

# 2019-20 Report to Community

Fiscal year ended March 31, 2020



Our Youth in Action



CHILD-BRIGHT  
Network

## About us

About CHILD-BRIGHT	3
Welcome messages	4-9
Meet our NYAP members	10-15

## Program & project updates

Citizen Engagement	16-17
Knowledge Translation	18-19
Training	20-21
Research	22-39
Data Coordinating Centre	40
Health Economics Service	41

## Network activities

Trainee profile	42
Launching the Policy Hub	43
Our reach	44-45
2019-2020 webinars	46-47
Our members	48-58
Financial partners	59

## 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 grant by the Canadian Institutes of Health Research (CIHR) under Canada's Strategy for Patient-Oriented Research (SPOR), and 28 generous funding partners from the public and private sectors across Canada.

## Our mission

Under Canada's Strategy for Patient-Oriented Research (SPOR), we will achieve brighter futures for children with brain-based developmental disabilities and their families across their lifespan by creating novel interventions to optimize development, promote health outcomes, and deliver responsive and supportive services.

## Our population

We work to make the future brighter for infants, children, and youth with lifelong brain-based developmental disabilities and their families. Brain-based developmental disabilities include, but are not limited to:

- Autism spectrum disorder
- Attention deficit hyperactivity disorder
- Fetal alcohol spectrum disorder
- Cerebral palsy
- Intellectual or learning disabilities
- Individuals at high risk for a brain-based disorder (e.g. preterm birth, congenital heart disease, genetic anomaly).



# Message from Annette Majnemer

## CHILD-BRIGHT Network Director

Dear CHILD-BRIGHT Community,

I am pleased to meet you once again in the pages of our Report to Community. This past year (Spring 2019-2020) has been a watershed year for the CHILD-BRIGHT Network, one marked by many successes, but also unique challenges brought on by COVID-19 that continue to have ramifications in the current 2020-21 cycle.

In challenging times, it can help to focus on what brings us joy, strength, and courage. That's why, in addition to sharing our yearly updates with you, this report shines a spotlight on the youth of our community. Our youth partners make their presence felt at every level of CHILD-BRIGHT. Their contributions serve as wonderful examples of the innovation, perseverance, creativity, and care that fuels our network.

The members of our National Youth Advisory Panel (NYAP), now in their third year of work together, are excited to share the fruits of a busy year with you. Not only does this year's report feature an update from inaugural NYAP Chair Mathias Castaldo, who at the conclusion of his two-year mandate looks back at the panel's accomplishments (see p. 8), but the youth members have also taken the initiative to write their own update pages (see pp. 10 to 15). They present the results of their combined efforts in the past year, including laying the foundations for their new consultation service and a collaboration with the Training Program to produce a youth webinar, both of which are scheduled to take place in Fall 2020.

In addition to this outstanding level of involvement from our youth partners, we have seen an upswing in engagement from our patient-partners more broadly. The dedication of our Parent Peer Mentor, Carrie Costello, has been crucial to keeping the lines of communication open with our parent-partners. We also launched two new feedback mechanisms to further strengthen engagement and drive change within our network: optional exit interviews with patient-partners leaving the network, and the establishment of an accessibility working group, now in its early stages of work. I am also proud to note an increased involvement of First Nations communities in our network this year, as our Prenatal Opioid Exposure project gained Chief and Council approval to work with two additional First Nations communities last year, allowing work to get underway this year (see p. 31).

In fact, work has proceeded apace for all our research project teams, with 12 of 13 project teams well into their recruitment stages (see pp. 26 to 38 for updates from all our research teams), as well as for our central office team, who welcomed Lorraine Reynolds as our new Director of Operations. The hard work of all across the board has been heartening, even as we now continue to adapt to the new realities of research while living with COVID-19.

Despite the setbacks the pandemic has occasioned, we have continued to reinforce connections throughout the network, and have seen unparalleled levels of cross-collaboration between projects and programs. Our Research Program and the Data Coordinating Centre partnered with PolicyWise on a new blog series aimed at demystifying data sharing and data management in research (see p. 40). Our Knowledge Translation (KT) Program conducted one-on-one calls with project teams throughout the year to guide them in producing new KT outputs (see p. 18), and our Training Program funded new grant initiatives, including the inaugural Collaborative Mentorship Grant, which aims to build connections between stakeholder groups to gain a better understanding of best practices in patient-oriented research (see p. 20).

This cross-pollination has also led to a flourishing of public-facing knowledge-sharing initiatives including webinars (see p. 46), as well as advocacy and education work in the policy-making sphere from our KT team, namely through their delegation to the United Nations.

Even as we take stock of the progress made on these fronts, we also turn to the future to ensure we can continue to build on these many accomplishments. A research priority-setting exercise is under way and the efforts of our sustainability planning have been collected in our sustainability report ([download it here](#)). Both will help steer our future years.

Thank you all for your continued commitment to our network in the past year, and I look forward to continuing to work alongside you to make the future brighter for children with brain-based developmental disabilities and their families, for many years to come.

Sincerely,

Annette Majnemer



# Message from Frank Gavin

## CHILD-BRIGHT Director of Citizen Engagement

Dear CHILD-BRIGHT Network Members,

In last year's letter I asked whether there was, in fact, a CHILD-BRIGHT community and answered my own question with a tentative "yes." This year that community, like others, has been tested in ways we could not have predicted and shown itself to be vulnerable but also resourceful and resilient.

The testing, of course, resulted from the COVID-19 pandemic. It affected the network in many ways, for instance by forcing us to cancel our conference in March, the one occasion when much of our network can gather and—overused as the phrase may be—build community. A parent member of the Citizen Engagement Council (CEC), Kate Robson, helped lead the conference planning team, and several parent, youth, and community partners had hands in developing a program that was outward-looking and future-focused. We hoped it would springboard our transformation from network to movement.

Then came the pandemic. As we know, it exposed many problems and vulnerabilities across society. What we heard from CHILD-BRIGHT families about its impact on them was that it wasn't creating new problems so much as exacerbating, sometimes acutely, problems they contend with every day. The helpful if inadequate supports their children receive in schools, for instance, have usually not accompanied whatever online learning materials have been made available. Respite care, whether provided by an institution or a grandparent, has largely disappeared. Not surprisingly, many such families have been less able to participate in research, but—tellingly—all have remained onboard.

We learned what we did about the effect of COVID-19 by listening, and we've been trying to listen more, listen better, and act upon what we've heard throughout our Citizen Engagement Program. This year we began to conduct exit interviews with patient-partners who left the network the previous year. As far as I know, this is unprecedented in the world of patient engagement where there has been a tendency to look away from areas of potential disappointment or contention. From those who left we heard of the need to do a better job of onboarding patient-partners and ensuring roles and expectations are clearer. We are now at work on both.

We've also attended to what the Parent Peer Mentor, Carrie Costello, has reported to the CEC. As detailed elsewhere in this report, we amended our compensation guidelines and changed our engagement surveys in response to what Carrie told us about what she had heard.

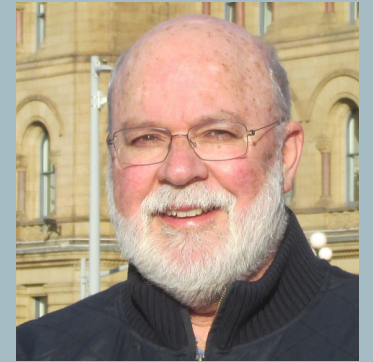
We also developed a protocol for collecting qualitative data through interviews with patient-partners and the researchers they work with to understand better what's going well and not so well.

Listening to what a parent network member told us about the problems she experienced with network processes and forms because of her invisible disability prompted us to form an Accessibility Working Group composed of parents, a youth, and a staff member to identify barriers we hadn't recognized as barriers and recommend ways to eliminate them. Meanwhile, our Recruitment Working Group continues to find or develop new channels to reach people and communities we have so far not connected with.

Elsewhere in this report there is much about our youth members. I will add only a note of gratitude for their remarkable persistence at a time in their lives when change is the order of the day. They are a touchstone for the whole network, reminding us that building a stronger community inside and outside the network is at the heart of what we, as a patient-oriented research network, are about.

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, and I currently live in Toronto. I am a recent graduate from OISE, with a 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.

The CHILD-BRIGHT Network's National Youth Advisory Panel (NYAP) is made up of 5 members: Logan, Hans, Lena, Gillian and myself. As the chair of the NYAP (currently ending my term), I am happy to report that the NYAP had a busy second year. We were pleased to welcome two new members to our team: Lena and Gillian, from Quebec and British Columbia.

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 a brain-based disability. 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 and come to a consensus on the best day to hold a meeting as it ensures 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 as some members speak English while others speak French. Lastly, the friendly and inviting environment that the NYAP has created makes it easy to ask questions and provide input into what is being discussed. The addition of Julia Tesolin, our new Administrative Assistant, has also allowed the NYAP to stay organized and run smoothly.

The NYAP's second year has been busy, with the welcoming of new members as well as the various projects that NYAP has been a part of. For instance, Gillian will be the NYAP's representative for the Training Committee's webinar series, which will focus on topics such as youth engagement in research.

With the help of the Communications team, the NYAP selected a new logo, which will be featured on the CHILD-BRIGHT website.

Furthermore, the NYAP created a tip sheet with eight tips to help guide researchers looking to engage youth in research, which has been published on the CHILD-BRIGHT website and shared via our newsletters and social media.

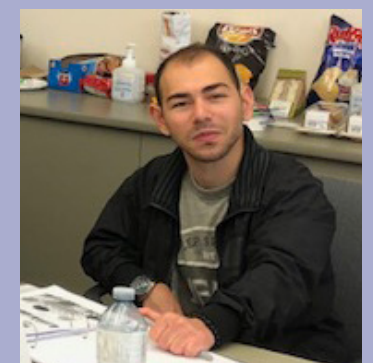
Panel members were involved in various working groups such as the Policy Hub, recruitment workgroup, and the Research Priorities Task Force.

One of the NYAP's largest projects that we have developed is the creation of an external consultation service. The consultation service will allow for researchers outside of CHILD-BRIGHT to consult with members of the NYAP. This consultation service will launch in the Fall of 2020.

The NYAP is excited to enter its third year, where the panel will continue to consult and work on various projects in and outside of the CHILD-BRIGHT Network.

It should be noted that the NYAP's success could not have been done without the time, dedication and hard work of Corinne Lalonde, CHILD-BRIGHT's Citizen Engagement Coordinator, who has organized the NYAP's meetings, updated the panel about CHILD-BRIGHT's activities, recruited new members, ensured the NYAP has a presence in CHILD-BRIGHT, introduced new projects for NYAP members to be a part of, and lastly ensured that all members have been happy and able to contribute to the NYAP.

Mathias Castaldo

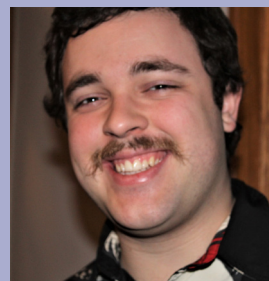


# Meet our NYAP members



## Mathias Castaldo

Mathias, chairperson of the NYAP, is a recent graduate with a Master's degree in Developmental Psychology and Education, and works as a Youth Facilitator at Holland Bloorview. He enjoys reading and running.



## Hans Dupuis

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.



## Logan Wong

Logan is pursuing his Masters of Social Work at Ryerson University. He enjoys sports and volunteering, and hopes to bring youth voices to conversations about research.



## Lena Faust

Lena is a Ph.D. student at McGill University and the McGill International Tuberculosis Centre. She loves spending time outdoors, and particularly enjoys hiking, skiing and scuba diving.



## Gillian Backlin

Gillian recently completed her technical writing certificate, and is currently looking for work in the communications field. She runs her own blog/online store called Spastic AND Fantastic, whose goal is to bring attention to the stigmas society has put on labels, such as "disabled."

Our National Youth Advisory Panel (NYAP) had a busy second year: members welcomed two new advisors, attended committee meetings in Vancouver, met monthly via teleconferences, expanded their roles, and developed a tip sheet for researchers hoping to increase youth engagement in patient-oriented research. The NYAP also worked on constructing an external consultation service for researchers outside of CHILD-BRIGHT seeking to consult with youth with lived experience of brain-based developmental disability, which will launch in the fall of 2020.

## Our geographical representation

Interested in putting your location on the map? We are always looking for new youth members. Reach out to us at [citizen.engagement@child-bright.ca](mailto:citizen.engagement@child-bright.ca)



The NYAP would like to acknowledge Mike Sametz (Calgary, AB), a panel member who is currently on a temporary leave, for his contributions. They also wish to express their thanks to its former NYAP members, Maya Pajevic (Calgary, AB) and Élise Robert-Huet (Montréal, QC), whose terms have completed this year.

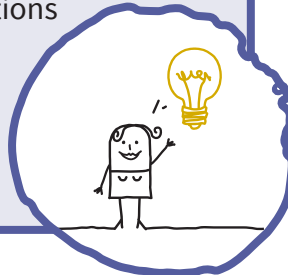
WRITTEN BY NYAP MEMBERS

## Our work in the past year

The NYAP has accomplished a lot this year in our 10 monthly meetings. Learn more below! Although the NYAP faced unexpected challenges due to the current pandemic, we still made great strides in our efforts to assist in promoting patient-oriented research. We look forward to seeing what's in store next!

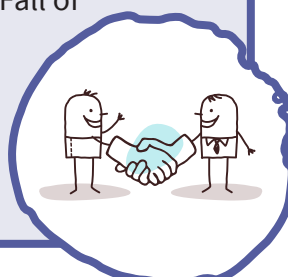
## NYAP logo

The panel showed an interest in the creation of a distinct NYAP logo that would help create an image of the NYAP as an entity in its own right. The Communications team presented the panel with four logo options and it was set to a vote. The NYAP selected one that they liked best, due to the colors and the image it presented, and it was shared to the CHILD-BRIGHT community in our internal newsletter. Check it out in the top-right corner of this page!



## Consultations

The NYAP also discussed the creation of a consultation service in which researchers working on childhood disability-related studies could book time with them to collect their insight as youth with lived experience with a brain-based developmental disability, and as youth with experience in patient-oriented research. Following many logistical meetings about this consultation service, our chairperson pitched the proposal to the CHILD-BRIGHT Executive Committee. Our proposal outlined why the NYAP would want to meet with external researchers, what researchers could gain by consulting with NYAP members, and the number and length of consultations. Their pitch was successful and starting in the Fall of 2020, NYAP members will be offering eight sessions between October and May, each one hour in length. It is important for research to become more approachable to the youth demographic. This was the NYAP's biggest project this year!



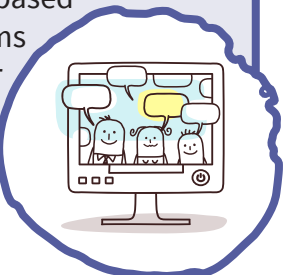
## Tip sheet

The NYAP created its own tip sheet with eight tips for researchers hoping to increase youth participation on their studies. It has been shared with researchers via channels such as social media (Twitter and Facebook), newsletters, and on the CHILD-BRIGHT website. These tips include advice that outlines important considerations when engaging youth with lived experience with a brain-based developmental disability in a project or program. These tips touch on the topics of vocabulary, language, clarifying objectives, offering accommodations, and providing feedback to youth on the impact of their contributions.



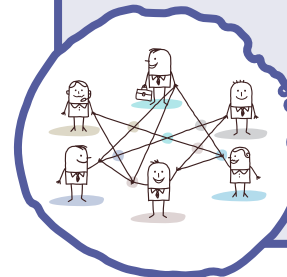
## Network roles

NYAP members have been filling network roles including on the Citizen Engagement Council (CEC), the Research Priorities Task Force, on the KT Committee, the Policy Hub, and on a recruitment group. NYAP members also provided input on the evaluation of grant proposals for innovative projects on various topics relating to brain-based disabilities in children. This included commenting on whether project teams incorporated effective patient engagement in their protocols, and whether KT strategies were interesting and targeted the relevant stakeholders.



## Conference

In preparation for the annual conference, which got cancelled due to the current pandemic, members of the NYAP had various roles to play in the planning process including serving on the programming committee, doing a site review for accessibility, volunteering with the central office staff, and presenting at the Citizen Engagement Council meeting to help inform the CEC about the role of the NYAP, its priorities, and how the NYAP thinks youth engagement connects to the CEC program as a whole. Although we didn't get a chance to meet this year, we are looking forward to connecting when it is safe to do so.



WRITTEN BY NYAP MEMBERS

## Our work in the next year

NYAP has some exciting projects underway. Firstly, the panel looks forward to the launch of the consultation service, as we believe it will assist in providing valuable information to researchers. We will mainly be advising on recruitment strategies, materials required to be shared with youth, accommodations and accessibility, and sharing knowledge to youth audiences. We will also be reviewing and finalizing our web pages for the CHILD-BRIGHT website. These web pages will include our mandate, profiles, description of the consultation service and request form for interested research teams who wish to consult with the panel. Secondly, NYAP will have the opportunity to participate in a youth-led webinar, part of the CHILD-BRIGHT Summer Learning Series, relating to youth engagement and involvement in research. Lastly, NYAP looks forward to expanding its network and collaborating with other youth with brain-based developmental disabilities and their families. We wish to explore ways in which we can connect and liaise with the youth involved in CHILD-BRIGHT projects and programs, as we believe we can collectively work together to make an impact on CHILD-BRIGHT's activities. We are also excited to work with youth outside of the CHILD-BRIGHT Network who may be involved in a panel similar to ours, as this will allow us to learn about the ways in which they are involved in their communities.



"I completed site visits to three hotels in preparation for the annual conference, and it also was my suggestion to create a tip sheet that will hopefully be a great success along with the consultation service launching. My hope for the panel is to help bring youth voices to conversations about research! By working as a team, we can make research proposals more accessible to the youth population."

Logan



"Last year I became a member of the Knowledge Translation (KT) committee, along with Lena. I want to help others with brain-based disabilities or autism, in any way I can, and hope to learn from this team along the way also."

Hans

"I was actively involved in writing up the NYAP's pages of the Report to Community. As a new member to NYAP, I hope to meet like-minded individuals and do my part in making others feel heard."

Gillian



"I am hoping to learn how research will impact target populations. In addition, I am hoping that the panel will be able to comment on how best to improve the research conducted so that it will have a positive impact on the target population."

Mathias

"Being a member on the Knowledge Translation (KT) and research committees, I've provided input from a youth perspective on the evaluation of innovation grant proposals, and helped in conducting a rapid review on COVID-19 outcomes in children with brain-based disabilities. By bringing together a diverse group of young adults with brain-based developmental disabilities, I hope that the panel will become a valuable platform that helps shape the research process in this field."

Lena



WRITTEN BY NYAP MEMBERS



# Citizen Engagement Program



In the last year, our Citizen Engagement program widened and deepened connections within both the program and the network by increasing engagement opportunities. It also fortified links with groups and individuals outside the network. Here are some of our highlights from the past year:

## Increased engagement opportunities in the network

Our program team helped increase engagement opportunities for patient-partners. While some of these garnered interest among current network members, others pulled in new members. For instance, three youth on the National Youth Advisory Panel (NYAP) joined the Knowledge Translation Program's Policy Hub while another two became committee members. Three patient-partners co-led webinars about different core issues in patient-oriented research in our CHILD-BRIGHT Summer Learning Series. We also ensured new positions were posted on CHILD-BRIGHT's online resource that matches stakeholders with network opportunities. Two 'matched' parents now work with the Research Program team to help choose topics for blogs about secondary data use, and to review the texts for these blog posts (see p. 23). Eight patient-partners have also become study recruitment ambassadors for various projects.

## Connecting with our Parent Peer Mentor

Our program's Parent Peer Mentor connected with 25 parents. These meetings facilitated communication and deepened relationships among the parents, their research teams, and network staff. The mentor's feedback led to significant changes both at the project and network level. For example, meeting times and formats prompted some teams to adapt their schedules to better accommodate their parent-partners. Some parents suggested it's easier to provide advice in a

one-on-one call rather than in a large group teleconference. In response to the mentor's report and recommendation, CHILD-BRIGHT amended its compensation guidelines to include compensation for patient-partners participating in network-level activities such as responding to surveys and participating in interviews.

## Connecting at SPOR events

Our Director took part in a capacity-building event hosted by the Ontario Child Health Support Unit (part of Ontario SPOR SUPPORT Unit-OSSU) and exchanged ideas and experiences with parents (e.g., from SickKids, CHEO, Holland Bloorview), many of whom participated in our research priorities consultation. He also participated in a policy forum organized by the OSSU about the uptake of research findings in child health.

## Connecting with our communities

The Citizen Engagement Program benefitted greatly from connecting with patient-partners both inside and outside the network. We have opened up the opportunity for those who have left our network to give feedback on their experience and recommend improvements by offering them exit interviews. We have reached out to our members and those outside CHILD-BRIGHT in our research priority setting exercise by asking them to respond to our surveys (see p. 22). After hearing from a member with an invisible disability, we also formed a working group to perform an internal accessibility audit and make recommendations to ensure our network (in its gatherings, processes, and materials) is accessible for all. The Citizen Engagement Council provided detailed advice for a survey created for families living with low incomes so they can recommend how to best engage more families like their own.

10  
youth members  
sit on network  
committees

# Knowledge Translation Program



This has been a year of increased engagement for the Knowledge Translation (KT) Program, one in which we strengthened connections with stakeholders, especially youth. Here are some of our activities from this past year:

## Strengthening network connections and enhancing project integration

We have increased connections between the KT Program and the network's research projects. We conducted one-on-one calls with each CHILD-BRIGHT research project to identify their KT goals. This was an opportunity for us to also outline our work, increase collaborations with the projects, and facilitate their integration into the overall KT vision of the CHILD-BRIGHT Network. The research projects provided feedback on the direction of the program, ensuring that it is tailored to their needs.

## Trailblazing KT innovation

We have continued to foster innovative KT by funding two new projects via our KT Innovation Incubator (KTII) grant competition. The first project, Making Sense of Connectedness, developed new ways to work with neurodiverse children, youth, and their families, by building an online hub of sensory environments. The second project, Ready2Work, developed an online vocational/employment readiness platform for people (including youth) with autism. These project teams are participating in a case study about what constitutes innovative KT in brain-based developmental disabilities research.

One of CHILD-BRIGHT's research teams, the IMAGINE team, also received an award from our ConneKT Fund to develop an e-booklet that describes genomic results and provides support to families. It will be available in English, Arabic, Chinese, Punjabi, and French.

## Integrating youth voices and supporting stakeholder engagement

We have increased youth, parent, and other stakeholder involvement in our activities. Their involvement was central in all our KT activities including the KT Committee, Policy Hub, and KTII. For example, they acted as peer reviewers of applications for funding from our KTII and assisted with research and policy reviews for the Policy Hub. They also contributed to the development of KT products such as infographics and blog posts. As part of their involvement, we ensured that our youth received experiential/hands-on KT training.

## Increasing policy engagement

We have conducted Policy Hub activities, which included consultations with key experts to better connect research and policy. As part of this policy engagement, our co-lead, Keiko Shikako-Thomas, and one of our parent-partners, Rachel Martens, joined the Canadian delegation to the United Nations in September 2019 to advocate for the needs of Canadian children with disabilities. After the meeting, in collaboration with other parent-partners, they created an infographic and drafted a blog entry to show how parents and youth can engage in the human rights conventions reporting and monitoring. More on our policy work on p. 43.

**5**  
youths involved  
in the KT Program  
(2 in the KT  
Committee & 3 in  
the Policy Hub)

# 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. During this year we:

## Hosted the CHILD-BRIGHT 2019 Summer Learning Series

In 2019, we hosted a webinar series organized around the theme of 'Building your Network' that showcased patient engagement strategies employed across CHILD-BRIGHT. Co-facilitated by researchers and patient-partners, the series explored:

- How researchers and family/patient advisors can build strong foundations for collaboration
- Challenges associated with recruiting participants, from both the parent and researcher perspectives
- Strategies that increase the likelihood of participation
- Reciprocity amongst stakeholders and the development of an authentic partnership
- How to support First Nation-centred research and meaningful collaboration.

The four-part series was developed in direct response to feedback provided by network stakeholders that highlighted patient-oriented research capacity-building gaps.

The series was viewed live by over 180 attendees, and the uploaded recordings were accessed more than 240 times.

## Collaborated with CHILD-BRIGHT's National Youth Advisory Panel (NYAP)

This year, we consulted with the NYAP to invite their input on a number of key initiatives for example, we collected their thoughts on how to strategically distribute a survey to collect information on the training needs of teams, and we invited their feedback on an infographic. Further strengthening our connection with NYAP members, we have been working with members of the group to provide them with a platform to present and share their ideas about involving youth in research.

## Launched the 2019 Summer Studentship Program

Now in its third year, CHILD-BRIGHT's annual Summer Studentship Program provided financial support for 10 trainees with diverse educational backgrounds across five network research projects. As part of our ongoing efforts to develop capacity for patient-oriented research in the next generation of researchers, this initiative not only provides experiential hands-on learning opportunities for students by embedding them directly within a research project, but introduces students to the basic principles of patient-oriented research through interactive online learning opportunities.

## Looked ahead by supporting old and new partnerships

Partnerships and new connections have been pivotal to helping us enhance patient-oriented research training outputs available to Canadians. Over the course of the last year, we have collaborated with several SPOR entities including all the chronic disease SPOR Networks and SUPPORT Units, as well as the SPOR Evidence Alliance and SPOR Canadian Data Platform to compete for a National SPOR training program to be funded by CIHR. Our proposal has been short-listed in the competition and we are currently finalizing the full application. Patient-partners, trainees, and Indigenous partners have played a key role in shaping our work on this initiative.

51  
CHILD-BRIGHT  
Network  
trainees

# Research Program



The 13 teams that make up CHILD-BRIGHT’s pan-Canadian patient-oriented Research Program are studying new diagnostic tests, therapies, service models, and technologies to optimize the health of children born with brain-based developmental disabilities and their families. The Research Program also advances special initiatives including, in this past year, initiatives on data reuse and identifying research priorities. Read more:

## Identifying new research priorities

Even as we focus on completing our 13 projects, we have also begun to ask ourselves how we should determine our future research priorities. Traditionally, researchers and clinicians decide upon research priorities with the patient and family in mind. However, engaging patient-partners in patient-oriented research also means collaborating with them to identify research priorities. In December 2019, we formed the Research Priorities Task Force, a group of network members including patient-partners and researchers, that is guiding our prioritization process.

The task force decided to seek the input of all relevant stakeholders in our community, both current network members and those not currently engaged in our network. With that in mind, the task force designed surveys asking our stakeholders about the topics and ideas that should be researched to improve outcomes for patients and families impacted by brain-based developmental disabilities. It also asked whether the network’s current research themes, BRIGHT Beginnings, BRIGHT Supports, and BRIGHT Futures (see p. 24), still resonated with the community, or if other areas should be considered.

More than 170 stakeholders responded to the surveys, and we look forward to analyzing the responses and discussing these priorities with our community further next year.

## Youth in action

National Youth Advisory Panel member Lena Faust was one of the three patient-partners on the task force. Lena helped ensure that the survey questions were appropriate for youth to answer. She also played a key role in developing the analysis plan, and she contributed to the analysis by advising on how responses should be categorized from the lens of a youth with disability and of a young researcher (Lena is pursuing her Ph.D. in epidemiology!).

## Developing a data reuse strategy

Our project teams are busy collecting data for their projects in hopes of answering their research questions. In doing so, they wondered if this data could be used by other research teams in the future to answer new research questions of their own? There is growing interest in reusing previously collected data to answer new research questions and this strategy can save time and money, and accelerate the rate of new discoveries. CHILD-BRIGHT has partnered with PolicyWise for Children & Families, a not-for-profit organization committed to using evidence to improve the well-being of children and families, to advance this initiative. This year, in collaboration with two patient-partners and members of our Data Coordinating Centre (see p. 40), we began writing a blog series that explores various considerations and points of view related to data reuse and we hope to engage you in this conversation. The first of seven blog posts will be published in June 2020. Follow the evolution of the series on the CHILD-BRIGHT blog!

In the following pages (pp. 24-39), we are excited to share updates from each of our projects and bring you along for the journey that these teams and study participants have undertaken to advance patient-oriented research and care. Patient-partners, community partners, and youth are essential members of our research project teams. As you read through the project updates, learn more about the key roles that these partners are playing to bring about a culture change in conducting pediatric research, and watch for the Youth in Action heart to learn more about the roles of youth in our work.

Youth in action!

# 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.



Research  
Project  
Updates



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

PRINCIPAL INVESTIGATORS



Mike Seed (SickKids)



Steven Miller (SickKids)

MATernal hyperoxygenation in Congenital Heart Disease (MATCH)

2019-2020 PROJECT UPDATE

Our team made great progress in recruiting participants for both parts of our study. We're using medical imaging to better understand the effect of giving mothers supplemental oxygen on the brain development of their baby with heart disease.

In the first part, we are providing pregnant moms with supplemental oxygen while imaging their fetus to improve our understanding of how oxygen reaches the fetuses' brains. So far, 37 mothers have participated in this part of the study.

In the second part, we are providing mothers with supplemental oxygen throughout their third trimester to understand whether this promotes fetal brain development. Eight moms have participated in this part, and there have been no adverse outcomes attributable to oxygen supplementation thus far.

We are collaborating with patients and health care consumers to understand how tolerable this form of therapy is for expecting mothers. We have also integrated youth voices to our research team. **Two of our team members are youths**; we hope to empower our young researchers to become experts in conducting a clinical trial.



(Meet Henry, 1 year old, and mom Jamie, shown in the top left corner of this page, two patient-partners on the MATCH project)

In the next year, we are excited to continue recruiting participants. Our study is also evolving in consultation with our youth- and patient-partners, as we consider adding a control group of children that have been treated at SickKids for single ventricle congenital heart disease.



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)

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

2019-2020 PROJECT UPDATE

The Parent-EPIQ project has three main goals: We work with parents to improve how we communicate with families about brain-based developmental disabilities, we track the health and development of preemies, and we implement practices to improve their development.

We're conducting studies to better understand how parents perceive their child's development. Preliminary results show that parents tend to view their child's development more positively than their health care providers do, and that a majority of parents also acknowledge developmental challenges. The study conclusions will help us provide parents with information they need in language they understand.

We continue to collect health data about preemies and make this information available to parents and health care providers. In December 2019, our second annual report provided information about the 6,432 preemies born in Canada between 2009 and 2016. In that time, there has been a reduction in incidences of cerebral palsy, hearing, and visual problems, but no improvement in thinking, motor, and language abilities.

Finally, our teams of health care providers and parents at 11 hospitals are implementing simple interventions to improve the language abilities of preemies. Families can do a lot by talking, reading, and singing to their newborn child! Educating medical staff and parents is also important; public libraries have been great partners to us in this respect.



(Our logo was revised this year based on suggestions by parents. The new logo features photos contributed by parents of their children born preterm)



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)

## Enhancing Brain Repair with Metformin (Metformin in CP)

### 2019-2020 PROJECT UPDATE

Our team has taken significant strides towards our goal of determining if metformin can be used as part of our intervention for children diagnosed with cerebral palsy (CP).

We started the year validating our study to ensure all was being performed in a safe environment and according to Health Canada’s regulations. Following confirmation of this, we officially launched our study in November 2019 to great interest from the CP community. This interest has continued despite the COVID-19 pandemic-related shutdown because of our fantastic partners and advocates within this community. Since then, we have broadened several entry criteria to increase the number of children who can participate, without sacrificing the safety of participants or the quality of results. We also added two highly qualified research assistants and several physiotherapists to our team, thereby increasing our capacity to enroll participants and effectively run our study.

Despite the shutdown, we continue to screen interested families for eligibility so we can enrol participants once in-person research activities can resume. We are also working with several CP-related organizations to increase community awareness and reach as many individuals as possible.

We continue to work with our fantastic **Stakeholder Engagement Committee**, which is composed of youth and adults with CP, as well as parents of children diagnosed with CP, to tailor our trial to the needs of children and families in the CP community. Based on their advice we will hold in-person information sessions for families to learn about our study, ask questions, and express their needs. We are excited to conduct study procedures in the coming months as restrictions are lifted, and have several families ready for their screening visit, and even more ready to continue the screening process.



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)

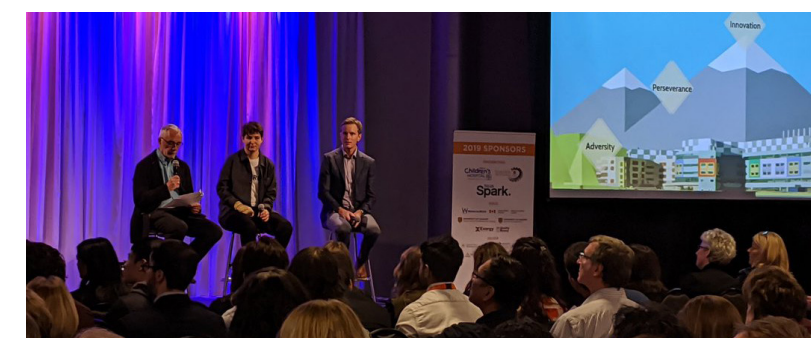
## Stimulation for Perinatal Stroke Optimizing Recovery Trajectory (SPORT)

### 2019-2020 PROJECT UPDATE

Our SPORT trial team is on track to answer the question: “Can non-invasive brain stimulation enhance motor function in children with weakness due to perinatal stroke?”

Across Canada, the SPORT team has welcomed and supported nearly 60 children and families in camp-based therapy programs. Via participation in these camps, we have watched children and families achieve many of their personal goals. We’ve also noted the exceptional commitment of our participants, who need to undergo brain imaging scans before and after the camps. Their commitment to this helps us map our observations, which in turn allows us to generate rich data which our team of experts is already analyzing.

We’ve also been impressed watching youth participants from our study in action; they inspire younger children to overcome their challenges and work towards their goals. National youth leaders, like **Maya Pajevic** (pictured below), have also championed knowledge exchanges by sharing about their lived experience at large and diverse public events. We are very proud of our youth members and participants!



(At the 2019 sold-out **Innovation 4 Health** event, the keynote address was an open discussion between CHILD-BRIGHT National Youth Advisory Panel member **Maya Pajevic** and her neurologist [SPORT lead] **Adam Kirton**. The event was moderated by **Jay Ingram**)



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)

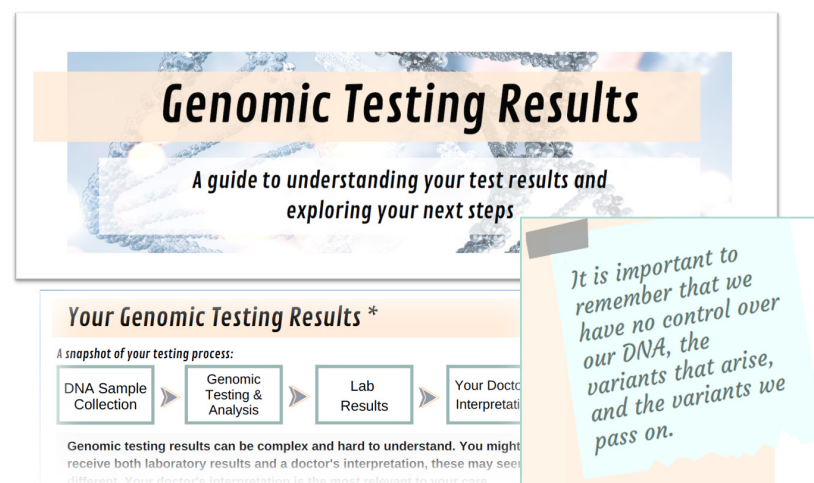
## Diagnosis Using Integrated Metabolomics And Genomics In Neurodevelopment (IMAGINE)

### 2019-2020 PROJECT UPDATE

Our team has been working to recruit families in our IMAGINE genomic and metabolomic study for children with atypical cerebral palsy. We are pleased with our progress. To date, we have enrolled 87 families, including 11 where two or more children are affected. We expect to reach our enrolment goal of 100 families by autumn 2020.

Analysis of the data gathered thus far has allowed us to provide a definite or probable genomic diagnosis for roughly half of the families. It is likely that further answers will emerge in the next 9 months from metabolomic studies and from new bioinformatic methods currently being developed by our team's bioinformaticians.

We have noticed that the emotional responses of families can range significantly when hearing their results, ranging from huge relief to profound sadness. Recognizing that this is a time where parents often need extra support, IMAGINE's summer student, **Julia Handra**, alongside parents Brenda Lenahan, Isabel Jordan, and Kelsey Ohs, co-designed a customizable e-booklet (pictured below) to help families navigate their family's post-result journey, which has been well received.



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)

## Prenatal Opioid Exposure and Neonatal Abstinence Syndrome

### 2019-2020 PROJECT UPDATE

We are interested in the impact of prenatal opioid exposure (POE) on children, mothers, families and caregivers, and First Nation communities.

In spring 2019, we worked with our community contacts and Community Advisory Group members to vet our research materials and methodologies. Community contacts were critical to finding qualitative research participants and helping coordinate focus groups and individual interviews.

We then began data collection. For the quantitative research, the team at ICES analyzed existing health information to determine the prevalence of POE and neonatal abstinence syndrome and maternal and infant characteristics, such as the mothers' age at delivery and the babies' birthweight. For the qualitative research, we gathered the perspectives of community members through 19 focus groups and 32 individual interviews. We heard from parents, aunties, grandparents, health and social service providers, daycare staff, educators, Elders, and community leaders. We then analyzed this information for key themes.

Over the winter, we presented the preliminary quantitative research findings via teleconference. Communities were pleased to receive this information, found it informative to their efforts, and provided valuable feedback.

Throughout the year, we shared our experience and expertise on supporting First Nation-centred research through a CHILD-BRIGHT webinar and a workshop at the Chiefs of Ontario Annual Health Forum.

In all, it's been a productive year where we effectively engaged and collaborated with participating First Nation communities as partners in research. Children and their families and caregivers were at the centre of all decision-making!





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)

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

2019-2020 PROJECT UPDATE

We have learned a number of lessons about the true value of our research and what matters in pain service delivery to children with severe neurological impairments in the past year, through our work with 40 children in our study. We learned that close and frequent contact between participants and our nurses is particularly effective in providing targeted pain services and ensuring a thorough investigation of pain and irritability of unknown origin. And for those whose pain persists, we are learning that acknowledging and paying continued attention to the child's pain experience makes a difference to the parents. The responses from participants have been overwhelmingly positive.

In January, we welcomed Laesa Kim (pictured below) to the team. In her novel role as Family Liaison, Laesa is connecting families with research and collecting information and stories from those who have been through our pathway, to capture their experiences and their motivation for participating. Embedding a patient-oriented research perspective in our work will strengthen our final analysis by giving us a contextual understanding of parents' experiences caring for their children while engaging with a research project such as ours.



*(Laesa Kim is an author and mom to a medically complex child, allowing her to uniquely make connections and translate between researchers and participants)*

In the last quarter of this fiscal year we developed and submitted an application to trial a drug called gabapentin with participants who continue to experience pain and irritability after all investigations for treatable causes have been exhausted. We hope that trialing this well-known drug will provide evidence for its efficacy, which is currently lacking in our pediatric population.



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

PRINCIPAL INVESTIGATORS



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



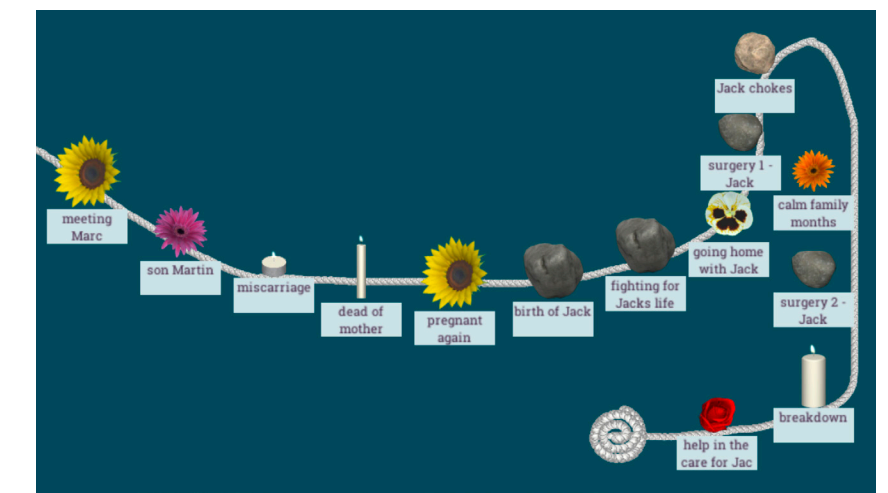
**Lucyna Lach**  
(McGill University Health Centre)

Strongest Families™ Neurodevelopmental Program (Strongest Families™ ND)

2019-2020 PROJECT UPDATE

In April 2019, the Strongest Families Neurodevelopmental study was ramping up and began enrolling families into a pan-Canadian study testing the effectiveness of the Parents Empowering Neurodiverse Kids online parenting program. With over 250 families currently taking part in the study, we are more than halfway to our recruitment goal and continue to work with our Parent Advisors to get the word out to families who may benefit from taking part in the study.

This year also saw the beginning of a new and exciting project entitled "Life Beyond Trauma", a 1-on-1 online health program for parents of neurodiverse children who have experienced trauma associated with their children's health and well-being. Elisa Kaltenbach, PhD, an expert in Narrative Exposure Therapy, arrived from Germany to coordinate the project. A second Parent Advisory Committee was established whose members contribute their expertise to all phases of this project, including development of program materials, study design, spreading the news about the study and interpretation of the results.



*(Life Beyond Trauma: Parents use the lifeline application to depict their path of life with symbols representing joyful and challenging events)*



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)

## Jooay App: Promoting Participation in Leisure

### 2019-2020 PROJECT UPDATE

The Jooay community grew by leaps and bounds in 2019-2020! Our Jooay App currently lists about 2,000 adapted and inclusive activities across Canada, helping over 3,000 families of children and youth with disabilities, clinicians, and educators to find leisure activities that can help them improve their health and have fun, too.

“We were excited to engage a new youth as a patient-partner in our research group. **Jess Silver** leads a non-profit organization, Flex for Access Inc., that promotes inclusive fitness, and we took part in its social media and awareness events.”



This year, we initiated several new partnerships with like-minded organizations to help improve inclusion in the community at large. We also continued to build partnerships with key Quebec leisure organizations and with families of children and youth with disabilities in multiple community events.

Our project has received interest internationally. In June 2019, at the United Nations Conference of the States Parties on the Convention on the Rights of Persons with Disabilities (CRPD), the Jooay App was mentioned by the Canadian Minister of Disability, the Hon. Carla Qualtrough, as one of the key strategies in Canada to promote the participation of children with disabilities in sports and leisure. The Canadian Public Health Association also introduced Jooay as one of the 3 promising practices in Canada which promote physical activity.

More and more, we are connecting with our community online. Our Facebook group, Community Connecting to Play, now has 175 members, and 891 people follow our Instagram account. During the pandemic, we have shifted our efforts to list online inclusive leisure activities on the app and Facebook group that children and families can do from home. We look forward to continuing to grow the Jooay community in the next year!



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: Treatments to Improve Emotional and Behavioural Self-Regulation

### 2019-2020 PROJECT UPDATE

Our team has been busy this year! In addition to continuing to recruit children with attention deficit hyperactivity disorder, in 2019 we began recruiting participants with autism spectrum disorder or congenital heart defects. We have enrolled 110 participants total thus far. We are primarily recruiting at SickKids; this past year, we also began recruiting at Holland Bloorview and at the Centre for Addiction and Mental Health, which will allow two of our co-investigators, Evdokia Anagnostou and Stephanie Ameis, to refer new potential participants to our study and increase our reach.

Two teenage partners with lived experience bring an important youth perspective to our work. They provide us with vital youth input relating to engagement in our work and the usability of the intervention we are investigating. Thanks to their feedback, we have explored new research ideas.



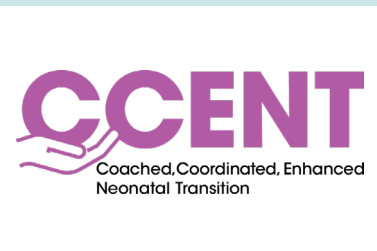
In the fall, we also hosted a webinar alongside two of our youth patient-partners: Austin and Noam. This was a highly valuable experience for all of us. Over the summer of 2019, we also welcomed a summer student, Angela Dou, who engaged fully in the CHILD-BRIGHT summer training content and was a great addition to our team.



(Victoria Lishak [Fellow], Rob McCready, and Noam McCready)



(Austin Cosgrove, Phoenix Cosgrove, and Susan Cosgrove)



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)

Coached, Coordinated, Enhanced Neonatal Transition (CCENT)

2019-2020 PROJECT UPDATE

CCENT is piloting a new way to support and empower families as they transition home with their baby from the neonatal intensive care unit. This year was a big one: we launched our study at all seven of our hospital sites and recruited 156 participants, or approximately 70% of our target of 225 participants. We completed the pilot and feasibility study at Sunnybrook and CHEO and are currently writing up the results.

We have started interviewing participants who received the intervention (at their child's 12-month follow-up appointment), and they are telling us how much they appreciated their interactions with the nurse navigator. Nurse navigators provide support through: 1) parental coaching and psychosocial support within an Acceptance and Commitment Training (ACT) framework, 2) care coordination, and 3) education about caring for a medically complex infant.

Participants have expressed gratitude over the presence of the nurse navigator and the ACT sessions that were offered to them: "Those ACT sessions were the most helpful," one parent indicated. "The strategy really helps (me) to step back and just take it a day at a time, and just focus on now, focus on what you have right now, and [...] get out of that real anxiety".

As the majority of our study sites have switched to virtual recruitment due to COVID-19, we are continuing to offer our intervention to eligible participants.



(Maggie-Lis Jensen)

*"My hope is that this project helps parents feel secure and safe. I can imagine how stressful it is for parents when their babies are hospitalized, and how hard it is to make time for the parents' mental health."*



**Youth partner Maggie-Lis Jensen, 15**



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)

BRIGHT Coaching

2019-2020 PROJECT UPDATE

This year, we made great strides in recruiting parents of preschool children with emerging developmental delays and in delivering our coaching program to participants.

In March 2020, we reached the halfway mark in our recruitment goal of 350 participants, 20 per cent of whom are fathers. Our parent advisors were instrumental in preparing recruitment materials, including a video about the program.

Participants who complete our program report high levels of satisfaction. One participant shared: "It improved my daily life; I was able to talk about things. When I went to appointments I wasn't lost, I was able to voice my opinion."

To share what we learn as we conduct research, in 2019-20 we published:

- Our research protocol, including a description of our randomized control trial
- A systematic review of the available evidence on the effectiveness of health coaching for parents of children with disabilities
- An assessment of our coaches' fidelity in delivering the program using our CO-FIDEL (COaches Fidelity in Intervention DELivery) rating tool
- An assessment of patient engagement from researcher and parent advisor perspectives, using the Public And Patient Engagement Evaluation Tool (PPEET).

Following our use of the PPEET, the CHILD-BRIGHT Measuring Patient Engagement Working Group implemented the tool to evaluate engagement in the network at large.





We developed and are now 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)

## READYorNot™ Brain-Based Disabilities Project

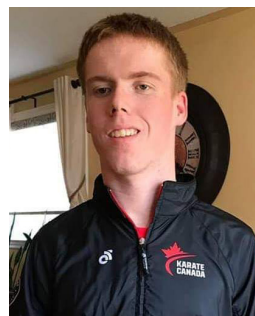
### 2019-2020 PROJECT UPDATE

To help youth with brain-based disabilities (BBD) prepare for the transition from pediatric to adult health care, we developed the MyREADY Transition™ BBD App in partnership with patients, families, health care stakeholders, and our industry partner 360Medlink.

We have collaborated closely with our Patient and Family Advisory Council (PFAC) since 2017. In 2019-20 we prepared a randomized control trial to see if there are benefits to using the app. The PFAC, which counts five young people among its members, was instrumental in helping the trial take shape.

The PFAC:

- Shared testimonials about what this research means to them, which were featured in recruitment videos
- Partnered on the design and content of reference handouts
- Co-facilitated our consultation with the Alberta Child and Youth Advisory Council (CAYAC) about encouraging youth participation in research and explaining concepts like study design, randomization and control group in lay language
- Provided tips for social media recruitment and virtual study visits to enrich participant experience
- Co-developed a presentation for the 2020 CHILD-BRIGHT Virtual Symposium about engagement experiences.

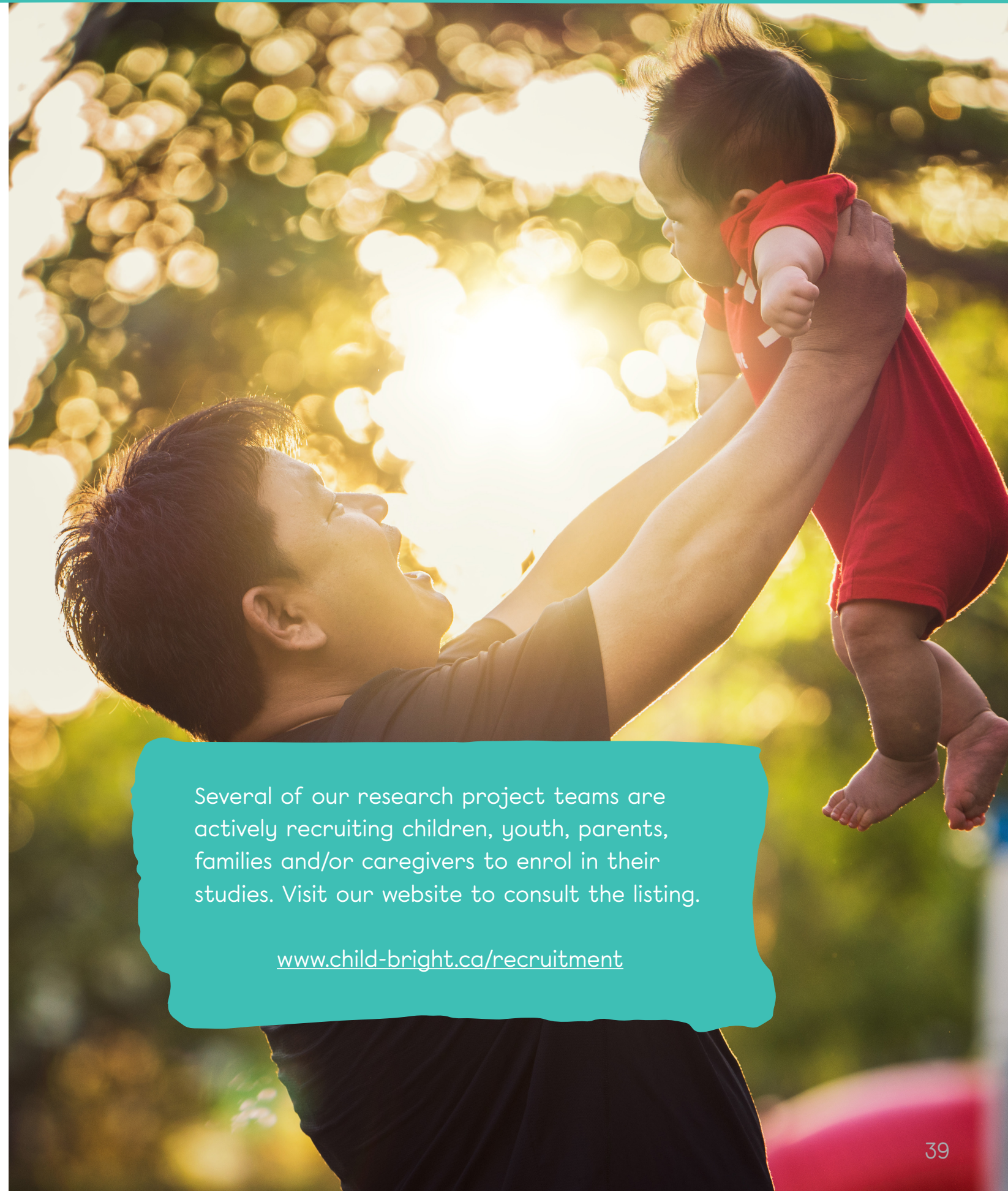


(Kyle Chambers)

*"I am a patient-partner in this research project. I sit in on PFAC meetings and give my opinion from a patient's point of view on how to go forward with certain tasks the PFAC team is doing. I also help to recruit people who qualify for the brain-based disabilities trial on social media, and by sharing our recruitment materials."*



**Youth partner Kyle Chambers, 19**



Several of our research project teams are actively recruiting children, youth, parents, families and/or caregivers to enrol in their studies. Visit our website to consult the listing.

[www.child-bright.ca/recruitment](http://www.child-bright.ca/recruitment)

# Network Services



## Data Coordinating Centre (DCC)

We help CHILD-BRIGHT research project teams develop secure, reliable, and rigorous systems for the collection, analysis, and reporting of study data.

Over the past year, we worked closely with eight CHILD-BRIGHT research teams to support their study-specific data management needs. Of these eight teams, three also required oversight from a network committee called the CHILD-BRIGHT Data Safety Monitoring Board (DSMB). The DSMB meets twice a year to review the safety and effectiveness of trials. For example, the DSMB ensures the safety of trial participants by monitoring whether there are any side effects to the treatments being tested. We support the DSMB in this process by consolidating data from the project teams and generating reports that the DSMB reviews.

This year, we participated in a new network task force to help plan a blog series on secondary data use with PolicyWise for Children & Families (for more on this series, see p. 23). This series, scheduled to launch in June 2020, explains and delves into topics relating to research data use.

We worked with members of the Health Economics service team to support their collection of high-quality data that can be analyzed, disseminated, and implemented into policy and practice.



(Pictured, left to right: DCC members Maryna Yaskina, Amanda Newman, Rick Watts, Pamela Marples, and Shana Rimmer)

We also worked with the CHILD-BRIGHT Central Office team to support their data management needs related to network membership, surveys, and annual reporting.

We aim to help network members and the public better understand issues surrounding data, and we look forward to engaging in more conversations around this topic in the next year!

## Health Economics

Our team provides ongoing support for the development and implementation of economic evaluations for multiple projects within the network. We evaluate the cost-effectiveness and cost-utility of emerging technologies, interventions, treatments, and services for a range of pediatric neurodevelopmental disorders geared at improving the quality of life of children and their caregivers.

At the project level, we help teams use tools that measure both the burden of illness and health-related quality of life for children and caregivers. For example, in the SPORT trial, we are asking participants about their abilities, activities, and emotions before and 6 months after participating in the camps to see whether this intervention improves quality of life. We also design and adapt tools for measuring resources used by families. For example, with the Mega Team project we ask families about their use of health services such as a psychologist or social worker, and we collect detailed information on the child's participation in school and recreational activities. At a broader network level, we're hoping to combine data from multiple CHILD-BRIGHT studies to gain a better understanding of the quality of life and resource use of Canadian children and youth with brain-based developmental disabilities.

This past year, Health Economics co-lead Wendy Ungar offered a network-wide webinar on Economic Evaluation in Child Health (for more on the network's webinars, see p. 46). This webinar provided an overview of the principles of economic evaluations in children's health and explored an example of pediatric economic evaluation in Autism Spectrum Disorder.

A graphic for a webinar. On the left is a circular portrait of Wendy Ungar, a woman with curly hair. To the right of the portrait, the text reads "Economic Evaluation in Child Health: Autism Spectrum Disorder". At the bottom of the graphic are four logos: CHILD-BRIGHT Network, SPOR (Strategy for Patient-Oriented Research), Children's Healthcare Canada, and Santé des enfants Canada.



## CHILD-BRIGHT trainee making her mark

Every year, CHILD-BRIGHT helps train the next cohort of students in patient-oriented research by enabling our project and program teams to hire trainees for the summer. Students become active members of the research team and explore the concept of patient engagement within the research process. The studentship experience lasts between 12 and 16 weeks, but if former CHILD-BRIGHT summer student Liel Cohn is any indication, the benefits of the learning experience extend well beyond those summer months.

Liel is the first former CHILD-BRIGHT summer student to be published as the lead author in a journal. Her systematic review “[Health Outcomes of Parents of Children with Chronic Illness: A Systematic Review and Meta-Analysis](#)” was published on January 6, 2020 in the *Journal of Pediatrics*. It finds that parents of chronically ill children experience poorer health outcomes than parents of unaffected children, demonstrating a need to screen parents for mood and anxiety disorders, in particular, and develop and put into place targeted interventions to better support caregiver wellbeing.

“I really had little to no research background [prior to beginning the studentship],” Liel explained to us following the paper’s publication in January. “I really was learning everything from the ground up.”

“CHILD-BRIGHT gives a different outlook on how to look at research. It really brings people together to think about how we can together as researchers, given our different values, opinions, and backgrounds, build a more patient-oriented research mindset. I definitely plan on bringing that with me.”

Liel intends to apply to medical school with the hope of becoming a paediatrician. We look forward to seeing her future work!



## Starting work on the CHILD-BRIGHT Policy Hub

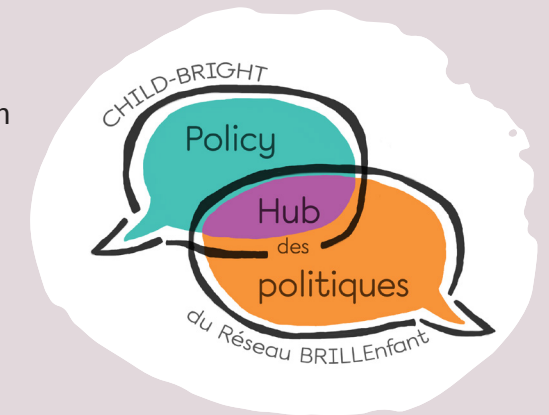
In 2019-2020, CHILD-BRIGHT began work on the creation of a Policy Hub in Childhood Disabilities. The goal of ‘the Hub’ is to gather the unique contributions of families, children, and youth with disabilities and align these contributions with research evidence, all in order to help influence policy developments that are relevant for children with disabilities in Canada.

Creating spaces for conversation between policy makers and our CHILD-BRIGHT community is a crucial step in relaying information to policy makers that will help them better understand and respond to children’s and families’ needs.

Our work in connecting our community members with policy makers comes in the context of Canada’s adoption of the Act to Ensure a Barrier-free Canada (Accessible Canada Act) at the federal level in June 2019. The passing of the first-ever legislation to support accessibility was a milestone; it is helping shift the culture relating to accessibility in Canada, as it creates these necessary spaces for interactions with decision makers. It has also created an opportunity for us to continue to advocate for the changes we need—and want to see—in the lives of children with disabilities and their families, including important provisions to ensure that persons with disabilities can exercise their human rights and enjoy full citizenship.

“Hopefully the passing of the first-ever legislation to support accessibility helps to facilitate the creation and implementation of robust accessibility laws at all levels of government. As an adult with a disability who has been waiting eagerly for this legislation, I see this as a huge step!” commented CHILD-BRIGHT Youth & Patient-Partner **Julia Hanes** following the adoption of the legislation.

We look forward to sharing more details about our work on the Policy Hub in the upcoming year!



# Our reach



## NORTH AMERICA

### CANADA



#### ALBERTA



#### BRITISH COLUMBIA



#### QUEBEC



#### MANITOBA



#### NEW BRUNSWICK



#### NEWFOUNDLAND



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# 2019-20 webinars

We invite you to catch up on webinars you may have missed, to meet some of our research team members (including patient-partners, identified with an \*) and learn about their ongoing work.

*Click on the link or 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

### Redefining outcomes of very preterm birth: including the parent's voice in research ([watch it here](#))

Introducing the Parents' Voice Project, spearheaded by the Parent-EPIQ team, and exploring the importance of partnering with parents in research.

*Presenters: Rebecca Pearce\*, Annie Janvier, Thuy Mai Luu, and Anne Synnes*



### Including youth insights in the development of novel and engaging video game-based interventions ([watch it here](#))

Introducing Mega Team as a video game-based intervention for children with brain-based developmental disabilities and strategies for meaningful inclusion of youth input within the design of this novel intervention, study design and implementation.

*Presenters: Jennifer Crosbie, Anne-Claude Bedard, Victoria Lishak, and Noam McCready\**



### Economic Evaluation in Child Health: Autism Spectrum Disorder ([watch it here](#))

Providing basic understanding of the principles of economic evaluations in children's health care.

*Presenter: Wendy Ungar*



\* Patient-partners

## CHILD-BRIGHT Summer Learning Series

### Trust and Teamwork: Best Practices for Collaborative Research ([watch it here](#))

Exploring how researchers and family and patient advisors can build a strong foundation for collaboration.

*Presenters: Kate Robson\* and Julia Orkin*



### Enhancing Participation in Research ([watch it here](#))

Discussing challenges associated with recruiting participants from parent and researcher perspectives, and identifying strategies that increase likelihood of participation.

*Presenters: Donna Thomson\* and Lucyna Lach*



### Available Tools to Develop Capacity for Patient-Oriented Research in BC ([watch it here](#))

Highlighting initiatives that are designed to enhance skills and promote the concept of patient-oriented research.

*Presenters: Colin Macarthur and Pierre Zwiegiers*



### Reciprocity: A Framework for Families and Researchers to Move on a Two-Way Street ([watch it here](#))

Focusing on parent/researcher reciprocity, the practice of exchanging things with others for mutual benefit, within an applied research setting.

*Presenters: Brenda Agnew\*, Heather Shearer\*, and Darcy Fehlings*



### Supporting First Nation-Centred Research & Meaningful Collaboration ([more info here](#))

Introducing some of the key historical, contextual, and ethical considerations when considering research involving First Nation peoples and populations.

*Presenters: Christi Poulette and Jennifer Walker*





# Thank you to our members, partners & collaborators

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 Kettle & Stony Point First Nation  
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 Oneida Nation of the Thames  
 Saugeen First Nation #29  
 Temagami First Nation  
 Walpole Island First Nation

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American Heart Association  
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BC SUPPORT Unit  
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Boston Children's Hospital  
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Canadian Association of Occupational Therapists  
Canadian Cerebral Palsy Registry  
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Canadian Family Advisory Network  
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Canadian Neonatal Follow-up Network  
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Centre for Innovation in Autism and Intellectual Disabilities  
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## Institutional affiliations of our members (con't)

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Children's Hospital of Eastern Ontario  
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College of Nurses of Ontario  
College of Occupational Therapists of British Columbia  
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College of Psychologists of Ontario  
College of Registered Nurses of Manitoba  
Concordia University  
Crisis Prevention Institute  
Dalhousie University  
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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  
ICES  
Indigenous Certification Board of Canada  
Institut de recherches cliniques de Montréal  
International Alliance for Pediatric Stroke  
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Jewish General Hospital  
Kids Brain Health Network  
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Maternal Infant Child and Youth Research Network (MICYRN)  
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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  
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Ontario SPOR Support Unit  
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Chronic Pain Network	Nunavut SPOR SUPPORT Unit
Diabetes Action Canada	Ontario SPOR SUPPORT Unit
IMAGINE-SPOR Chronic Disease Network	Primary and Integrated Health Care Innovations (PIHCI)
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## Meet our financial partners

CHILD-BRIGHT is made possible thanks to a 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.



### PLATINUM PARTNERS (\$1M +)



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



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



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Wondering how we plan to amplify the impact of our patient-oriented research program in future years, to achieve our vision for a brighter future for children with brain-based developmental disabilities?

[Click here to download  
our 2020 CHILD-BRIGHT  
Sustainability Report](#)

