across Canada using a mobile and web app called Jooay. This past year, we've made progress towards our goal on all fronts:

- We updated our app to ensure all activities are up-to-date for 10 provinces
- We created new ways for users to filter activities, so they can find the activities best suited to their family
- We developed an interface for organizations and users to enter new activities into the database easily; this will help us grow the number of activities listed in our database
- We incorporated a news feed (similar to the Facebook news feed), which allows users to stay updated with what's happening around them, and see what other families are up to
- We developed a new chat feature that allows users to interact with each other and join an online community
- On the research front, we studied which aspects of the online community can help parents to facilitate leisure participation for their child with disabilities. We presented this work at an international conference and exchanged with other researchers, parents, and clinicians about developing collaborative communities to promote leisure
- We did research on how families and clinicians are using the Jooay app to improve the types of features that will be most helpful to them in the future
- We started investigating how socio-demographic characteristics of cities and regions in Canada can influence the offer of inclusive activities. We then talked to policy makers and community organizations about possible solutions to start addressing these factors through the Leisure Policy tables in British Columbia and in Quebec.

Jooay is available on all devices (iPhone, Android, and computer) and a total of 2,400 users now log into Jooay to consult the more than 1,700 activities listed!



Celebrating connections

CONNECTING WITH THE GENERAL PUBLIC

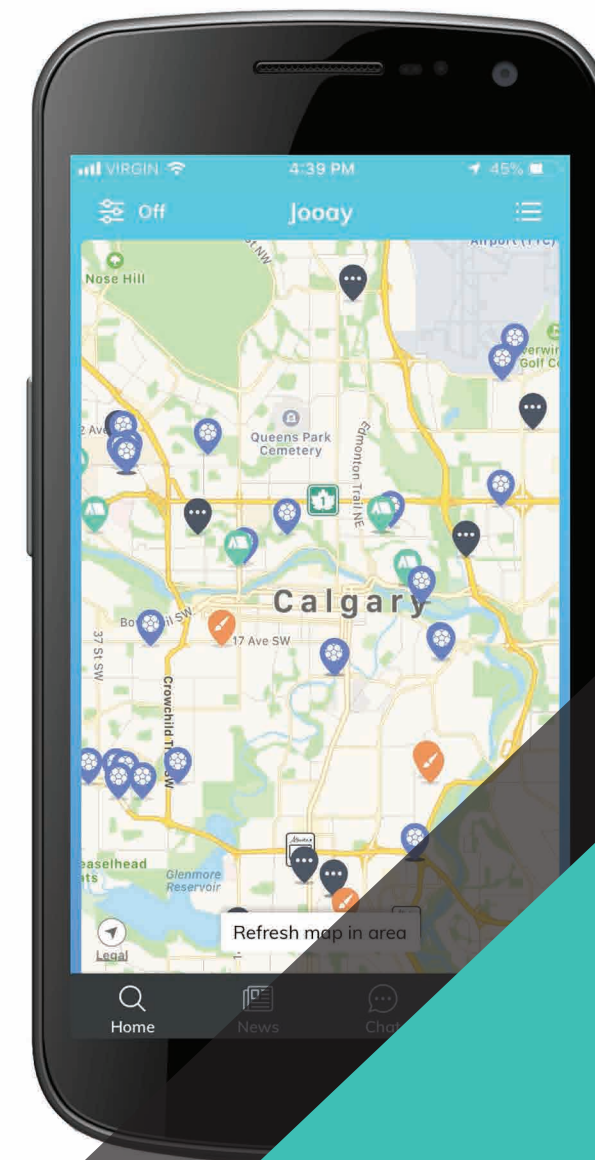
To better connect with the general public and disseminate information about the Jooay app, we welcomed 6 provincial ambassadors to our team this year (based in Saskatchewan, British Columbia, Alberta, Ontario, Quebec and Newfoundland). The ambassadors organize activities in local schools or parasport facilities, and distribute posters in various facilities.

Our ambassadors help ensure a constant online presence by sharing information about Jooay. This has helped us increase our number of social media followers. More than 2,000 people now follow our work either via our Facebook, Instagram or Twitter accounts.

The visibility they bring to our project has helped us strengthen connections with agencies that offer adaptive activities to the public. For example, this year, we developed collaborations with AlterGo, the *Association québécoise pour le loisir des personnes handicapées*, SandBox project, and numerous other community groups.



(Jooay team participated at the SandBox Project event, Ottawa, September 2018)



Download
the app at
www.jooay.com



A BRIGHT Supports Research Project

MEGA TEAM: Treatments to Improve Emotional and Behavioural Self-Regulation

PROJECT UPDATE

We have had an exciting and productive year. In our study, we are asking whether a take-home video game can improve executive functioning in children with ADHD, ASD, and congenital heart disease (CHD). Since receiving approval to launch our project in May 2018, we have recruited 46 participants with ADHD and recently began recruiting children with ASD and CHD. In response to the popularity of Mega Team, we are adding two additional sites in Toronto, which will be opening soon.

This year we grew our team to add more expertise in cognitive rehabilitation and conduct of clinical trials. Victoria Lishak a Post Doctoral Fellow, and Anne-Claude Bedard, an investigator on our team, have been instrumental to Mega Team's productivity this past year.

We were invited to speak about Mega Team at a variety of venues this past year. Audiences were particularly keen to hear how feedback from participants in our pilot trial was incorporated into our current work, and how our incredible family and youth advisory committee members continue to contribute to Mega Team. One of our most exciting community opportunities this year was participating in the *Brain Bonanza* at the Museum of Nature in Ottawa where we showed our game to hundreds of children and told them about Mega Team.

We're trying to improve memory and executive functioning skills in children with various brain-based developmental disabilities through cognitive-based video game training.

PRINCIPAL INVESTIGATOR



Jennifer Crosbie (SickKids)



(Mega Team at Brain Bonanza at the Museum of Nature in Ottawa)



Celebrating connections

CONNECTING WITH YOUTH ADVISORS

We are grateful to have an active and engaged family and youth advisory group. We are particularly lucky to have 2 adolescent members, Noam, who is 13, and Kaya, who is 14. Both have lived experience with brain-based disabilities and also have siblings or family members who identify with these population groups.

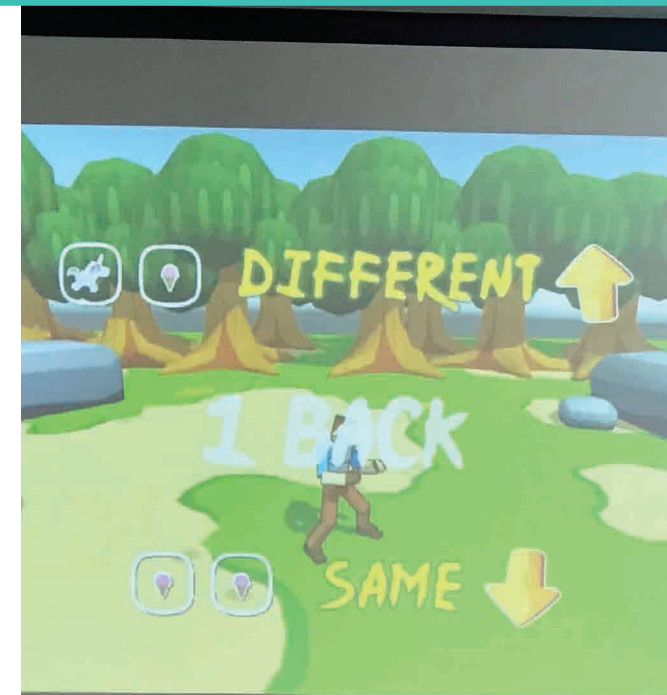
Given that Mega Team is a video game-based intervention, the input, ideas, and feedback we get from our adolescent members—who are very close to our project's target age range—is invaluable. Design is an important element of our Mega Team game and correlates strongly with participant engagement, so hearing impressions first hand from youth provides us with key insight.

Furthermore, youth members, along with our parent advisory group members, have been integral in working with the team to explore how participants can take what they learn from Mega Team training and apply it in day-to-day life.

Input from our advisory group is at the heart of the patient-oriented nature of our CHILD-BRIGHT Mega Team project.



(Family and youth advisory and research team. Left to right, back row: Victoria Lishak, Jennifer Crosbie [PI], Noam McCready. Front row: Kaya Cosgrove, Mithula Sriskandarajah, Susan Cosgrove, Rob McCready)





A BRIGTH Futures Research Project

Coached, Coordinated, Enhanced Neonatal Transition (CCENT)

We are testing new ways to support parents as their child transitions from the NICU to home.

PRINCIPAL INVESTIGATORS



Julia Orkin
(SickKids)



Eyal Cohen
(SickKids)



Nathalie Major-Cook
(CHEO)



Paige Church
(Sunnybrook Health Sciences Centre)

PROJECT UPDATE

In the CCENT study, we are testing ways to improve the care that families receive as their babies transition from the neonatal intensive care unit to home.

This year, we completed our pilot trial and launched our study. We are currently recruiting at four Canadian sites: Sunnybrook Hospital, CHEO, the Ottawa Hospital, and SickKids. We will begin recruiting at Mount Sinai, at the BC Children’s Hospital, and at the Montreal Children’s Hospital in the summer of 2019.

We selected and trained all our study team members, including the nurse navigators and research assistants, for whom we also developed comprehensive manuals that describe study operations at our sites. With support from consulting psychologists, we also revised our acceptance and commitment training manual. The revisions applied were based on feedback received during the pilot trial and help improve the sessions so they better suit the needs of the participants.

In addition, in response to feedback received from our CCENT family advisory committee, we developed a family toolkit, which serves as an educational resource for our participants.



(CCENT Nurse Navigator Team. Top row, left to right: Eleanor Warren [CHEO/The Ottawa Hospital], Annette Van Bergen [Mount Sinai Hospital], Amie Nowak [BC Children’s Hospital], Bottom row, left to right: Rosanna Manarin [Sunnybrook Health Sciences Centre], Andrée-Anne Matte [Montreal Children’s Hospital], Kimberly Colapinto [Sickkids])



Celebrating connections

CONNECTING WITH SUPPORT SERVICE TEAMS

Our CCENT team has greatly benefited from collaborations with the CHILD-BRIGHT Health Economics (HE) team (see p. 53). The HE team helps improve the accuracy, quality, and integrity of the data we collect and use within our project.

More specifically, this year, the HE team helped revamp the Resource Use Questionnaire for our study. This questionnaire, originally developed by the Technology Assessment at SickKids (TASK) team, allows us to capture information about children with brain-based developmental disabilities across different sectors, for example, relating to their health, education, and the community services they use. The HE team recommended modifications to make our questionnaire more relevant and clear for families in our project. They also helped troubleshoot technical issues that we were facing.

Thanks to their input, we expect to better understand if the CCENT model is cost effective, when compared to usual care, to help improve parent and child outcomes.



“My hope for this study is that what we come up with not only smooths the discharge process, but also helps parents reclaim some of what hospitalization can take from us ... optimism, confidence, and belief in our own competence as parents.”

Kate Robson, Parent



BRIGHT Coaching

We are evaluating whether an online education tool and coaching resource can help parents as their preschool children with delays transition to school entry.

PRINCIPAL INVESTIGATORS



Annette Majnemer
(McGill University Health Centre)



Maureen O'Donnell
(Child Health BC)

PROJECT UPDATE

This year, we developed an online education tool and coaching program that we hope will empower parents with resources, knowledge, and support as they wait for developmental services for their child.

The content of our comprehensive program includes various elements such as telephone coaching sessions, a parent exercise book, and online peer support and resources.

To test whether our program could meet the needs of parents, we conducted a pilot project in 4 sites across Canada, in British Columbia, Manitoba, Nova Scotia, and Quebec. This helped us get preliminary feedback on our program and helped us understand how we could make its content more understandable.

We also finalized all our program materials, in both French and English. These include a coach manual, parent exercise book, peer support website, research questionnaires, recruitment materials, and a research assistant manual.

With our pilot completed and study materials ready, we were then able to move to the recruitment phase of our project. So far, we have recruited 20 participants and we hope to welcome more participants in the coming months!



Celebrating connections

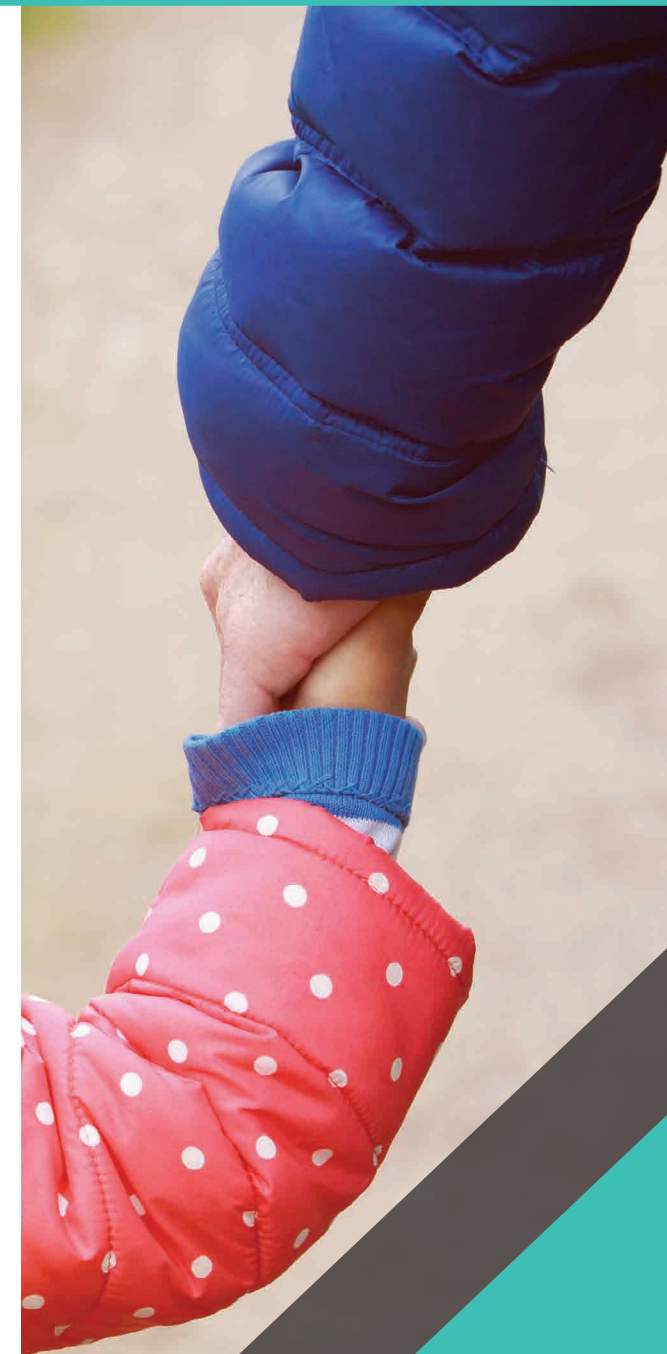
CONNECTING WITH PROGRAM TEAMS

One of our team's parent advisors, Carrie Costello, helped initiate a wonderful collaboration this year with the CHILD-BRIGHT Knowledge Translation (KT) team. Earlier this year, Carrie recommended that we apply for the KT Program's new network fund, the CHILD-BRIGHT conneKT Fund (see p. 60). Carrie was interested in bringing a series of parent and children's workshops to Manitoba to highlight the importance of bringing siblings of children with a developmental delays into family centered care.

We agreed with this recommendation and in partnership with Kristy Wittmeier, one of our research leads in Manitoba, Carrie successfully put together an application and was granted funds by the KT Program team to run these workshops.

"Siblings are often the longest relationship a person with a disability will have, but they are figuratively (and literally) left in the waiting rooms in our current system," says Carrie. "My project did not fit the typical research grant mold, but the KT Program was open to looking outside the typical mold and was very encouraging".

As a result, the Let's Talk Sibs events were born, and gathered over 125 parents, youth and health care professionals this year to engage on this important topic, via workshops and 'sibshops' for youth.





A BRIGHT Futures Research Project

READYorNot™ Brain-Based Disabilities Project



We are developing and evaluating an e-health application designed to help patients and families transition from the pediatric to the adult health care system.

PRINCIPAL INVESTIGATORS



Ariane Marelli
(McGill
University
Health Centre)



Jan Willem
Gorter
(McMaster
University)

PROJECT UPDATE

Youth with brain-based developmental disabilities require seamless transition from the pediatric to adult health care systems. This transition can be disruptive for youth and families and have a negative impact on a patient's health. In many pediatric centres, there are no dedicated resources for transition of care. Our team at READYorNot™ is developing and evaluating e-health aids to help youth and families take charge of this transition.

This year, we developed the MyREADY Transition™ BBD App in collaboration with patients, families, health care stakeholders, our Patient and Family Advisory Council (PFAC), and our industry partner 360Medlink. We also worked with Spectrum Productions, a multimedia company that employs people with autism, to film and produce videos featuring actors with brain-based disabilities. Patient engagement is central to the design and testing of our intervention, through partnership with PFAC members and through interviews and focus groups with patient, family and health care stakeholders. We will soon deploy the app across recruitment sites in Alberta, Ontario, Quebec, and the Maritimes in a randomized control trial to test whether it will help youth take steps to better manage their health.



(READYorNot™ Team at the 2018 CHILD-BRIGHT Annual Meeting)



Celebrating connections

CONNECTING ACROSS NETWORKS

In partnership with Kids Brain Health Network, CanChild, and McMaster University, members of the CHILD-BRIGHT READYorNot™ team were instrumental in helping launch a new online Family Engagement in Research course. The course aims to empower families and research trainees as active partners in research.

Donna Thomson and Connie Putterman, parent-partners with READYorNot™, worked with CanChild post-doctoral fellow Andrea Cross to co-create and co-instruct the course.

One key objective of the Family Engagement in Research course was collaboration and development of trust in the relationship towards effective partnerships among families and research trainees, and we brought this topic directly back to our READYorNot™ team, many of whom were certified in the course this year. We applied some of the tools offered in the course to gather information about everyone's social media presence and group memberships, to leverage those connections for the good of this research project.

These types of partnerships across institutions and networks pave the way in Canada for patient-oriented research and effective family partnerships in research.



(Jan Willem Gorter, researcher, and Donna Thomson, parent-partner co-presenting at the 2018 AACPD Meeting)



Data Coordinating Center



We help CHILD-BRIGHT research project teams develop secure, reliable and rigorous systems to collect, analyze and report study data. We ensure that research data is collected in an appropriate manner, kept private and secure, and used to maximum effect.

Moving beyond start-up activities!

Over the past year we have shifted our focus from study start-up activities (such as building databases) to study support activities (such as managing data and databases).

Data management involves routine quality assurance to ensure that critical data is not missing from the study database, that staff enter data accurately and correctly, and that study procedures and the data collected comply with the study protocol and with the principles of Good Clinical Practice. (GCP is the standard for ethical and scientific conduct of clinical research in Canada.)

These activities are very important to ensure high quality data at the end of the study that can then be analyzed, disseminated, and implemented into policy and practice.

Health Economics



We evaluate the cost-effectiveness and cost-utility of emerging technologies, interventions, treatments and services for a wide range of pediatric neurodevelopmental disorders. We work with members across the network to facilitate cooperation between platforms and stakeholders, including the Data Coordinating Centre.

Supporting 7 network research teams

This year, our team provided ongoing support for the development and implementation of economic evaluations for seven projects within the network.

- We are measuring the impact of illness and the health-related quality of life for children and caregivers by using tools such as the Health Utilities Index, Kidscreen, and CarerQol.
- We are measuring how much it costs families and health care systems to care for patients with brain-based developmental disabilities by using tools such as the Resource Use Questionnaire.

By conducting thorough health economic analyses in CHILD-BRIGHT, we hope to advance the field of childhood disability to better inform policy and care.

The importance of connections

“One benefit of CHILD-BRIGHT that proved to be a delightful surprise is the quality of friendship that I found. Everyone is kind and supportive.”

Parent & Researcher

“Our research team involves health care professionals, educators, parents of children with disabilities, researchers, and partners from municipal, provincial and national organisations providing services or funding to children with disabilities and their families. Partnerships are essential to our project.”

Researcher

“By sharing my story and my experience within the READYorNot™ team, I hope to help make the lives of children like my son better in the future.”

Parent

“I wanted to get involved in research to see where I compare to other people with disabilities and I wanted to see how the research can grow and develop to help people with disabilities.”

Youth (17 years old)

“Inclusion of youth and parent partners is informative for all aspects of the research process but is particularly vital in thinking differently and more broadly about measures of outcome and impact.”

Researcher

“I can help to bring the research to the wider disability family community. My role is both empowering and gratifying.”

Researcher

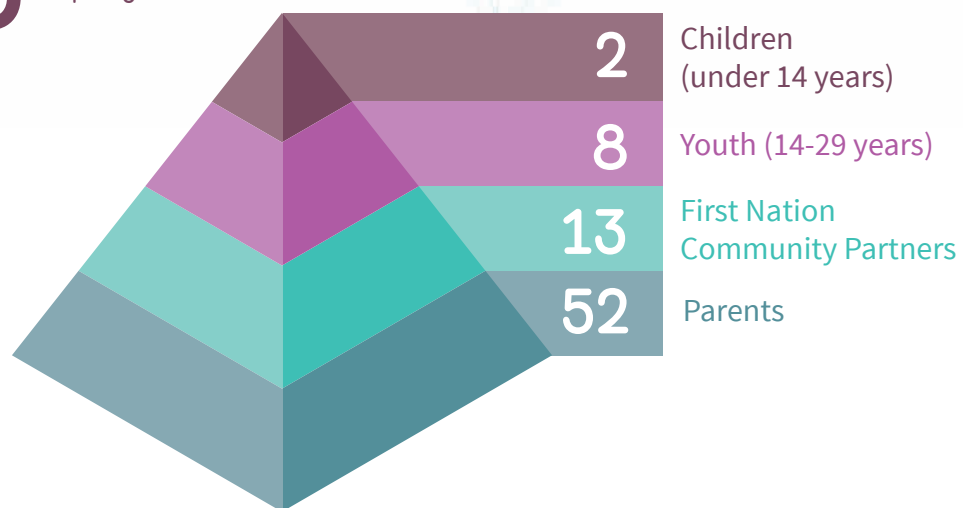
“Our administrative team is working hard to bring together our different citizens to share their unique perspectives in our various programs and research projects; they help ensure all voices are heard.”

Director

“Youth provide a perspective about technology usability and engagement that adults simply do not have.”

Researcher

75 patient-partners involved in research projects





Gathering at our 2018 Annual Meeting

As a pan-Canadian network, we look forward to in-person gatherings so were thrilled to welcome 117 network members at our 2018 CHILD-BRIGHT Annual Meeting in Montreal from December 5 to 7. Members of all our programs and project teams, including 20 patient-partners, research team leads, committee members, and staff came together to discuss our shared mandate and brainstorm ways to strengthen our connections!

Diverse programming

Each of our 13 research teams presented about their work and responded to attendee questions and suggestions. A range of sessions then took place allowing members to discuss topics such as recruitment, stakeholder engagement, equity in research, and sustainability. Patient-partners took a leadership role in the programming by helping to plan and lead several of the sessions.

Learning from each other

To encourage an exchange of ideas among attendees, we also hosted a poster session comprising 22 posters. Members engaged in cross talks on topics such as how to meaningfully involve patient-partners in their research and how to incorporate sex and gender into the projects. We also put in place a networking corner and board to help members post advice, share thoughts, contribute comments, ask questions, share their contact info, or 'pitch' ways in which they could positively contribute to the work of other teams.



Training our youth panel members

This summer, Mathias Castaldo, Maya Pajevic, Hans Dupuis, and Logan Wong, four members of our new National Youth Advisory Panel (see p. 12) traveled to Toronto to attend their first training event together. This inaugural training session was a combined effort by CHILD-BRIGHT and Holland Bloorview Kids Rehabilitation Hospital, and was designed to introduce the new youth panel members to their roles within our patient-oriented research network. The session was hosted by Dolly Menna-Dack, Chair of CHILD-BRIGHT's Youth Engagement Steering Committee, who was mandated to put in place this team and its terms of reference.

Learning from leaders in the field

Youth members learned about key themes in research such as communication methods, core concepts in ethics, and common issues in pediatric ethics. They also graduated from CHILD-BRIGHT's *Introduction to Health Research* training module. Frank Gavin, Chair of CHILD-BRIGHT's Citizen Engagement Council, joined the group to participate in an education session on reviewing research, as well as a workshop on understanding implicit biases and why advisors need to keep these in mind.

And having lots of fun too!

In addition to icebreakers, fun introductions and meals together, the youth benefitted from a tour of Holland Bloorview, and also joined the Holland Bloorview's Youth Advisory Council end-of-year party! "It was great to put names to faces of the other members of the network, and also to get introduced in a very positive way to the realm of research," said NYAP member Maya Pajevic.

Funding innovative KT projects

This year, we launched our second annual KT Innovation Incubator grant fund competition to promote and facilitate innovative knowledge translation projects in childhood disability in Canada. Funding of up to \$12,000 was awarded to two teams:

“Making Sense of Connectedness” team

This team, co-led by Natalie Miyake (autism advocate and parent, West Island Association for the Intellectually Handicapped), Anabel Sinn (addtothenoise.com), and Dr. Melissa Park (School of Physical & Occupational Therapy at McGill University), will use the grant funds to create, with youth and their families, inclusive spaces for neurodiversity in their local communities and an online hub of universal sensory design strategies to engage the public about the impact of sensory experiences on well-being.

“Ready 2 Work” team

This team, led by Priscilla Burnham Riosa (Department of Applied Disability Studies at Brock University), will develop and pilot an online vocational/employment readiness platform alongside self-advocates with autism spectrum disorder (ASD), their families, and professionals who operate vocational programs for people with ASD.

Both teams will receive support from the CHILD-BRIGHT Knowledge Translation Program team, including the expertise of the KT Advisory Committee.

Congratulations to both winning teams for these highly innovative projects!

Funding innovative training projects

This year, we launched our inaugural Training Innovation Fund competition to help fund innovative training activities in Canada that will foster patient-oriented research (POR) training or mentoring within research projects focused on childhood brain-based developmental disabilities.

This competition culminated in CHILD-BRIGHT funding two teams that will develop novel POR training outputs expected to be available in 2020.

“Learning Together: The use of simulation to enhance and enable authentic and meaningful research partnerships” team

This team, led by Kathryn Parker and Nadia Tanel at Holland Bloorview, will develop a suite of five simulation-based learning modules to address complex challenges experienced by patients and researchers while engaging in patient-oriented research.

“Development of a partnership model for collaborative research with youth with disabilities” team

This team, led by Gail Teachman at Western University, will pilot a model for meaningfully engaging youth with disabilities as collaborators in developing modules that train health care providers to approach childhood disability as an interaction between physiological and social determinants of disability.

Launching the CHILD-BRIGHT ConneKT Fund



This year, we launched our CHILD-BRIGHT ConneKT fund. We provide grants of up to \$5,000 to CHILD-BRIGHT research teams to help finance knowledge translation events that increase engagement with community partners, achieve meaningful stakeholder participation, and build positive relationships between stakeholders and project members. This year, we provided grant fund for 2 initiatives:

“Let’s Talk Sibs!” initiative

A series of events that gathered both parents and children to discuss how to support siblings of children with brain-based disabilities. Parents participated in workshops while siblings aged 8-12 participated in ‘sibshops’ to connect and share with other siblings while having fun (more on p. 49).

“Jooay KT Café” initiative

A series of events and forums to celebrate the launch of a new version of the Jooay app (see p. 42). Via these events, the team disseminated information about the Jooay app to a larger community, promoted its online community of support, and enabled discussions on how community members could collaborate on the development of Jooay going forward.

Partnering with First Nation Communities



First Nation community members, previously underrepresented in our network, now make up 20% of our community partnerships. Many contribute to our new Prenatal Opioid Exposure and Neonatal Abstinence Syndrome project (see p. 36) as core research team members or community advisory group members who help champion research efforts that are sensitive and responsive to the unique needs of each community.

Growing impact across the network

First Nation community partners are educating our membership on methodologies and practices of importance to their community members. For example, they co-led a discussion on engagement with Indigenous communities at our 2018 Annual Meeting. They also steer new network training initiatives. In August 2019, First Nation members hosted a webinar introducing key historical, contextual, and ethical considerations to consider when doing research involving First Nation peoples and populations. As a result, research teams are learning from these new members and incorporating new elements into their work. For example, our IMAGINE project team (see p. 34) now uses traditional blanket designs and fabrics as an analogy to describe genomic variability across ancestries, an analogy that they noticed was received very positively in four sharing circles where participants self-identified as Indigenous.

(Photo: Sacred Fire Arbour, Atikameksheng Anishnawbek)



Becoming comfortable with discomfort

At CHILD-BRIGHT we are all learning to collaborate not by avoiding the uncomfortable but by exploring it and working through it—whether in expressing conflicting views when discussing what should be the primary outcome of a trial or in deciding whether a tool we’ve been using to measure engagement is worth using again. As shared by a parent member of our Citizen Engagement Council recently, it is important to become comfortable with discomfort. She was speaking specifically of situations in which patient-partners and researchers collaborate on research teams, but her comment could easily apply to our whole enterprise.

Moving beyond engagement

Though patient-oriented research in general and CHILD-BRIGHT in particular are still quite new, we are well-past the dewy-eyed stage where authentic patient engagement seems achievable mainly through good intentions and a few simple precepts. In fact, some are questioning the adequacy of “engagement” since they think it suggests something preliminary to the sometimes messy but ultimately more satisfying work of partnership. Perhaps paradoxically, authentic engagement may mean moving beyond engagement.



We aim to influence policy in Canada by mobilizing knowledge generated through our work into action to help shape Canada’s health care system to better support children with disabilities and their families. Some of our initiatives this year towards this goal include:

We hosted a national Policy Forum

Our Policy Forum connected policy experts from across Canada with 34 CHILD-BRIGHT members including patient-partners, service providers, and researchers. The overarching goal of the event was to initiate a dialogue on how to best mobilize our research findings towards implementation and policy change. Participants not only addressed the divide between research findings and policy but developed a mutual understanding of the individual and collective roles that various CHILD-BRIGHT stakeholder groups can play in shaping policy initiatives. We plan to build on the momentum of this event by organizing sessions focused on practical considerations needed to advocate for policy change.

We are launching a Policy Hub for childhood disabilities

Our Childhood Disability Policy Hub will engage policy makers, families, youth with disabilities, researchers, and community partners to identify priorities and opportunities to bridge patient-oriented research and policy making at different levels. It will align policy windows of opportunity with the unique contributions from CHILD-BRIGHT members to create an evidence-based, patient- and family-informed communication channel for policy. We expect to inform the development of organizational and public policy that can address the challenges faced by Canadian children with disabilities by gathering the best available research and lived experience examples.

Evaluating sex and gender variables in research



This past year, Nancy Poole, CHILD-BRIGHT's Sex and Gender Champion, has worked closely with network teams to advance sex- and gender-based analyses on multiple levels.

Study participants

Our research projects are collecting the sex and gender of participants to explore whether interventions have different effects on males/females and boys/girls. For example, will the Mega Team video game training be more effective in males or females, and how might this influence guidelines going forward?

Sociodemographics and family structure

In addition to collecting the sex and gender data of participants, investigators are collecting data on the child's caregivers, parents, family structure, and other sociodemographic variables that can influence the outcome of a child with a brain-based developmental disability.

Stakeholder engagement

Lastly, as a patient-oriented research network, we strive for a diverse patient-partner population representative of adults and youth of both sexes and genders and from across the sociodemographic and geographic spectrum. By collecting this information we have already learned that we need to engage fathers more, and are consulting with Dr. Poole to reach this goal.

Giving youth a voice on an international stage



Liam, 15, spoke on behalf of youth with brain-based developmental disabilities in New York at the United Nations' 11th annual Conference of the States Parties to the Convention on the Rights of Persons with Disabilities. Attended by National governments and civil society organizations from around the globe, the goal of the event was to share knowledge about how government and society can advance the rights of people with disabilities and create more inclusive societies.

Liam's mom, Susan Cosgrove (CHILD-BRIGHT's first Parent Mentor) shared: "For such a young person, Liam didn't take the opportunity to influence global leaders lightly. He was there to show them what was possible for a young person when his rights were respected and enforced and to share his hopes for his adult life. He talked about his rights as a Canadian youth with disability and his hopes for the future. He dreams of one day being a mechanic, with a family and a home. He knows that he will require more assistance and support than his non-disabled peers for his entire life. He is willing to put in that extra effort and plans on using his future voting rights to encourage governments to match his efforts with their support. That was his message, that was his voice."

Our reach

We strive to be a model of effective patient-oriented research, both here at home in Canada and across borders, and are happy to partner and collaborate with stakeholders to accomplish this goal.

NORTH AMERICA

CANADA



ALBERTA



BRITISH COLUMBIA



QUEBEC



MANITOBA



NEW BRUNSWICK



NEWFOUNDLAND



USA



NORTHWEST TERRITORIES



NOVA SCOTIA



ONTARIO



PRINCE EDWARD ISLAND



SASKATCHEWAN



YUKON



SOUTH AMERICA

BRAZIL



CHILE



COLUMBIA



EUROPE

FRANCE



ITALY



NETHERLANDS



PORTUGAL



SPAIN



SWITZERLAND



UNITED KINGDOM



AFRICA

SOUTH AFRICA



ASIA

CHINA



INDIA



ISRAEL



JAPAN



OMAN



SINGAPORE



THAILAND



OCEANIA

AUSTRALIA



NEW ZEALAND



- Network members
- Host research institutions
- Patient-partners
- Conferences/speaking engagements
- Webinar attendees
- Grant/fund awardees
- Network funders
- Recruitment sites

2018-19 webinars

We invite you to catch up webinars you may have missed, to meet some of our research team members, and learn about their ongoing work.

Scan the QR code using the camera on your mobile device or computer to access the free recording directly

Webinars in collaboration with Children's Healthcare Canada (previously CAPHC)

CAPHC PRESENTS! THE COACH APPROACH: SUPPORTING FAMILIES OF CHILDREN WITH DISABILITIES

Exploring the coach or navigator approach, a new model that is now increasingly used in pediatric health care contexts.

Speakers: Maureen O'Donnell, Tatiana Ogourtsova, Annette Majnemer and Eyal Cohen



CAPHC PRESENTS! A TALE OF RESEARCH & CLINICAL COLLABORATION: THE SPORT TRIAL

Exploring how research and clinical care can be integrated within the realities of a busy children's hospital with the SPORT research team.

Speakers: Alicia Hilderley, Megan Metzler and Adam Kirton



PARENTS EMPOWERING NEURODIVERSE KIDS

Exploring how to help parents manage the challenging behaviours of their children with children with neurodisabilities with the Strongest Families Neurodevelopmental Program team.

Speakers: Patrick McGrath, Lucyna Lach, Donna Thomson and Karen Turner



CHILD-BRIGHT Summer Learning Series

CHILD-BRIGHT & CANADA'S STRATEGY FOR PATIENT-ORIENTED RESEARCH

Exploring how Canada's SPOR initiative aims to improve health research, and how CHILD-BRIGHT fits within this.

Speaker: Pierre Zwiegers



EXPLORING SOME OF THE BARRIERS, DRIVERS, & BENEFITS OF PUBLIC PARTICIPATION IN RESEARCH

Exploring what authentic patient engagement looks like, factors that influence it in the research process, and how it can positively impact health research outcomes.

Speaker: Pierre Zwiegers



HOW IS PATIENT ENGAGEMENT INCORPORATED INTO A RESEARCH PROJECT?

Exploring how researchers can involve patients as research partners, and different opportunities available for patient engagement throughout each stage of the research.

Speaker: Pierre Zwiegers



PATIENT ENGAGEMENT IN ACTION: A CASE STUDY IN PATIENT-ORIENTED RESEARCH

Showcasing the READYorNot project, to explore their journey, get a sense of how the process of patient engagement evolved throughout the process and how certain challenges were addressed.

Speaker: Sonya Strohm, Connie Putterman, Barb Galuppi



Financial partnerships

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 28 generous funding partners from public and private sectors across Canada. Together, they provide \$25 million in support and contribute valuable expertise as active network partners.

Leveraging the expertise of our funders

We had the honour of hosting some of our network funding partners at our 2018 CHILD-BRIGHT Annual Meeting, including our Platinum partners from the Montreal Children's Foundation & Opération Enfant Soleil, who graciously hosted a roundtable discussion titled "How to keep donors and foundations engaged in research". Their insight and expertise helped educate our members, including research team leads, on ways to engage and support donors, ways that are critical to maintaining successful partnerships with the funders whose support we value so dearly!

Welcoming a new financial partner

This year, with the addition of the Prenatal Opioid Exposure and Neonatal Abstinence Syndrome project, we were also pleased (and grateful!) to welcome ICES as a new Silver-level financial partner.

Meet our financial partners



PLATINUM PARTNERS (\$1M +)



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



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



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



Thank you to our members, partners & collaborators

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Noam McCready	Sue Robins	
Rob McCready	Kate Robson	
Samadhi Severino	Julie Rose	...and many others who
Robert More	Michael Sametz	elect to remain anonymous

Community partners

Aamjiwnaang First Nation	Mohawk Council of Akwesasne,	Walpole Island First Nation
Atikameksheng Anishnawbek	Department of Health	
Beausoleil First Nation	Oneida Nation of the Thames	
Mississaugas of the Credit First Nation	Saugeen First Nation	...and others who
	Temagami First Nation	elect to remain anonymous

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Julia Hanes	Maria Marano	Paul Yoo

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Carrie Costello

Youth groups

KidsCan
Spectrum Productions

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Catherine Lau
Hana MacDougall
Christine Marcotte
Michelle Marquis

To Nhu Nguyen
Sujitha Sugan
Pierre Zwiegiers

Institutional affiliations of our members

Ability Online Support Network
Alberta Association of Occupational Therapists
Alberta Children's Hospital
Alberta Health Services
Alberta Kinesiology Association
Alberta SPOR SUPPORT Unit
American Academy for Cerebral Palsy and Developmental Medicine
American Academy of Pediatrics
American Heart Association
American Society of Echocardiography
Association of Child Life Professionals
Association of Physical Educators of Quebec
BC Children's Hospital and Research Institute
BC SUPPORT Unit
BC Women's Hospital + Health Centre
Boston Children's Hospital
Brigham and Women's Hospital
Canada / Israel Autism Research Initiative
Canadian Association of Genetic Counsellors
Canadian Association of Health Services and Policy Research
Canadian Association of Occupational Therapists
Canadian Cerebral Palsy Registry
Canadian Family Advisory Network
Canadian Institutes of Health Research
Canadian International Development Agency
Canadian Neonatal Follow-up Network
Canadian Nurses Association
Canadian Paediatric Society
CanChild
Canuck Place Children's Hospice
Centre de recherche interdisciplinaire en réadaptation du Montréal métropolitain
Centre for Addiction and Mental Health
Centre for Innovation in Autism and Intellectual Disabilities
Centre hospitalier universitaire (CHU) Sainte-Justine
Centre of Excellence for Women's Health
Centre de réadaptation de l'Ouest de Montréal
Child Health BC
Children's Healthcare Canada
Children's Hospital at London Health Sciences
Children's Hospital of Eastern Ontario

Institutional affiliations of our members (con't)

Children's Hospital Research Institute of Manitoba
Children's Hospital Zürich Eleonoren Foundation
College of Family Physicians of Canada
College of Nurses of Ontario
College of Occupational Therapists of British Columbia
College of Physicians and Surgeons of Alberta
College of Psychologists of Ontario
College of Registered Nurses of Manitoba
Concordia University
Crisis Prevention Institute
Dalhousie University
EvidenceNetwork.ca
Families Forward
Family Support Institute of BC
Fetal Alcohol Spectrum Disorder (FASD) Society for British Columbia (BC)
Fetal Heart Society
Ganohkwa Sra Family Assault Support Services Board
Giant Steps School
Gilette Children's Specialty Hospital
Glenrose Rehabilitation
Harvard Medical School
Health Quality Ontario
Health Sciences Centre (HSC) Winnipeg and HSC Children's Hospital
Holland Bloorview Kids Rehabilitation Hospital
Indigenous Certification Board of Canada
Institut de recherches cliniques de Montréal
International Alliance for Pediatric Stroke
IWK Health Centre
Jewish Federation of Greater Toronto
Jewish General Hospital
Kids Brain Health Network
Laurentian University
Lethbridge-Layton-Mackay Rehabilitation Centre
Mackay Centre School
Maternal Infant Child and Youth Research Network (MICYRN)
McGill University
McMaster Children's Hospital, Hamilton Health Sciences
McMaster University
MCT8-AHDS Foundation
Ministry of Ontario

Institutional affiliations of our members (con't)

Montreal Children's Hospital - McGill University Health Center (MUHC), and the Research Institute of the MUHC
Mount Sinai Hospital
National Society of Genetic Counsellors
Network of Alberta Health Economists
Nova Scotia Board of Examiners in Psychology
Nova Scotia Early Childhood Development Intervention Services
Nova Scotia Health Authority
Office des personnes handicapées du Québec
Ontario Association of Social Workers and Social Service Workers
Ontario Brain Institute
Ontario College of Teachers
Ontario SPOR Support Unit
Ontario Tech University
Opération Enfant Soleil
Ordre des CPA du Québec
Ordre des ergothérapeutes du Québec
Ordre des psychologues du Québec
Ordre des travailleurs sociaux et des thérapeutes conjugaux et familiaux du Québec
Para-cycling National Team
Patients Canada
Plan Institute
Planned Lifetime Advocacy Network
Providence Health Care
Province of Ontario Neurodevelopmental Disorders Network
Rare Disease Foundation
Registered Nurses' Association of Ontario
Rehabilitation Centre for Children
Royal College of Physicians and Surgeons of Canada
Ryerson University
Saint Elizabeth Health Care
Sherbrooke University
Society of Clinical Research Associates
Specialized Services for Children and Youth
Stollery Children's Hospital
Strongest Families Institute
Sunny Hill Health Centre for Children
Sunnybrook Health Sciences Centre
The Hospital for Sick Children

Institutional affiliations of our members (con't)

Therapeutic Recreation Ontario
Thunderbird Partnership Foundation
Toronto Transit Commission - Advisory Committee on Accessible Transit
Universitat Heidelberg
Université de Montréal
Université Laval
University of Alberta
University Of British Columbia
University of Calgary
University of Guelph-Humber
University of Manitoba
University of Minnesota
University of New Brunswick
University of Ottawa
University of Pittsburgh
University of Toronto
University of Vermont
UPMC's Children's Hospital of Pittsburgh
Vancouver Coastal Health
Western University
Winnipeg Health Sciences Centre
Winnipeg Regional Health Authority
Women and Children's Health Research Institute
York University

Industry partners

360Medlink
Ehave

Igloo
Spectrum Productions

Partner SPOR entities

ACCESS Open Minds
Alberta SPOR SUPPORT Unit
British Columbia SPOR SUPPORT Unit
Chronic Pain Network
Diabetes Action Canada
IMAGINE-SPOR Chronic Disease Network
Can-SOLVE CKD
Manitoba SPOR SUPPORT Unit
Maritimes SPOR SUPPORT Unit
Newfoundland and Labrador SPOR SUPPORT Unit
Northwest Territories SPOR SUPPORT Unit
Nunavut SPOR SUPPORT Unit
Ontario SPOR SUPPORT Unit
Primary and Integrated Health Care Innovations (PIHCI)
Quebec SPOR SUPPORT Unit
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