CHILD-BRIGHT Network
Réseau BRILLEnfant

Report to Community

2017-18

As per March 31, 2018

Learning Together

“We’re learning to bring people together.”

To Nhu Nguyen, Operations Director & Corina D’Alesio-Worth, Clerical Assistant

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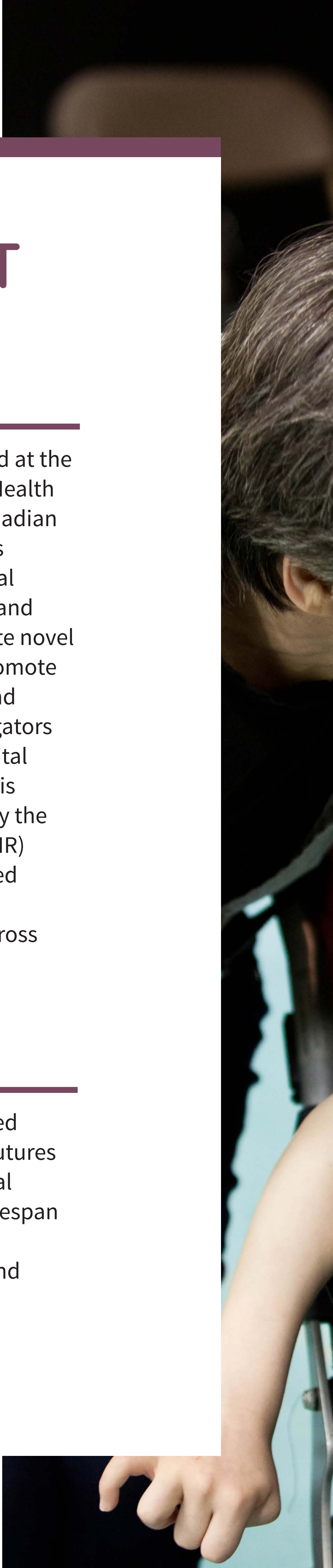


About CHILD-BRIGHT

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 27 generous funding partners from 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.

Join us online to
follow our work!

WWW.CHILD-BRIGHT.CA

Message from Annette Majnemer

CHILD-BRIGHT
Network Director

Dear network members,

As I look back on our second year of activities—our first complete year of operations together as a network—I'm struck by how far we have come! We have learned a great deal by working together and have evolved from a collection of ambitious multi-centre research project teams to a genuine pan-Canadian patient-oriented research network. At CHILD-BRIGHT, we are rapidly learning together how to authentically engage youth and parents into our network's projects and programs, and are working hand-in-hand with researchers, health professionals, educators, and many other stakeholders to reach a common goal. Thank you to all our members, and allow me to share with you some of our most prized accomplishments for this reporting period:

In our research teams

During the past year, all our research project teams have made wonderful progress. Eleven projects received their necessary ethical approvals, 3 projects are preparing for pilot testing, 8 are recruiting participants, and all teams worked to finalize their project database infrastructures. Members from different projects and from across our 3 research themes also grew closer and increased collaborations to enhance research activities and patient engagement.

We have also been working to add a collaboration with First Nations communities, in the form of a 13th network research project. We look forward to telling you more about this next year!

On the training front

In the summer of 2017, we launched our inaugural Summer Studentship Program. We welcomed and supported 6 summer trainees and helped them develop core

> “Together, we’re learning to build a national patient-oriented network.”

Annette Majnemer,
CHILD-BRIGHT
Network Director

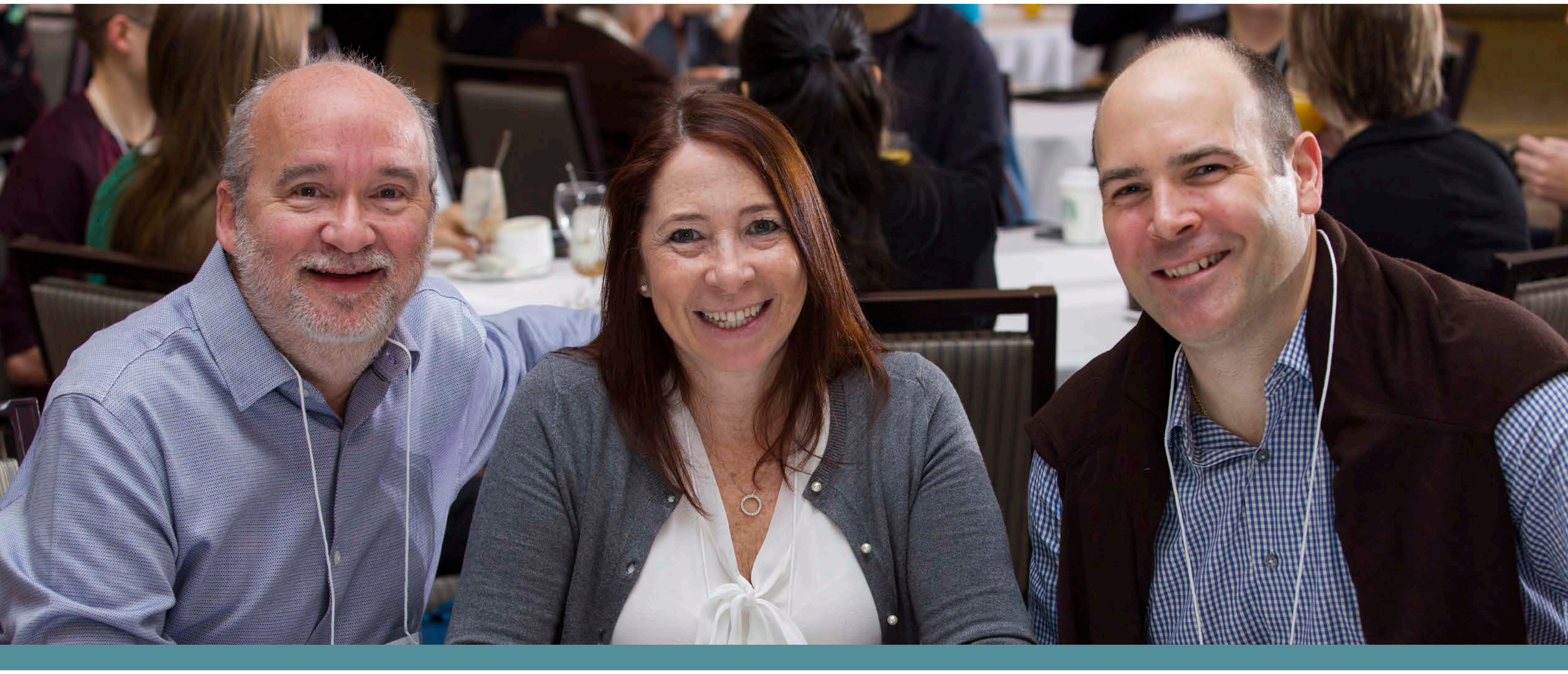
research competencies while also training them about patient-oriented research via an interactive online training program.

We also partnered with the Canadian Child Health Clinician Scientist Program, Ontario Child Health Support Unit, and the BC SUPPORT Unit, to develop online patient-oriented research modules tailored to both patient-partners and researchers in the child health domain. This initiative, called the Patient Oriented Research Curriculum in Child Health (PORCCH), will soon launch its first modules! Through partnerships such as this, and close collaborations with other SPOR networks, we are exploring novel training initiatives and limiting duplicative efforts.

Broadening citizen engagement

Within our Citizen Engagement Program team, we prioritized making engagement opportunities more accessible to the general public. Earlier in our mandate, we identified that there existed a barrier to patient engagement in research projects. Often, engagement depended on pre-existing relationships with investigators, or geographic proximity to research centres. We wanted to improve this at CHILD-BRIGHT so to make opportunities more widely available to all, we created an online matching tool, which we launched in July 2017. So far, 51 patients, youth, and family members have used our new web-based tool to express interest in either applying to one of our posted opportunities, or joining our general patient pool of applicants for future opportunities.

We also organized and held our inaugural annual meeting in November 2017, the Brain-Child-Partners Conference, and were thrilled to gather with our extended team of members to connect, share and co-learn from each other. Thank you to the 302 participants who joined us!



To advance knowledge translation

We launched and held our first Knowledge Translation (KT) Innovation Incubator grant competition this year, to promote and facilitate innovative KT projects in childhood disability. Twelve teams from across Canada submitted applications and in March 2018, we announced that the Child-Sized KT project team, led by Shazhan Amed at UBC, was our first inaugural grant winner! Dr. Amed and her team will develop an innovative online platform to help youth and families share their stories and more actively participate as partners in research. We were thrilled to put together a very diverse review panel for this grant competition, composed of parents of children with disabilities, researchers, clinicians, trainees, youth with disabilities, occupational therapists, and policy makers, all of whom brought their unique set of expertise to this decision-making process.

On the administrative front

At our central office, we continued to work to build efficient communication channels, are fine-tuning our processes and infrastructure, and we also linked up with our peer SPOR networks to share information and to document some of the challenges of our work, to help guide CIHR SPOR on future patient-oriented work. For example, we are documenting challenges that we have observed relating to the administration of patient compensation, and putting forward tangible recommendations that we hope will help guide a future standard approach to patient-partner compensation and expense reimbursement.

Moving ahead together

We are forging ahead on our mandate of defining and implementing patient-oriented research in Canada, with the shared goal of helping to create brighter futures for children with developmental disabilities and their families. Thank you to all our members for helping make this possible. By working together, we are learning from each other and making great strides.

We hope you enjoy reading more about CHILD-BRIGHT's incredible early achievements in this year's *Report to Community*.

Gratefully,

Annette Majnemer

Annette Majnemer

Message from Frank Gavin

CHILD-BRIGHT NETWORK
Director of Citizen Engagement

Dear CHILD-BRIGHT community,

Welcome to our network and to the second issue of our *Report to Community.*

Like many of you reading this document, I am part of a wonderful community of parents of children who live with brain-based developmental disabilities. We know the challenges intimately, but we know even more deeply the very real potential of our children. We are thus committed to contributing our knowledge, skills, and energy to research that will help our children and other children live the best and fullest lives we and they can imagine. As CHILD-BRIGHT's Director of Citizen Engagement and Chair of its Citizen Engagement Council, I am very grateful for the contributions so many of you have already made and for the many gifts that have come from working alongside you. Thank you!

Our community of citizens is growing. As of March 31, 130 patient-partners (mostly parents, but also other family members and youth themselves) were involved in our network, and our numbers continue to grow. We are working alongside researchers, policy makers, and health professionals in many different capacities, to help make research more patient-oriented and to help improve care and outcomes for children, youth, and families like ours across the country.

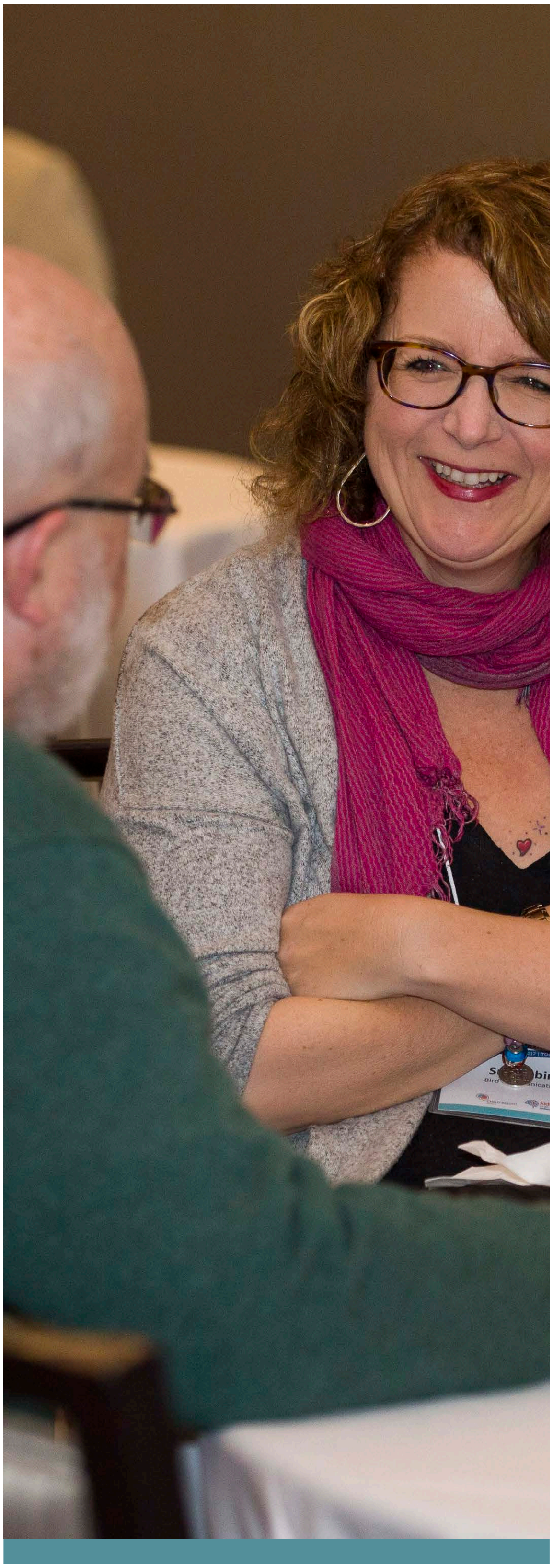
In the past year, we have moved ahead on many initiatives, but two in particular stand out that I want to share with you.

We welcomed a parent mentor

To better support and learn from parents involved in our work, we created a new parent mentor position at CHILD-BRIGHT. Parent members of the Citizen Engagement Council took the lead in defining the role and in assessing and interviewing the candidates. In January, we hired and welcomed Susan Cosgrove in this role. Susan is a mom raising three extraordinary children with brain-based developmental disabilities. In her new role, she will connect

> “We’re learning to engage patients and families in our work.”

Frank Gavin, Director,
CHILD-BRIGHT
Citizen Engagement



and collaborate with parents from all over Canada to learn more about their life and experience with disability in their home provinces and about their needs and experiences as research partners. She will also help us evaluate how their involvement in research is shaping the work of CHILD-BRIGHT. We are thrilled to welcome her to our team!

We are forming a youth panel

We are now on the verge of realizing our goal of forming a youth panel! In the last year, we formed a Youth Engagement Steering Committee and mandated this team to help establish the mandate, terms, and priorities of this future youth panel. Based on their work, we can report that a CHILD-BRIGHT National Youth Advisory Panel is now in its infancy. We have recruited several youth with lived experience with brain-based developmental disabilities and expect that all the members of the panel will be in place by summer 2018. One of the panel members will join the Citizen Engagement Council along with a youth member of the research teams.

As one of only seven nationally funded Strategy for Patient-Oriented Research (SPOR) networks funded under CIHR, citizen engagement is key to our success, and we are always looking for new members to join us! So as you read this report, whether you are a patient, family member, researcher, educator, health professional, or any other stakeholder, please consider how you can contribute to our journey.

We need your voice in our network to continue learning together!

I look forward to hearing from you,

Frank Gavin

“I’m learning to voice my opinion and thoughts.”

Katie Suggitt
& dad Richard

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).

In Canada, as many as 850,000 children under the age of 14 are living with a brain-based developmental disability and face life-long challenges with mobility, language, learning, socialization, and/or self-care that impact the quality of their lives.

1 in 10

children are born premature

1 in 13

children have learning disabilities

1 in 20

children have developmental disabilities

1 in 68

children have autism spectrum disorder

1 in 500

children have cerebral palsy

Our Governance

At CHILD-BRIGHT, we have put in place a lean governance structure, designed to maximize cooperation between network staff, researchers, patient-partners, and stakeholders. Patient-partners serve in all network program & service teams, and hold key positions on network committees. Central office team members are embedded in each program, and have direct and timely access to the Executive Committee. And our advisory bodies are linked to our Steering Committee via one Executive member and meet at least quarterly. We value this close and efficient collaboration!

Citizen Engagement Program ●

Training Program ●

Research Program ●

Knowledge Translation Program ●

Data Coordinating Centre ●

Health Economics ●

Programs & Services

Oversee and carry out patient-oriented work

Data Safety Monitoring Board

Central Office Team ●

Management

Responsible for network logistics, resources and infrastructure

Executive Committee ●

Expert Advisors

Consult and provide guidance to the executive

Citizen Engagement Council ●

Partnership & Sustainability Advisory Council

International Scientific Advisory Committee

Executive

Hold ultimate accountability & decision authority

Network Steering Committee ●

● Includes patient-partners

> “We’re learning to work together.”

Donna Thompson,
Patient-Partner
& Nathalie Major-Cook,
Principal Investigator

The Importance of Engagement

To successfully accomplish our goal of making patient-oriented research a reality in Canada, we track patient engagement in all aspects of our work, monitor its impact, and share what we have learned with the Canadian Institutes of Health Research, as part of Canada's Strategy for Patient-Oriented Research (SPOR).

What do we mean by patient-oriented research?

Patient-oriented research is an active partnership of patients, researchers, health professionals and decision-makers in research so as to build a sustainable and accessible health care system that optimizes the health of Canadian citizens. At CHILD-BRIGHT, we aim to improve outcomes for children with brain-based developmental disabilities and their families.

Who do we consider 'patients'?

Within the SPOR family, the term 'patient' is overarching and includes individuals with personal experience of a health issue, as well as their caregivers, including family and friends. At CHILD-BRIGHT, we also use the term 'patient-partners' to reference all 'patients' actively involved in one of our projects, programs, committees or work.

Patients provide unique expertise on their everyday experiences living with the condition, and can share their experiences with the health care system and with providers of care. They influence everything we do at CHILD-BRIGHT, for example, the design of our studies, the outcome measures we use, and the interpretation and use of our findings.

How do we measure engagement?

We track and classify engagement from all stakeholders involved in our network according to four levels, as shown on our diagram to the right. It is our hope that as many members as possible will not only engage in our work, but reach the Champion level and lead their own initiatives to improve outcomes for our target population.

130

patient-partners currently involved in our work

173

training event attendees

13

training events

Levels of Engagement

1 HELP US RAISE AWARENESS

- Stay informed about CHILD-BRIGHT through the website (child-bright.ca) and through the CHILD-BRIGHT newsletter
- Help raise awareness by following CHILD-BRIGHT on social media

2 PARTICIPATE AND LEARN

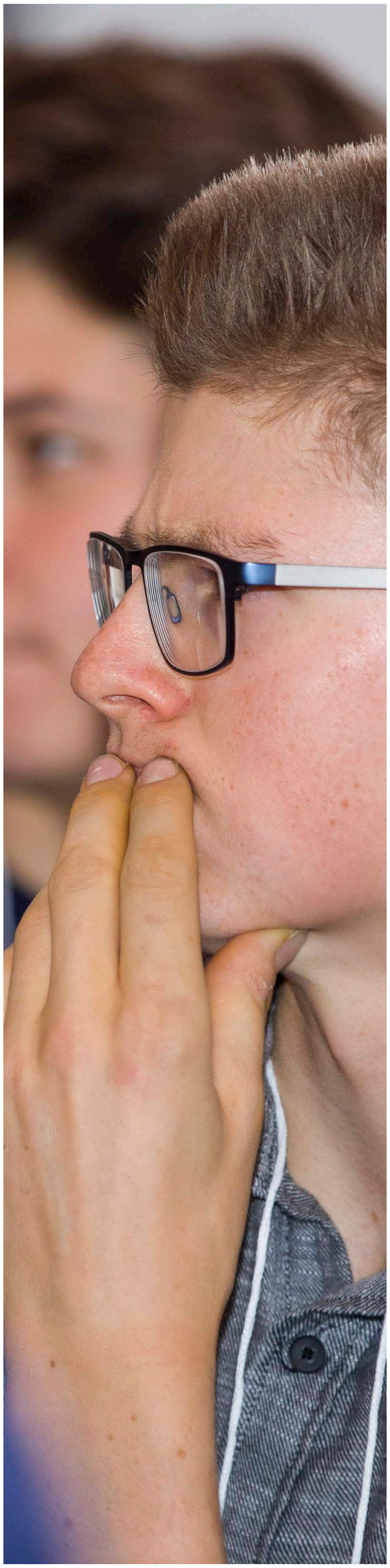
- Learn about CHILD-BRIGHT by attending CHILD-BRIGHT events in person or online (training sessions, webinars, scientific cafés, CHILD-BRIGHT conferences, etc.)
- Participate (or facilitate my child's participation) in a CHILD-BRIGHT research study
- Participate by submitting questions, comments or ideas to CHILD-BRIGHT and/or by sharing or commenting on CHILD-BRIGHT social media posts and website content

3 CONTRIBUTE & PARTNER WITH US

- Contribute by responding to CHILD-BRIGHT surveys or by attending a focus group
- Contribute by submitting content destined for CHILD-BRIGHT publications (website, newsletter, report to community, etc.)
- Get involved in CHILD-BRIGHT events as a sponsor or a speaker
- Collaborate as a team member (patient-partner, trainee, researcher, employee, other) on a CHILD-BRIGHT research project, or as a committee member in a network program

4 CHAMPION OUR CAUSE

- Lead initiatives that help CHILD-BRIGHT achieve and grow its mandate and visibility, as a principal investigator, mentor, chairperson, or funding partner



Citizen Engagement

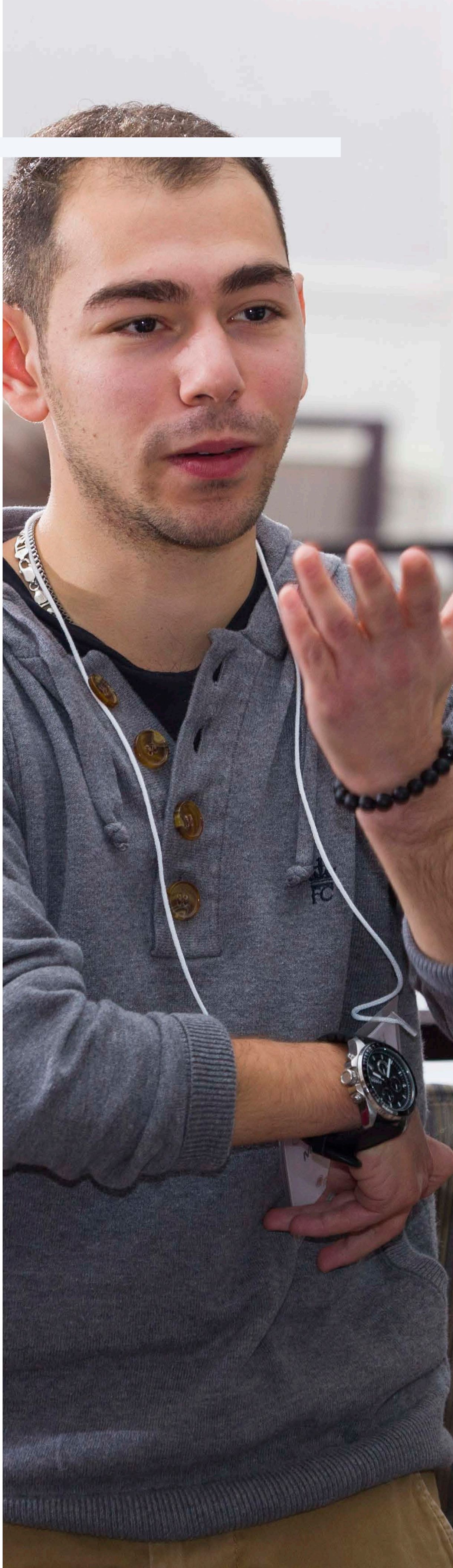
As a network working under Canada's Strategy for Patient-Oriented Research (SPOR), we aim to engage all people touched by brain-based developmental disabilities, especially patients and families, as meaningfully as possible in all aspects of our work. The Citizen Engagement Program team leads this effort. Here is an overview of our activities this year.

Launched a community engagement matching tool

In August 2017, we launched a community engagement matching tool. This new network tool helps us advertise opportunities for patient involvement in our programs and research projects, and subsequently match interested citizens to these opportunities. All candidates who apply but are not matched are added to our general network pool of candidates and are invited to contribute to other activities across the network, as they become available, such as joining a review panel to evaluate poster abstracts, providing feedback on network publications, or helping us select an accessible venue.

Hired a parent mentor

We hired a Parent Mentor. In her new role, Susan Cosgrove will collaborate closely with parents from our network living throughout Canada to learn about their unique experiences, discuss how parents and patients can shape the future of research, and help ensure they are engaging optimally with our network.



Community Matching Tool

51

new applicants in our general pool

6

identified as youth with brain-based developmental disabilities

80%

identified as family members or caregivers

Developed a stakeholder engagement framework

As a network working under Canada's SPOR mandate, we must demonstrate to CIHR that we are meaningfully engaging stakeholders in our work. To document stakeholder engagement, and better illustrate their growing level of engagement and commitment over time, we developed a 4-level stakeholder engagement framework. Learn more about this on p. 19.

Updated network guidelines & committee terms of reference

This year, our Citizen Engagement Council completed a substantial revision of its terms of reference and reviewed our network's patient compensation guidelines to further clarify the framework under which our network institutions, researchers, patient-partners, funding partners and other stakeholders work together.

Rallied expertise to form a youth panel

We are also in the process of building a CHILD-BRIGHT National Youth Advisory Panel. To this end, we have formed a temporary Youth Engagement Steering Committee that is mandated to establish the future youth panel's mandate and objectives. They are also helping us identify youth leaders in Canada that can best represent our diverse population of youth with brain-based developmental disabilities.

Brain-Child-Partners Conference 2017

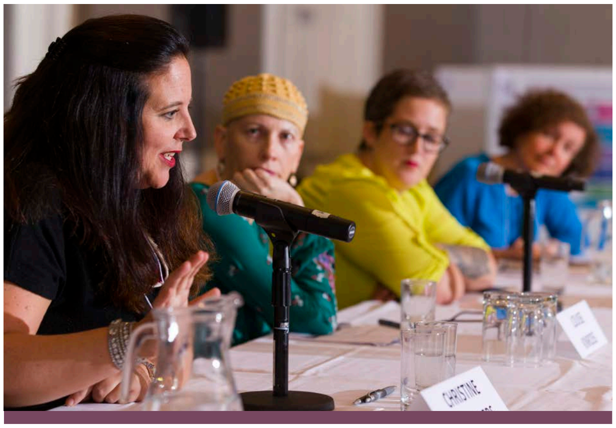
From November 6 to 8, 2017, researchers, youth, family members, health professionals, educators, policy makers, and all interested in partnering to advance research in brain-based developmental disabilities gathered in Toronto for our first national conference, the Brain-Child-Partners Conference 2017.

Co-hosted with Kids Brain Health Network, the Brain-Child-Partners Conference brought together 302 people touched by childhood neurological disabilities and, under the theme of 'Reciprocity', we listened, collaborated and exchanged ideas, with the goal of positively impacting each other's work.

The event programming was designed to encourage an open and reciprocal exchange of ideas, and we were thrilled to see this unfold! Active dialogue took place on topics such as advances in brain research, mental health, helping families navigate transitions, patient engagement, effective communication channels, the cooperation between basic and applied research, and so much more.

Young researchers and trainees also presented their work, met and exchanged with experts in their fields, and took part in a poster competition.

Thank you to all who attended! We look forward to continuing our collaborations together!



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

CHILD-BRIGHT Network

kids brain health network

$312,200

invested to host our event

$150,900

in revenues from registrations, sponsorships and exhibitors, to help fund our patient-oriented work

40

youth/family attendees whose registration, travel and accommodation expenses were fully covered

Knowledge Translation

The Knowledge Translation Program is developing strategies and research methodology to effectively translate the results of our research findings to families, to health care professionals, and to society at large.

Welcomed new collaborators

We welcomed trainees Jonathan Lai, Zachary Boychuck (Ph.D. candidate) and Miriam Gonzalez as members of the Knowledge Translation (KT) committee this year. They contribute to our goals of engaging policy makers and hard-to-reach populations, such as recent immigrants to Canada, in the network. Our committee convened five times this year, one of which was an in-person meeting during the Brain-Child-Partners Conference. This meeting allowed us to work towards clarifying our relationship with CHILD-BRIGHT research projects, recognizing how we can identify barriers to meaningful stakeholder engagement, how we can showcase success in stakeholder engagement, and how we can consolidate best practices through:

- KT support and expertise
- Advancing the science of KT through research studies
- Sparking and supporting innovative KT activities.

Overview

2

webinars

1

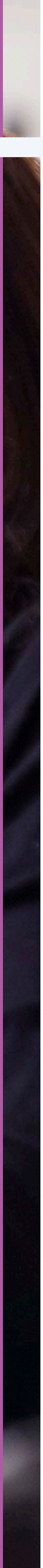
BRAINstorm workshop at the Brain-Child-Partners Conference

13

committee members

$20,000

dedicated to fund an innovative knowledge translation project



Launched a KT grant competition

Our program fostered innovation in KT this year by launching our inaugural Knowledge Translation Innovation Incubator grant competition. We led a webinar in September and a workshop at our Brain-Child-Partners Conference in November to explain and convey the importance of innovation and how a research team could go about developing an innovative KT project for this competition. Read more about it on p. 26.

Developed new tools

To assist the development of an integrated Knowledge Translation (iKT) approach, members of the KT committee created a tracking tool to support the planning of iKT activities. This tool is meant to help CHILD-BRIGHT research projects in better articulating the goal of an activity in terms of the KT impact they aim to achieve, their target audience and stakeholders involved. Once completed, this tool will help disseminate best practices across the network.

Shared our expertise

In collaboration with the Method Development platform of the QC SPOR SUPPORT Unit, we prepared and submitted a manuscript and a guidance sheet to a scientific journal based on our work to perform the rapid transcultural adaptation of a questionnaire from English to French. The written outcome of our collaboration is intended for other researchers who are interested in conducting this type of adaptation. The purpose of the questionnaire that we adapted is to track the progression of stakeholder engagement in CHILD-BRIGHT research projects and outcomes at the network level.

KT Innovation Incubator Grant Competition

To promote and help support innovative knowledge translation projects in childhood disability in Canada, CHILD-BRIGHT launched a KT Innovation Incubator grant competition in 2017, awarding up to $20,000 to a team dedicated to improving life outcomes for children with brain-based developmental disabilities and their families.

Our inaugural winning team, selected from 15 submissions received from teams across Canada, was Child-Sized KT, a team composed of researchers, clinician-scientists and a family partner based at the BC Children's Hospital. Child-Sized KT, in partnership with children, families, and health professionals, will develop an online platform to help youth and families actively participate as partners in research. More specifically, the team will:

- Document child and family partner stories about the value of research engagement
- Gather feedback from children and their families, and assess the usefulness of the stories in motivating child and family research engagement
- Co-design an online family portal that uses these stories and gaming features (e.g. point scoring, badges, missions, communities) to motivate children and families to learn about health research, why their involvement is important, and how to access research opportunities.

Child-Sized KT Team


Stephanie Glegg


Rosa Livingstone

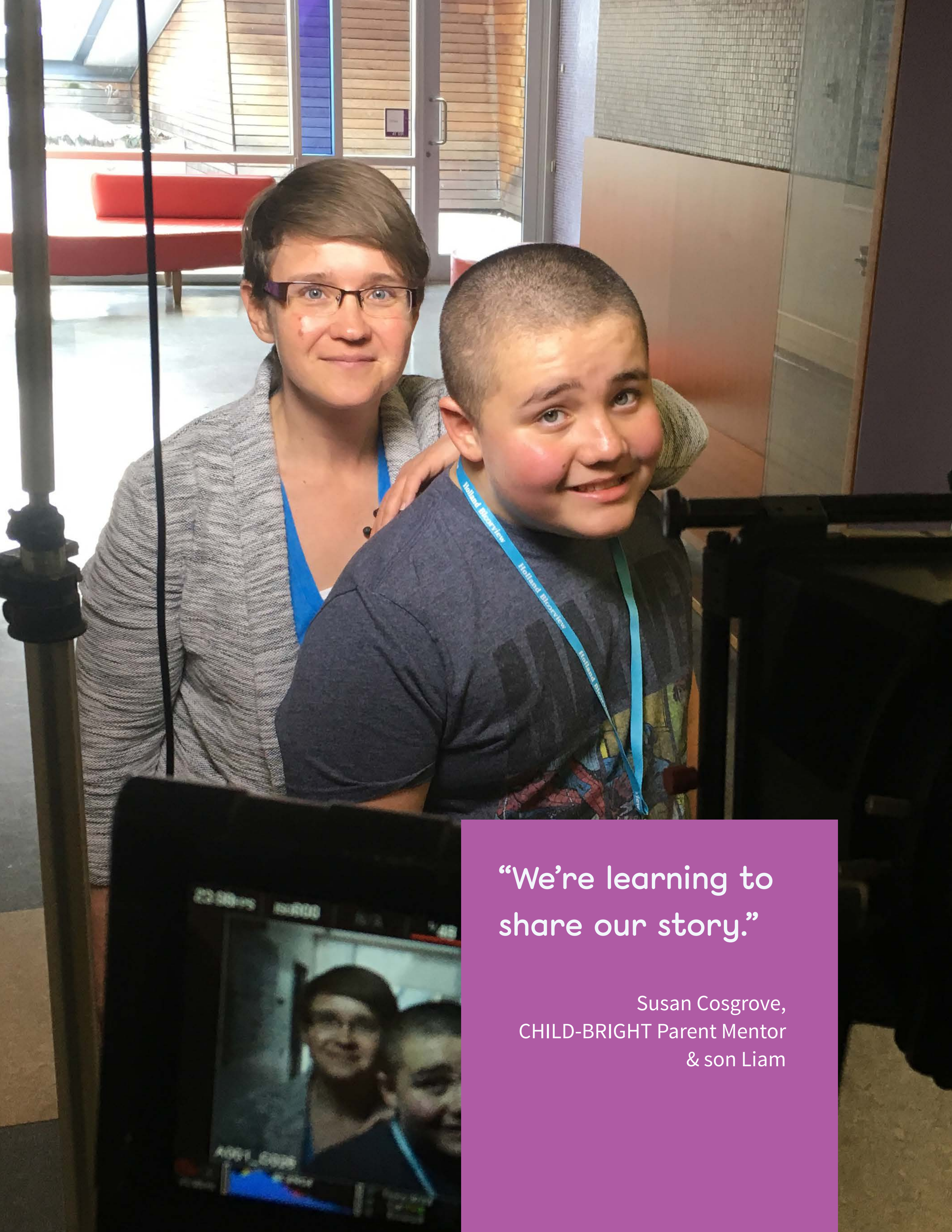

Elodie Portales-Casamar


Shazhan Amed


John Jacob


Dawn Mount


Ian Pike



“We’re learning to share our story.”

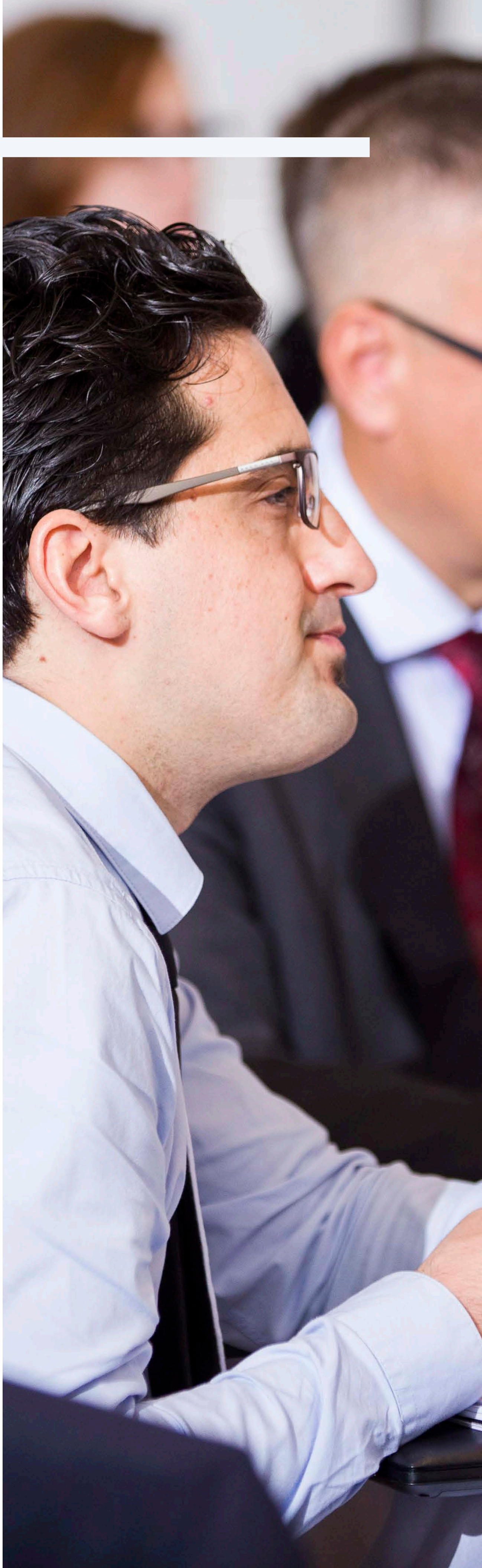
Susan Cosgrove,
CHILD-BRIGHT Parent Mentor
& son Liam

Training

The Training Program team is responsible for establishing the training and mentoring agenda of the network. We engage with multiple stakeholder groups including patients and their families, researchers, and policy makers, to foster a culture of patient-oriented research that will positively affect not only the future of health research in Canada, but lead to improved outcomes for patients and their families.

Increased capacity for patient-oriented research in Canada

In collaboration with other networks doing patient-oriented work, we facilitated 13 Patient-Oriented Research (POR) training events this year; 7 web-based learning events, and 6 in-person workshops. A total of 173 participants attended these sessions, which were geared to different groups in Canada. The sessions generated fruitful discussions around POR and helped us identify crucial improvements needed to enhance engagement with our training curriculum, such as responding to ongoing feedback, and offering alternate formats of delivery such as self-paced online sessions.



We invest in patient-oriented training

$20,500

dedicated to Summer Studentship Program training

$17,500

dedicated to supporting our PORCCH partnership

$7,500

dedicated to trainee travel support

Built collaborative partnerships

Developing partnerships and learning from the experiences of other groups is a fundamental part of our program. This year, thanks to an initiative with the BC SUPPORT Unit, Ontario Child Health Support Unit (OCHSU) and the Canadian Child Health Clinician Scientist Program (CCHCSP), we are supporting the development of a Patient Oriented Research Curriculum in Child Health (PORCCH), an online training curriculum in patient-oriented research that has a strong pediatric focus. We are also collaborating with other CIHR chronic disease SPOR networks to develop a Community of Practice around effective training strategies and opportunities, for example, the networks are currently developing a centralized repository of relevant training materials that will be a comprehensive resource for patients and their families.

Started training the next generation of researchers

This year, we launched our inaugural Summer Studentship Program. As part of this summer program, we provided 6 students the opportunity to work on network-sponsored research projects and gain valuable research experience. We also initiated them to patient-oriented research through a series of webinars designed specifically for them, to better educate them on POR and how it can be implemented in a research project.

We also welcomed trainees within our projects, programs and committees throughout the year, including at our 2017 Brain-Child-Partners Conference, where we provided them with custom training, development, and networking opportunities. Meet our trainees and 2017 Summer Studentship Recipients on p. 30-31.

Training the Next Generation of Researchers

We are proud to provide training opportunities in patient-oriented research to future generations of researchers, health professionals and leaders. Through a series of online, in-person, and experiential learning opportunities, we are helping drive the necessary cultural shift towards patient involvement in all aspects of research moving forward.

Meet our 2017 Summer Studentship Recipients, who joined our network committees or research teams for a 12 to 16-week period over the summer, and our 2017-18 cohort of trainees, future researchers who are working alongside us to advance Canada's patient-oriented research mandate.

SUMMER STUDENTSHIP RECIPIENTS

CHELSEA YEO

Strongest Families™ ND Project

SHANNON MORRISON

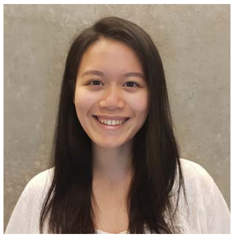
Strongest Families™ ND Project

SIMON ROBINS

PIUO Project

LIEL COHN

CCENT Project



ELISA LAU

IMAGINE Project

BRETT PAFFRATH

SPORT Project

CHILD-BRIGHT TRAINEES

SPORT Project

HSING-CHING CHERIE KUO (Postdoctoral Fellow)

LAURAN COLE (MSc Candidate in Neuroscience)

READYorNot Project

LINDA NGUYEN (Doctoral Candidate in Rehabilitation Science)

SHARON HOU (Doctoral Candidate in Clinical Psychology)

"I was interested in joining CHILD-BRIGHT to contribute to the development of an evidence-based mobile app for youth in transition to adult care. My experience at CHILD-BRIGHT will inform my competency as a scientist and practitioner."

Jooay Project

PAUL YEJONG YOO (Doctoral Candidate in Rehabilitation Science)

CHRISTINA SOOKLALL (MSc Candidate in Rehabilitation Science)

Knowledge Translation Committee

MIRIAM GONZALEZ (Postdoctoral Fellow)

JONATHAN LAI (Postdoctoral Fellow)

"I'm interested in using integrated Knowledge Translation to build a learning health system for children and families. At CHILD-BRIGHT, I will work with leaders in this field."

IMAGINE Project

NICOLE LIANG (BSc Candidate in Integrated Science)

BRIGHT Coaching Project

TATIANA OGOURTSOVA (Postdoctoral Fellow)

"I hope to learn more about patient-oriented research & knowledge translation. The application of these two methods could lead to advancement in current clinical practices and could optimize patient-related outcomes."

Research

CHILD-BRIGHT's pan-Canadian research program team is studying new diagnostic tests, therapies, service models, and technologies to optimize the physical and mental health of Canadian children with brain-based developmental disabilities as well as the well-being of their caregivers and families.

Collaborated across research teams to maximize impact

Our network's 12 research projects fall under 3 research themes: BRIGHT Beginnings, BRIGHT Supports, and BRIGHT Futures (see p. 34). This year, we prioritized enhancing collaborations within each theme.

The research teams from each theme met a total of 12 times this year. A major topic of conversation was whether projects were measuring the same variables. Teams found that they were all collecting participant, family, and demographic information. As a result, the Research Program decided to standardize these collection forms for the projects.

Collecting profile and demographic information in a uniform way across the network will allow us to leverage the size and impact of CHILD-BRIGHT projects and help advance research for children with brain-based developmental disabilities across Canada.

Work is under way!

8

research projects have begun recruiting patients

62

Patient-partners contribute to our 12 research projects

5

research projects have put in place Parent Advisory Groups

Made scientific peer reviews more patient-oriented

In Year 1, the CHILD-BRIGHT projects were anonymously reviewed by colleagues before being approved. We recognized that this review process could be made more patient-oriented by incorporating parents.

This year, we adapted our peer review process to include a parent reviewer. This process was adapted from colleagues at Holland Bloorview's Research Family Engagement Committee. It was positively received by everyone and is something to build upon in the future.

Leveraged the expertise of partners

In January, Thierry Lacaze, Network Lead of KidsCAN Trials, joined our BRIGHT Beginnings theme meeting to share strategies for strengthening Canada's clinical trial environment. We value collaborations such as this, which help us strengthen our own clinical trial environment.

Started incorporating sex- and gender-based analyses into research

SPOR recognizes the importance of incorporating sex- and gender-based analyses into research. This means tracking variables such as sex (a biological trait) and gender (a social construct) in research projects. At a more advanced level, it means attempting to answer bigger questions, such as the differential roles that mothers and fathers play in caring for their child, or the influence of the sex and gender of the person delivering an intervention. In the last year, with Nancy Poole, Sex and Gender expert at CHILD-BRIGHT, we started tackling these questions within our teams.

Our Research Themes

BRIGHT Beginnings *(5 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 five 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.

> “We’re learning to combine efforts across the research field.”
>
> Steven Miller, CHILD-BRIGHT Co-Director & Research Program Lead

> “We’re learning the value of communicating research activities to stakeholders in real-time.”

Christine Marcotte,
Communications Manager &
Alan Cooper, Research Coordinator

2017-18
Research Project Updates

Status of Research Projects

Although our projects are distinct from each other, they share common milestones and deliverables. The following table shows the progress of our 12 projects as of March 31, 2018.

STEP 1: REGULATORY AND ETHICS APPROVAL

Research projects that involve human participants require approvals from research ethics boards. Four of our 12 projects are clinical trials, that is, they are evaluating the safety and effectiveness of a new treatment or intervention, and these clinical trials require additional regulatory approval from Health Canada. These approvals ensure that participants are treated fairly and that studies follow appropriate procedures. This year, 11 CHILD-BRIGHT projects received ethics approval, and the 4 projects (MATCH, Metformin in CP, SPORT, and MEGA TEAM) classified as clinical trials were approved by Health Canada.

STEP 2: PARTICIPANT RECRUITMENT AND ENROLLMENT

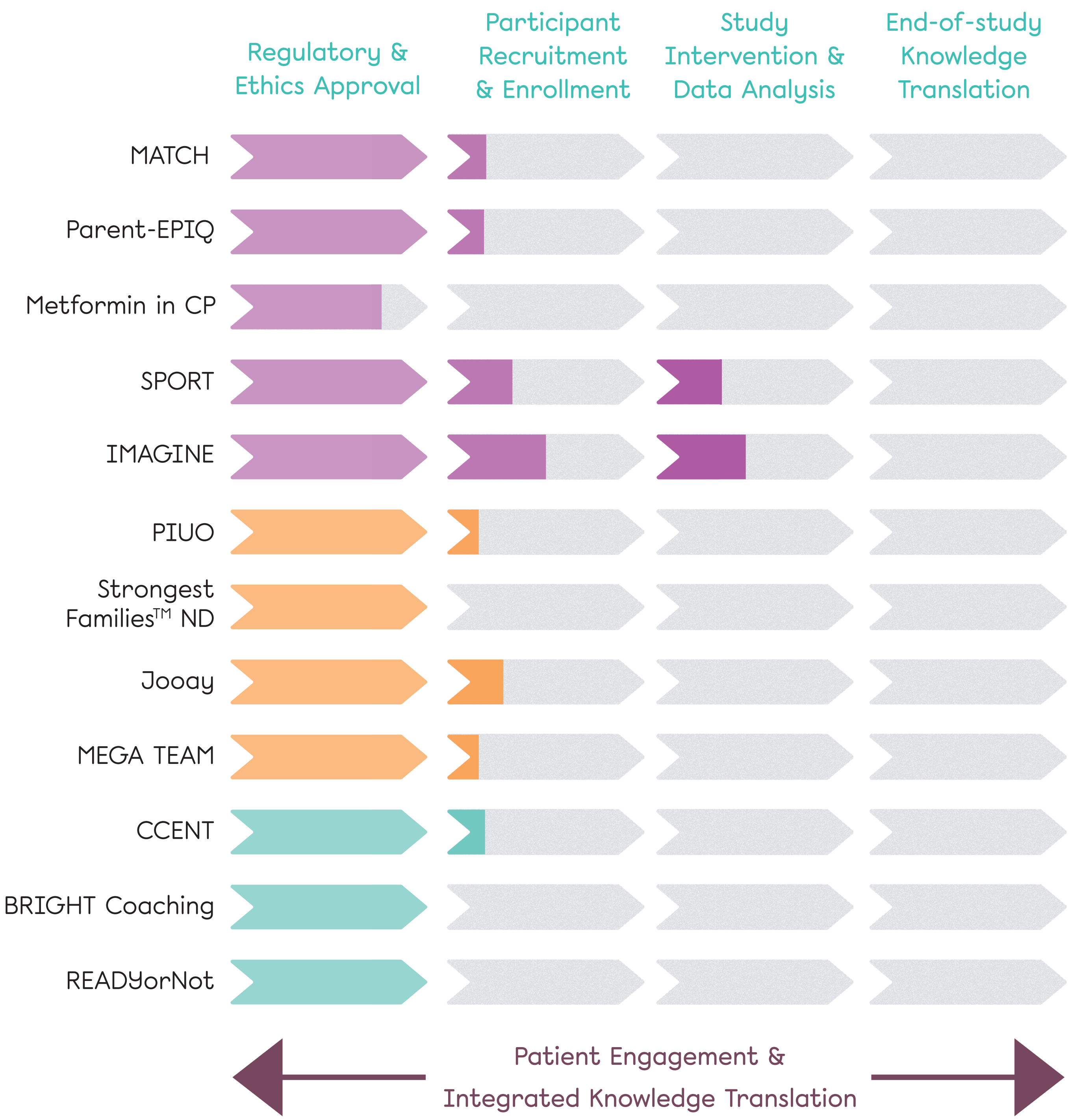
Each study must recruit and enroll a predetermined number of participants in their study. Recruitment begins once teams receive their necessary regulatory and ethics approvals. Potential participants must meet the project’s inclusion criteria, and they must sign consent forms before being officially enrolled. Eight of our 12 projects have begun recruiting patients, and the remaining studies all expect to begin recruiting later in 2018.

STEP 3: STUDY INTERVENTION AND DATA ANALYSIS

After participants are enrolled, they take part in a carefully designed intervention. Sometimes, the viability of an intervention is tested on a small scale, called a pilot project, before the intervention is implemented in the large-scale trial. Some CHILD-BRIGHT research teams (MATCH, CCENT, BRIGHT Coaching) will be or are conducting a pilot phase for their trial before the large-scale trial, whereas the others have already conducted a pilot trial or will enter directly into a large-scale trial. After all participants receive their intervention and full data sets are collected, research teams analyze the data using a predetermined analysis plan.

STEP 4: END-OF-STUDY KNOWLEDGE TRANSLATION

End-of-study Knowledge Translation refers to dissemination of study findings after the study is complete, for example, in scientific journals and at conferences. At CHILD-BRIGHT, this will start to take place for most projects in approximately 2 years, and we will work alongside our multiple stakeholders to ensure that we disseminate findings in ways that are accessible to the general public.



Patient-partners and knowledge users are involved and provide leadership at all stages of the research process.

MATernal hyperoxygenation in Congenital Heart Disease (MATCH)

PRINCIPAL INVESTIGATORS

Mike Seed
(SickKids)

Steven Miller
(SickKids)

AGE RANGE

20 weeks gestational age–18 months

START DATE

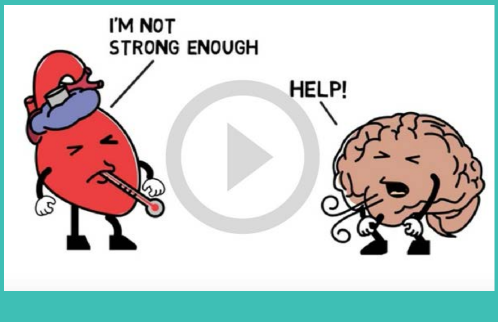
April 2017

STATUS

Recruiting for pilot project

LEARN ABOUT OUR WORK

www.bit.ly/MATCH_Project



PROJECT DESCRIPTION

Fetuses with congenital heart disease have slower brain development than those without heart disease. This is associated with reduced oxygen delivery to the developing brain. Supplementary inhaled oxygen during the third trimester could be a safe and feasible method of improving oxygenation of the fetal brain. In this study, we will evaluate whether supplementing mothers with oxygen helps brain development in fetuses with congenital heart disease.

BRIGHT Beginnings

Projects to optimize brain & developmental outcomes

> “In my experience as a clinician, parents of children with congenital heart disease often ask about their child’s future brain development and milestones. We hope our work will help answer some of their questions.”
>
> Steven Miller,
> Principal Investigator

PROJECT UPDATE

The care of infants with congenital heart disease has now advanced to include a limited number of therapies that aim to improve the heart defect before birth. To our knowledge, this is the first study that directly targets brain growth to improve the neurodevelopmental outcomes of children born with congenital heart disease.

During this past year, our research team overcame key regulatory and ethical approval processes that led to the recruitment of our first participant for our pilot project in early 2018. Throughout the next year, we will continue our pilot project until we understand various experimental parameters well enough to begin the clinical trial.

DID YOU KNOW?

Promoting the brain development of newborns with congenital heart disease, while they are still in the womb, requires collaboration across several disciplines: obstetrics, cardiology, neurology, radiology, and MRI scientists. They must all come together with the single-minded goal of improving the neurodevelopmental outcomes of the children.

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

PRINCIPAL INVESTIGATORS

Anne Synnes
(BC Women's Hospital)

Prakeshkumar Shah
(Mount Sinai Hospital)

AGE RANGE

NICU-18 months later

START DATE

April 2017

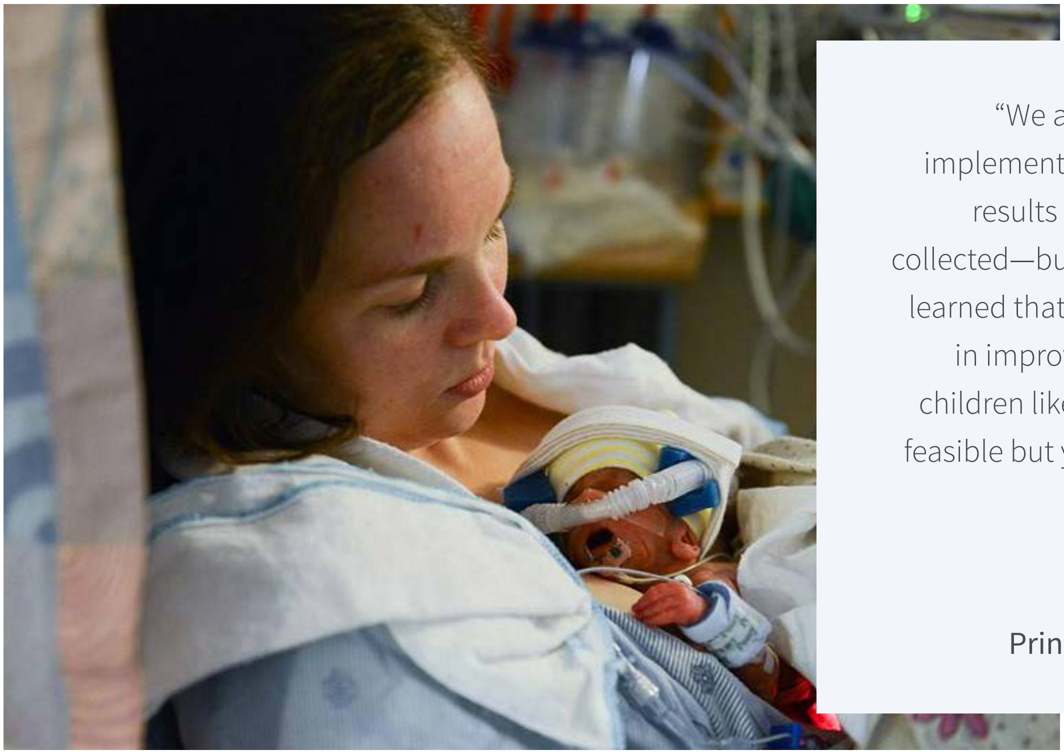
STATUS

- Engaging parents to understand their perception of impairments in preemies.
- Delivering new training to clinicians that promotes language development.
- Obtaining ethics approval to evaluate outcomes at Canadian Neonatal Follow-Up Clinics.

PROJECT DESCRIPTION

Children born premature often face developmental challenges. These challenges are usually described to parents using medical terminology that can be difficult to understand. In this study, we will involve parents and families of children born premature to help identify what information is meaningful to them and to help put in place proven interventions that will improve the language and thinking abilities of children born premature. The aim of our national parent participatory study is to bring parents of children born very premature to the forefront of defining and guiding initiatives to measure and improve the development of children born premature.

BRIGHT Beginnings | Projects to optimize brain & developmental outcomes



> “We are still in the early implementation phase—and results have not yet been collected—but we have already learned that involving parents in improving outcomes for children like theirs is not only feasible but yields unexpected ‘aha’ moments!”
>
> Anne Synnes,
> Principal Investigator

PROJECT UPDATE

The Parent-EPIQ project is making great progress! Twelve of our hospital sites have been using videos and worksheets to implement individualized and effective interventions to support learning and language development in preemies. We have learned that many clinicians don’t focus on language in the first year of life despite language development starting in the womb. Educating staff and parents will be an important activity at many sites in the upcoming year and parents will help us do this in a family focused way.

This year, we will also be consulting parents across Canada to gather their input on three key aspects of our research: their definition of ‘impairment’ (to see if it matches ours), their perception on the severity of different disabilities, and what outcomes matter most to them.

DID YOU KNOW?

Amongst Canadian children born premature at less than 29 weeks (normal pregnancy is 40 weeks)

46% have developmental challenges

17% of which are considered severe. Language difficulties are the most common, found in 35% of these children[1].

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[1] Arch Dis Child Fetal Neonatal Ed. 2017 May 102(3):F235-F234.

Enhancing Brain Repair with Metformin (Metformin in CP)

PRINCIPAL INVESTIGATORS

Donald J. Mabbott
(SickKids)

Darcy Fehlings
(Holland Bloorview Kids
Rehabilitation Hospital)

AGE RANGE

5–12 years

START DATE

June 2016

STATUS

Obtaining ethics approval
Recruitment to begin in 2018-19

VISIT OUR LAB’S WEBSITE

http://research.hollandbloorview.ca/ResearchCentresLabs/CPDiscoveryLab

> “When we were presented with the opportunity to be a part of CHILD-BRIGHT and particularly this ground-breaking trial, myself and colleagues at Three to Be jumped at the opportunity! As a mother of triplets with cerebral palsy, stem cells = HOPE. It is a therapy that has the potential to actually regenerate and heal the brain.”
>
> Dana Geall (Florence),
> Family Advisor & Funding Partner
> Representative

PROJECT DESCRIPTION

Children with cerebral palsy who were born premature face a lifetime of motor impairments, some of which can be treated with physiotherapy. Recent findings suggest that the drug metformin could help motor recovery by recruiting stem cells in the brain to help repair injury. Here, we will evaluate whether metformin combined with physiotherapy enhances motor and thinking skills in children with cerebral palsy.

BRIGHT Beginnings

Projects to optimize brain & developmental outcomes

PROJECT UPDATE

Over the past year, our project team has completed key administrative and operational objectives that will enable us to successfully launch the project and start our clinical trial in the near future. Health Canada has accepted the application for our trial, and our institutional ethics boards are reviewing our application. Once our application is approved, we will begin the recruitment of 50 participants: 25 who will receive physiotherapy, and 25 who will receive physiotherapy and metformin. We will monitor the safety and feasibility of the trial, asking whether motor and thinking skills change after the intervention, and using magnetic resonance imaging (MRI) to assess brain structures following the intervention.

DID YOU KNOW?

Children with cerebral palsy are frequently born premature with injuries in white matter, which forms the connections between nerve cells in the brain[1].

Metformin might help recruit more stem cells to become white matter cells[2].

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[1] Report of the Australian Cerebral Palsy Register, Birth Year 1993–2006, February 2013.

[2] Stem Cell Reports. 2015 Aug 11;5(2):166–73.

Stimulation for Perinatal Stroke Optimizing Recovery Trajectory (SPORT)

PRINCIPAL INVESTIGATOR

Adam Kirton
(University of Calgary)

AGE RANGE

5–18 years

START DATE

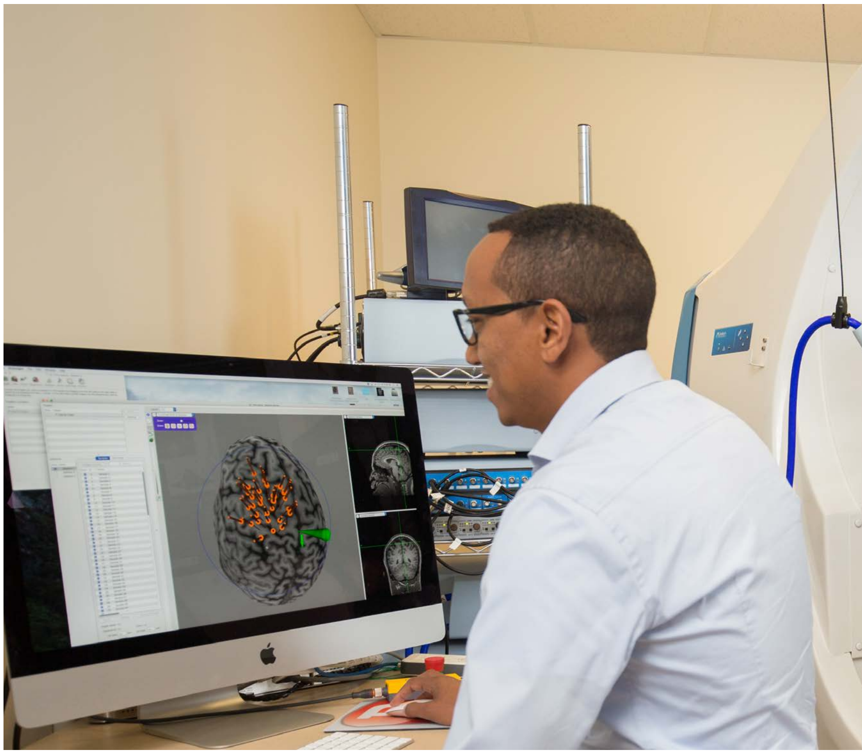
July 2016

STATUS

Recruiting for trial

GO ON A VIDEO TOUR OF OUR LAB

www.child-bright.ca/sport



PROJECT DESCRIPTION

Children with perinatal stroke often experience lifelong neurological disability. Non-invasive brain stimulation can help children learn motor skills and may help adults with motor impairments after stroke. We don't yet know how much it can help children with perinatal stroke. Here, we will conduct a clinical trial across Canada to test whether non-invasive brain stimulation improves function in children with motor difficulties such as cerebral palsy and, if so, what mechanisms underlie these improvements.

BRIGHT Beginnings

Projects to optimize brain & developmental outcomes

PROJECT UPDATE

This past year, we brought together national teams of kids, families, and multidisciplinary experts to initiate the first multicentre trial of non-invasive neurostimulation to enhance motor learning therapy in children with cerebral palsy secondary to perinatal stroke.

Our trial is conducted at summer camps. During these two-week camps, children receive an intensive motor learning intervention to improve their motor function.

This past year we conducted camps in Calgary.
This coming year we will conduct camps in Calgary, Edmonton, and Toronto.

DID YOU KNOW?

Perinatal stroke causes most hemiparetic cerebral palsy and lifelong disability, and affects

up to 10,000 Canadian children.

Non-invasive brain stimulation can enhance the brain's ability to learn motor skills and may help children with cerebral palsy realize personalized functional motor function goals.

Diagnosis Using Integrated Metabolomics And Genomics In Neurodevelopment (IMAGINE)

PRINCIPAL INVESTIGATORS

Jan M. Friedman
(University of British Columbia)

Clara van Karnebeek
(University of British Columbia)

AGE RANGE

Under 19

START DATE

April 2017

STATUS

Recruiting for trial

Cerebral palsy (CP) is one of the most common forms of childhood disability, affecting about

1 in 500

children

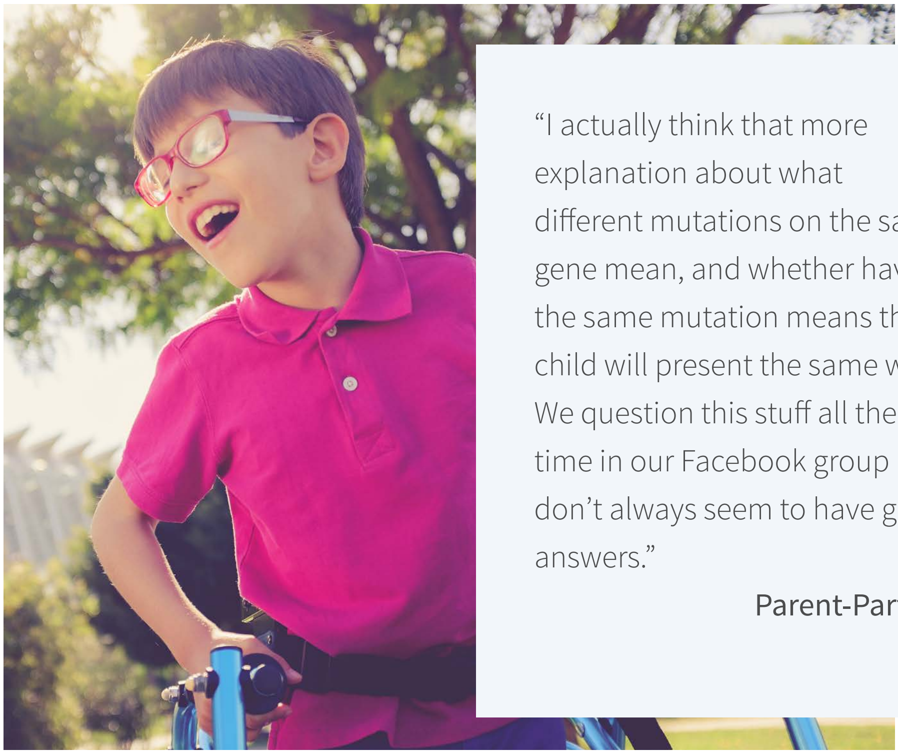
PROJECT DESCRIPTION

Brain injuries in early life are commonly thought to cause cerebral palsy in many children, but in some children the underlying cause is a metabolic or other genetic condition. Advances in genomics and metabolomics now allow us to diagnose these other causes of atypical cerebral palsy, and we believe that doing so will enable us to devise more personalized treatments that improve the outcomes for affected children.

BRIGHT Beginnings | Projects to optimize brain & developmental outcomes

"Linguistic barriers are a challenge for about 1/3 of our study participants so we are translating our study material into commonly spoken languages, including Punjabi, Hindi, Somali, and Kurdish."

Nicole Liang,
Trainee



"I actually think that more explanation about what different mutations on the same gene mean, and whether having the same mutation means the child will present the same way. We question this stuff all the time in our Facebook group and don't always seem to have good answers."

Parent-Partner

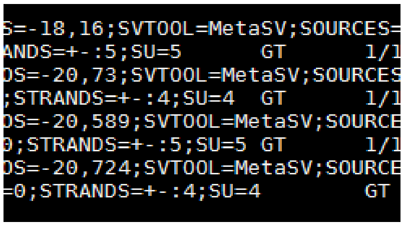
PROJECT UPDATE

We have screened over 300 families thus far, with the goal of identifying 100 families who have a child affected by atypical cerebral palsy who qualify for our study. We have enrolled over 30 and are now at the stage of reviewing preliminary results. We hope to have some answers for this first batch of participating families very soon.

Because the process is long and sometimes stressful—taking up to six months to obtain preliminary results—we are also working with parent-participants to improve our communication methods with families throughout the study. Our goal is to keep them well informed as we await the results of their study samples.

DID YOU KNOW?

Bioinformatics is the science that makes sense of data like this:



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0;STRANDS=+-:5;SU=5 GT      1/1
OS=-20,724;SVTOOL=MetaSV;SOURCE
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Bioinformaticians work with clinical and molecular geneticists to determine which, if any, genomic variants may be responsible for a child's condition.

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

PRINCIPAL INVESTIGATORS

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

Tim Oberlander
(BC Children's Hospital & University)

AGE RANGE

0.5–18 years

START DATE

April 2017

STATUS

Recruiting for trial

VISIT OUR LAB'S WEBSITE

www.paindetectives.org

PROJECT DESCRIPTION

Children born with severe brain-based developmental disabilities frequently experience persistent unexplained periods of pain and irritability, often compounded by a limited capacity to communicate their distress. Here, we have designed a systematic approach to address the management of the children's pain with the goals of reducing pain symptoms, improving the day-to-day lives of the child and family, and simplifying treatment options for clinicians.

BRIGHT Supports

Projects to integrate mental health support into care

> “Contributing to research can be a healing experience for families who have gone through a difficult health journey. Knowledge translation from the family/patient perspective is enhancing the evolution of research and making it more accessible for both the researcher and the families.”
>
> Gillian Treschow, Parent Advisory Group Member

PROJECT UPDATE

Through the hard work of our entire study team, the principal investigators, our collaborators, our Parent Advisory Group members and our study staff, we now have a finalized protocol in place and have started enrolling participants in Vancouver, our main study site. We will soon be ready to see patients in Ottawa, Calgary and Toronto as well.

Many children experience pain and irritability on a daily basis but don’t have an explanation for this pain, or a way to treat it. We are very much looking forward to engaging with, and being able to support, these children and their families.

DID YOU KNOW?

We asked 6 physicians who specialize in pediatric pain which 5 medications they would prescribe and in which order, based on a fictional case of a non-verbal child experiencing pain and irritability of unknown origin. They came up with

9 different medication pathways!

A common approach does not yet exist, and there will be great value to standardizing clinical guidelines.

Strongest Families™ Neurodevelopmental Program (Strongest Families™ ND)

PRINCIPAL INVESTIGATORS

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

Lucyna Lach
(McGill University Health Centre)

AGE RANGE

3–14 years

START DATE

October 2016

STATUS

Intervention in development.
Recruitment to begin in 2018-19

VISIT OUR WEBSITE

www.crfh.ca/neuro

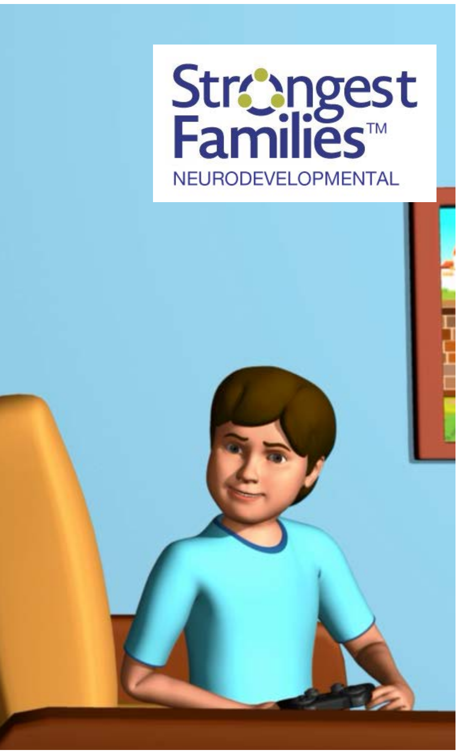
Sample animation from a skill demonstration video (animation by *Between the Lines Animations*)

PROJECT DESCRIPTION

Children with brain-based developmental disabilities often face emotional and behavioural difficulties. These challenges can negatively impact their quality of life and the quality of life of their families. Our Strongest Families™ project explores whether emotional and behavioural regulation can be improved in children with neurodisabilities through parenting programs that include education, telephone support, parent-to-parent connections, and resource information.

BRIGHT Supports

Projects to integrate
mental health
support into care



> “I am most proud of parents’ involvement in our project. They are a very committed group. Our Parent Advisory Committee has made our Strongest Families™ Neurodevelopmental intervention much stronger and more relevant to our families.”
>
> Patrick McGrath, Principal Investigator

PROJECT UPDATE

This past year, we developed the content for our Strongest Families™ Neurodevelopmental Program with a very interdisciplinary team!

We produced a set of animated modules for parents who are living with children who have different kinds of neurodisabilities and challenging behaviour. These modules have been adapted with direct input from parents who are living with these daily challenges, which ensures that the modules are relevant and that other parents will be able to relate to them.

DID YOU KNOW?

Mental health disorders such as anxiety, depression and disruptive behaviour occur

3 to 5 times
more often

in children with neurodisabilities than their peers with only a small percentage of those children (10 to 30%) receiving mental health care[1,2,3].

[1] J Child Psychol Psychiatry. 2002 Nov;43(8):1087-98.
[2] JAMA. 2006 Oct 25;296(16):1981-9.
[3] J. Intellect. Dev. Disabil. May 2015;40(3):239–247.

Jooay App:
Promoting Participation in Leisure

PRINCIPAL INVESTIGATOR

Keiko Shikako-Thomas
(McGill University)

AGE RANGE

0–21 years

START DATE

October 2016

STATUS

Feasibility study in progress

VISIT OUR WEBSITE

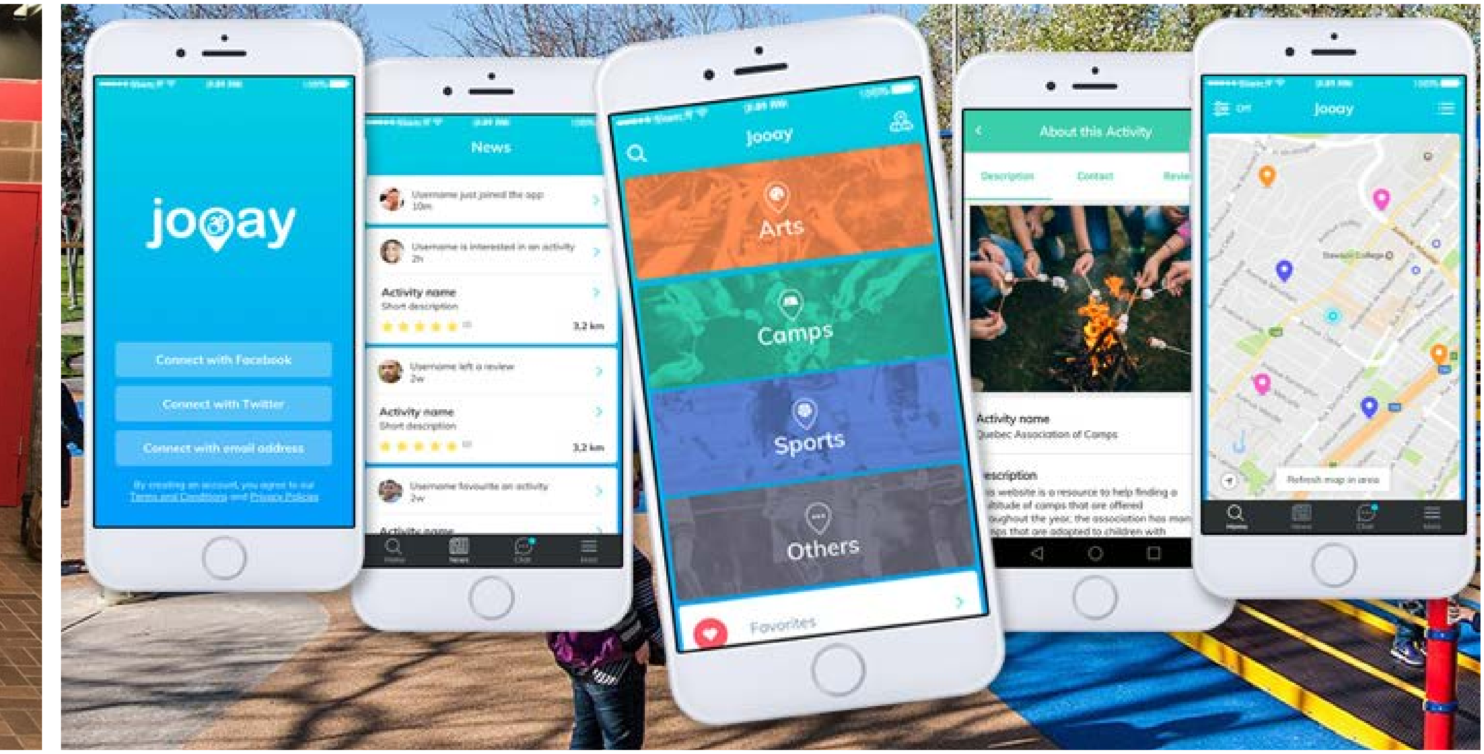
www.jooay.com

PROJECT DESCRIPTION

Participating in sports and other leisure activities is an important part of childhood development; however, accessing appropriate activities and information is a challenge for children with disabilities. We created "Jooay," a mobile and web-based app, to provide families with information about appropriate leisure activities available in communities across Canada. In this project, we are seeking ways to optimize the use of this technology, to increase its use for more children and families, and to use it as a tool to inform policy and community changes.

BRIGHT Supports

Projects to integrate mental health support into care



PROJECT UPDATE

With the help of parents, youth with disabilities, clinicians, educators, and community leaders, we launched a brand new mobile app accessible in all platforms this year, with an interactive chat and community of support for parents to exchange information and gain and offer support.

We also launched an ambassadors program where leaders in local communities can help us understand the needs, gaps and possibilities available to promote healthy living for children with disabilities in all provinces across Canada!

DID YOU KNOW?

The UN Convention on the Rights of the Child (1989) stipulates that play is a fundamental human right, yet children with disabilities rarely meet their recommended standards for physical activity. In fact,

less than 20%

of parents of children with disabilities are aware of adapted leisure opportunities near their home.

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

PRINCIPAL INVESTIGATOR

Jennifer Crosbie (SickKids)

AGE RANGE

6–12 years

START DATE

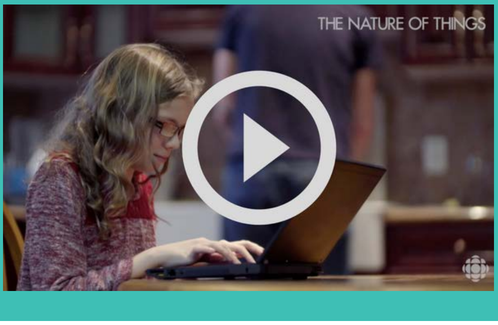
May 2017

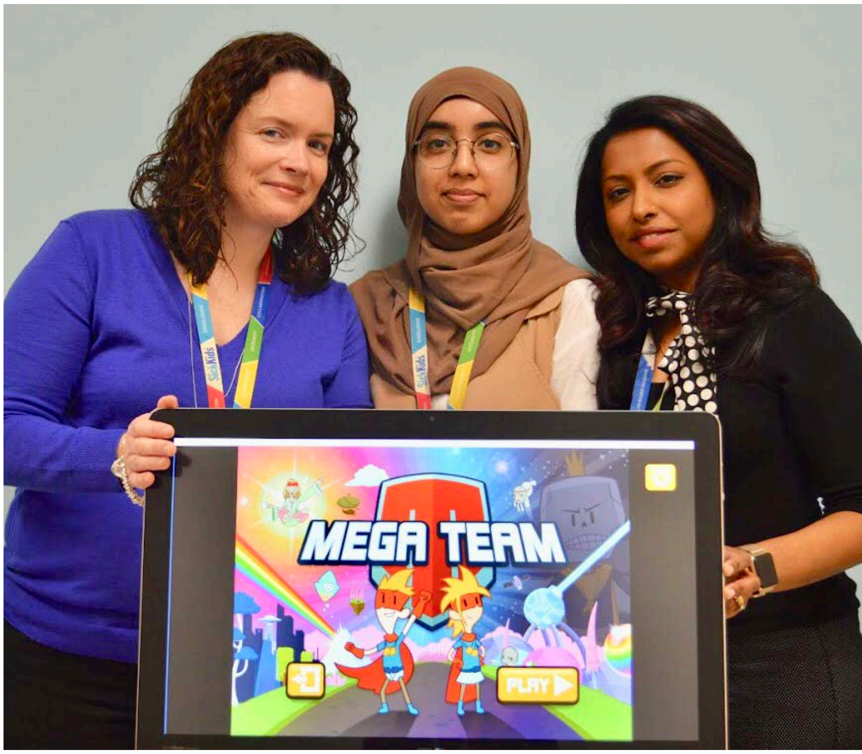
STATUS

Recruiting for trial

WATCH US ON 'THE NATURE OF THINGS'

http://www.cbc.ca/natureofthings/features/could-a-video-game-help-rewire-the-brains-of-children-with-adhd





PROJECT DESCRIPTION

Children with disorders that impact neurodevelopment often have difficulties with executive functions and regulating emotions. Cognitive-based video game training has been shown to improve outcomes, however, this training has been expensive, has required professional supervision, and has been investigated only within a narrow group of children. The Mega Team study will test the effects of a highly engaging, take-home video game-based intervention designed to improve executive functioning in children with various brain-based developmental disorders.

BRIGHT Supports

Projects to integrate mental health support into care

PROJECT UPDATE

The Mega Team project has had an exciting year! We collaborated with our most important stakeholders—children, youth and their families—to gather valuable feedback to improve the Mega Team video game, including selecting study outcomes that matter to families. Our study protocol was evaluated by expert scientists at SickKids and we received final approval for our study from the SickKids Research Ethics Board. We have trained our staff, both for administrative tasks and to conduct study visits, and have started enrolling individuals with attention deficit hyperactivity disorder (ADHD) for our study. We will soon begin recruiting children and youth with autism spectrum disorders (ASD) and individuals with congenital heart disease (CHD). Our team is extremely excited to get started!

DID YOU KNOW?

Executive function deficits are highly impairing and impact individuals across a wide range of mental health and medical conditions. They impact self-regulation, attention, impulsivity, and academic efficiency and accuracy. Game-based cognitive rehabilitation programs have been shown to be a promising (and non-medication based) intervention to help improve executive functions.

Coached, Coordinated, Enhanced Neonatal Transition (CCENT)

PRINCIPAL INVESTIGATORS

Julia Orkin (SickKids)

Eyal Cohen (SickKids)

Nathalie Major-Cook (CHEO)

Paige Church (Sunnybrook Health Sciences Centre)

AGE RANGE

4 to 6 weeks old–18 months old

START DATE

January 2017

STATUS

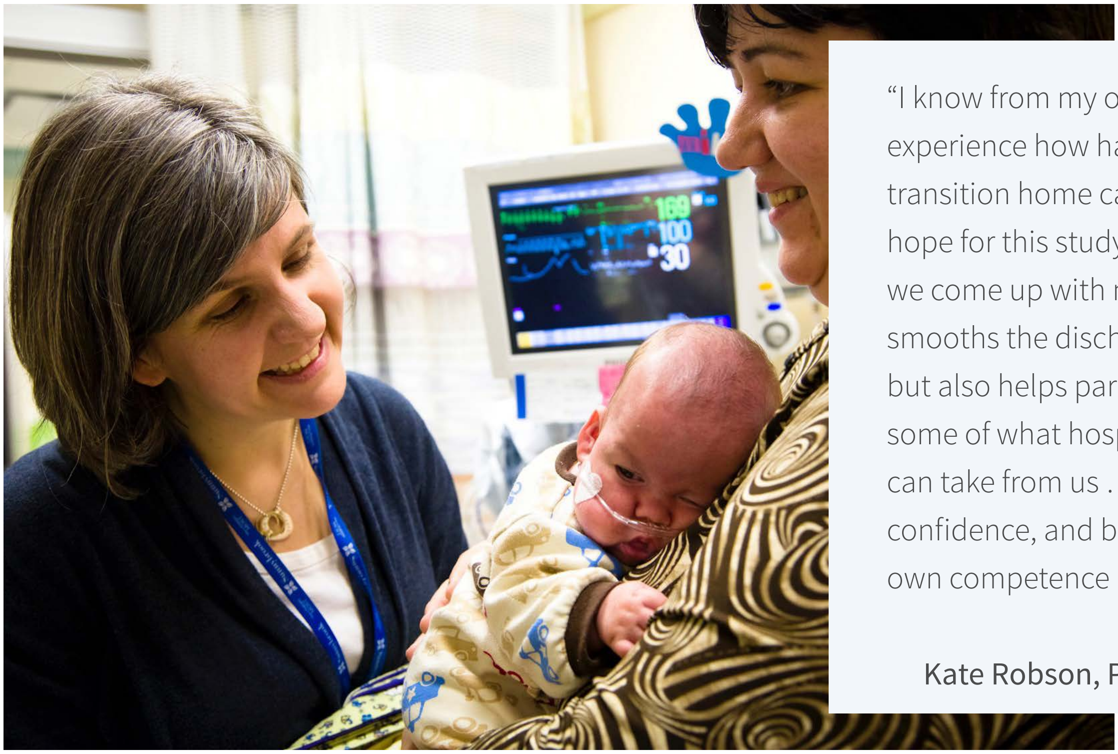
Recruiting for pilot project

PROJECT DESCRIPTION

Better medical care has helped many women with challenging pregnancies deliver babies; however, some babies are born with serious and chronic conditions. Their families face a number of challenges when transitioning from the hospital to their homes. This project will evaluate a new type of care for these families. We will assign families a point person that focuses on three components of support: 1) care coordination, 2) parent education and empowerment, and 3) mindfulness using an Acceptance and Commitment Therapy (ACT) framework. We will compare the experience, stress, and health of the families in the intervention arm with the experience, stress, and health of the families in the control arm.

BRIGHT
Futures

Projects to redesign health care services to be more responsive to family needs



> “I know from my own NICU experience how hard the transition home can be. 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-Partner

PROJECT UPDATE

We are thrilled that our project has launched at two sites (CHEO and Sunnybrook), and we have families enrolled with a key worker to support their transition from the Neonatal Intensive Care Unit (NICU) to home. The key worker will work closely with these families using a novel parental coaching model aimed at improving both child and parent health outcomes.

Over the past year, we have worked with our parent partners to ensure this parental coaching model is relevant and family centred. We are excited about our project’s progress and look forward to launching the study at additional sites over this coming year.

DID YOU KNOW?

Acceptance and Commitment Therapy (ACT) is a mindfulness-based behavioural therapy that aims to reduce psychological suffering emerging from avoidance or entanglement in negative thoughts. Through engagement in the ACT framework, individuals learn skills to increase psychological flexibility and reduce suffering. To our knowledge, this is the first study to use an ACT framework to support parents of infants during the challenging transition out of the NICU into the community.

BRIGHT Coaching

PRINCIPAL INVESTIGATORS

Annette Majnemer
(McGill University Health Centre)

Maureen O'Donnell
(Child Health BC)

AGE RANGE

3–6 years

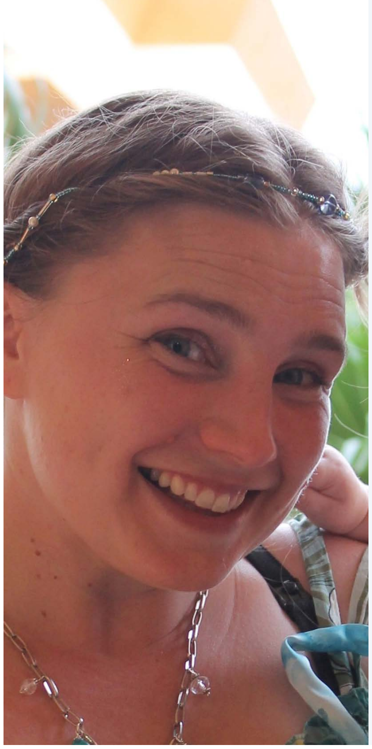
START DATE

January 2017

STATUS

Intervention in development.
Recruitment to begin in 2018-19

BRIGHT Coaching
TALK - LEARN - SHARE



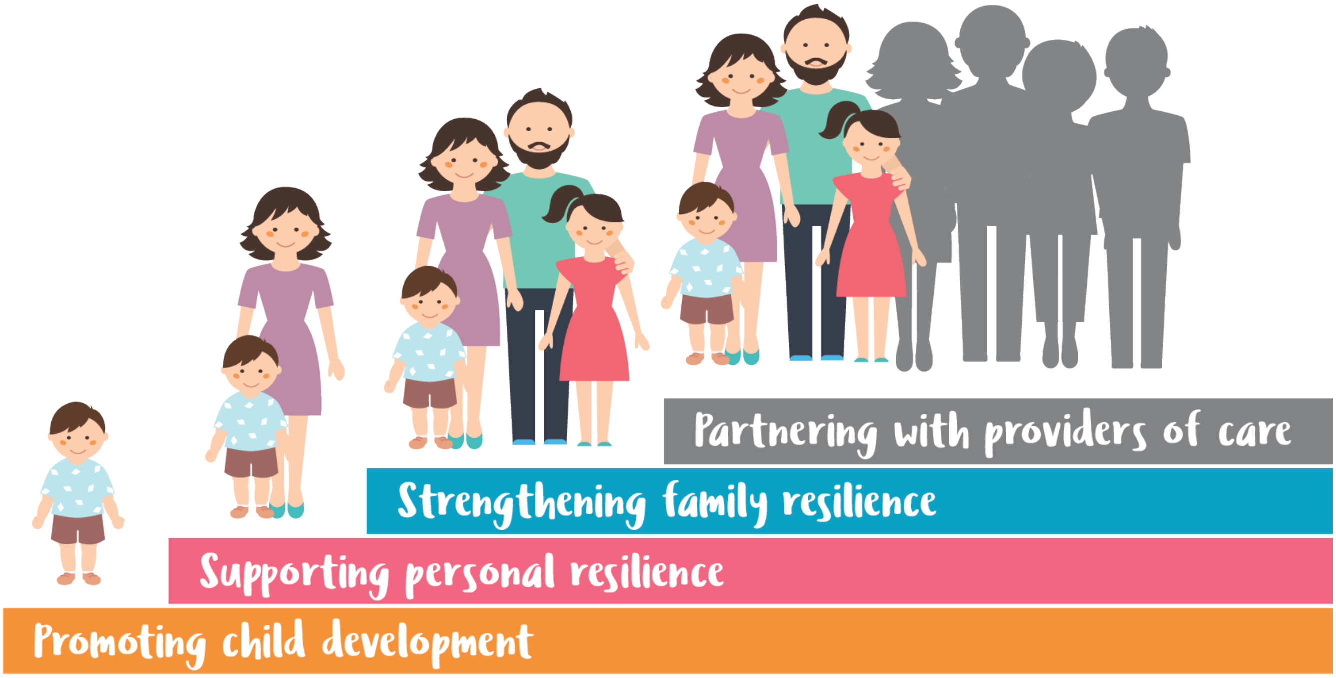
> "As I see the pieces falling into place, I am thrilled that people who have children being diagnosed now will have the chance to empower themselves through this project. I hope every parent in the future has access to this!"
>
> Carrie Costello,
> Parent Advisory
> Committee Member

PROJECT DESCRIPTION

Healthy children develop critical skills during the preschool years. But children with developmental delays may struggle in the development of such skills. For parents, accessing the best diagnostic and interventional care and the best services during this important period of their child's development is often difficult. This study asks whether a standardized and nationally available online education tool and coaching resource is feasible and helpful to parents as their preschool child transitions to school entry.

BRIGHT Futures

Projects to redesign health care services to be more responsive to family needs



PROJECT UPDATE

This year, our team has expanded to include four research assistants, four family coaches, one coach lead, and a total of 10 parent advisors. Together, our team, which also includes clinicians and researchers, co-developed a Coach Manual to guide and empower families as they await assessment and services for their child.

Our coaching program focusses on four themes: promoting child development, partnering with service providers, strengthening personal resilience, and strengthening family resilience. Via a newly developed online platform, we will also educate families and give them access to peer support forums, so that all families enrolled in this study can better communicate and collaborate.

DID YOU KNOW?

The content of our coaching intervention was determined through iterative feedback from many stakeholders and knowledge users, including 10 parent advisors, 16 clinicians and researchers, and more than 180 Canadian families who completed an online survey about their preferences and knowledge needs as their preschool child or children awaited assessment.

‘READYorNot’ Moving Ahead with Transition of Care from Adolescence to Adulthood

PRINCIPAL INVESTIGATORS

Ariane Marelli
(McGill University Health Centre)

Jan Willem Gorter
(McMaster University)

Khush Amaria (SickKids)

AGE RANGE

16–18 years

START DATE

April 2017

STATUS

Intervention in development.
Recruitment to begin in 2018-19

PROJECT DESCRIPTION

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 their families and have a negative impact on a patient’s health. In the majority of pediatric centres, there are no dedicated resources for transition of care. With the ‘READYorNot’ (READiness in Youth fOR traNsition Out of pediaTric Care) project, we are developing and evaluating e-health aids to help patients and families take charge of this transition.

BRIGHT Futures

Projects to redesign health care services to be more responsive to family needs

> “This is the way all tools and resources for youth should be developed - in collaboration and alongside those who use it (the youth in transition), those who prescribe it (the health care providers in busy clinics) and the research scientists who want to make sure it works as it should.”
>
> Khush Amaria,
> Principal Investigator

PROJECT UPDATE

We are working on an e-health application to help youth develop the skills and knowledge necessary to take charge of their own health and prepare themselves for the transition to adult life.

We are very grateful to the members of the Patient and Family Advisory Council as well as the participants involved in focus groups, for having given us the opportunity to get their feedback on our work. It’s very exciting to work together with youth to co-create such an intervention tool because in the end that makes the tool meaningful and interesting to youth and their families.

DID YOU KNOW?

When the transition to adult health care for patients with brain-based disabilities is unplanned or poorly supported, patients and families experience adverse outcomes including costly hospitalizations, inequity of health care services, and other indirect costs such as missed school or work. This transition is currently highly stressful and requires comprehensive planning.

Health Economics Service

The Health Economics team evaluates the cost-effectiveness and cost-utility of emerging technologies, interventions, treatments and services for a wide range of pediatric neurodevelopmental disorders.

Over the past year, we have focused on providing ongoing support for the development and implementation of economic evaluations within the CHILD-BRIGHT Network to 7 research project teams (Metformin, SPORT, Strongest Families™ ND, Mega Team, CCENT, BRIGHT Coaching, and READYorNot). Examples of our work includes:

- Supporting the incorporation of tools for measuring burden of illness and health-related quality of life. Examples include the Health Utilities Index, Kidscreen, and CarerQol.
- Designing and adapting tools for measuring cost of care for families and health care systems. This work primarily focuses on the Resource Use Questionnaire.
- Working with members across the CHILD-BRIGHT Network to facilitate cooperation between platforms and stakeholders.

7

project teams receiving support

4

projects receiving support with outcomes measures

5

projects receiving support with cost measures

Data Coordinating Centre (DCC)

The Data Coordinating Centre (DCC) helps CHILD-BRIGHT research projects develop secure, reliable and rigorous systems to collect, analyze and report study data. They ensure that research data is collected in an appropriate manner, kept private and secure, and used to maximum effect.

Located at the Women and Children's Health Research Institute (WCHRI), University of Alberta, the DCC team provides support to CHILD-BRIGHT research projects and programs. Our primary areas of support include research database setup, data management, data analysis and interpretation, data reporting and visualization.

This past year the DCC spent over 580 work hours engaging with the CHILD-BRIGHT research teams and supporting their study setup and data requirements. Much of this time was spent developing relationships with the project and program teams, learning about their objectives, reviewing their data collection forms and processes, providing advice and guidance, developing statistical analysis plans, and building study databases. While we worked with many CHILD-BRIGHT researchers in 2017-18, there are some teams that we spent more time with, learning from one another in order to move childhood brain-based disability research forward.

6

data transfer and service level agreements

7

statistical plans

7

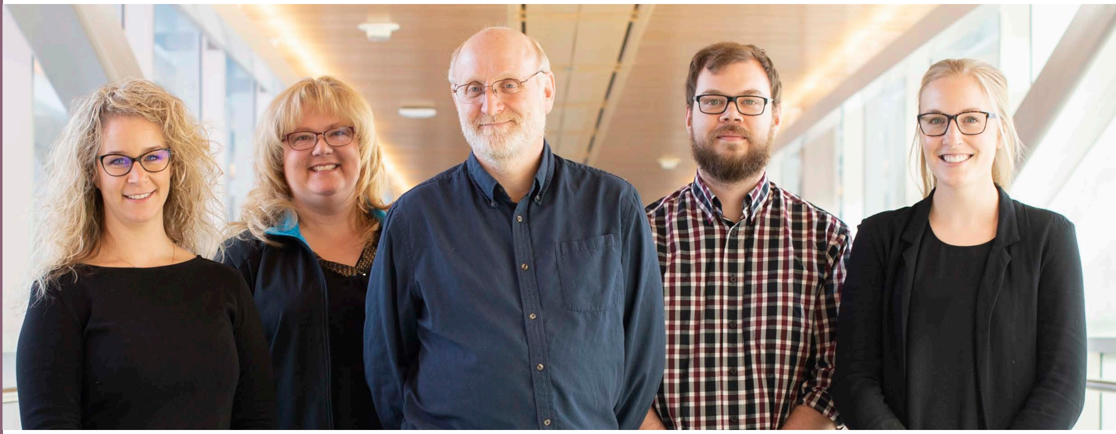
research project databases developed

1

data management plan

1

data safety monitoring report



“I’m learning that sharing my experience can help others.”

Avi Karp,
Patient-Partner

Collaborating to Find an Accessible and Welcoming Venue

In preparation for an upcoming meeting where our CHILD-BRIGHT team plans to gather some of our network members, including youth with brain-based developmental disabilities, we recently set out to book a venue. Knowing that we wanted our venue to be accessible, comfortable and work-conducive for all guests, including our younger members, we invited Avi Karp, a 19-year-old student and entrepreneur with personal knowledge about accessibility, to help us evaluate our leading venue.

“I have been living with Multiple Sclerosis (MS) since I was 12 years old and my MS has affected my mobility at times in the past,” says Avi. “When CHILD-BRIGHT asked me to help them select a good venue for others with similar issues, I was excited and honoured. I felt my personal experience would be an asset.”

“Avi provided very insightful feedback and observations as we were touring the venue,” says Corina d’Alesio-Worth, from the CHILD-BRIGHT Administrative team. “Some of the tips he shared were:

- To visualize the space from different perspectives, like imagining we were navigating the room in a wheelchair. Would the space between the tables be too narrow?
- To test EVERYTHING: a broken automatic door button could be a big problem for someone using a wheelchair.
- To pay attention to the user experience. For example, one ‘accessible’ path was very narrow and led us past dumpsters. How would that impact the user experience?
- Not to overlook smaller details like access to a casual meeting space, to good food, to a strong Wi-Fi signal and to the ports needed to connect a PlayStation. These smaller but great extra touches would help our younger guests be more productive and feel more satisfied with their overall experience at our event.”

“This was my first time being called to help a network in this way, and I think it was a great idea,” says Avi. “It makes much more sense to have someone with a brain-based disability evaluate the venue for an event for others with brain-based disabilities.”

We want to sincerely thank Avi for his time and insight. We have already been in touch with our venue manager to ensure key technical fixes are completed before our meeting, and we are rethinking the path by which our guests will enter the venue to ensure that the user experience is welcoming for all equally. Partnering with Avi was very helpful in guiding our preparations, and we hope that by sharing some of his expert tips, you can also benefit from them (and share them with venue managers too!).

> “We’re learning to build strong partnerships.”
>
> Michael Shevell, Chair,
> CHILD-BRIGHT Partnership &
> Sustainability Committee

Our Financial Partners

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

CIHR IRSC
Canadian Institutes of Health Research
Instituts de recherche en santé du Canada

Strategy for Patient-Oriented Research
SPOR
Putting Patients First

PLATINUM PARTNERS ($1M +)

- la fondation de l'hôpital de montréal pour enfants / the montreal children's hospital foundation
- SickKids
- BC Children's Hospital Foundation
- IWK Health Centre

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- ALBERTA INNOVATES
- Fonds de recherche Santé Québec
- MICHAEL SMITH FOUNDATION FOR HEALTH RESEARCH – Discover. Connect. Engage.
- women & children's health research institute / STOLLERY CHILDREN'S HOSPITAL FOUNDATION
- three to be

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

- CHEO RESEARCH INSTITUTE | INSTITUT DE RECHERCHE
- ehave
- Alberta Children's HOSPITAL RESEARCH INSTITUTE
- Holland Bloorview Kids Rehabilitation Hospital
- McMaster University
- New Brunswick Health Research Foundation / Fondation de la recherche en santé du Nouveau-Brunswick
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- SUNNY HILL HEALTH CENTRE FOR CHILDREN
- Research Manitoba
- Hamilton Health Sciences RESEARCH
- UBC THE UNIVERSITY OF BRITISH COLUMBIA Faculty of Medicine
- UBC
- maternal infant child & youth research network / réseau de recherche en santé des enfants et des mères

BRONZE PARTNERS ($1 TO $99,999)

- Saint Elizabeth – *Well beyond health care*
- BC WOMEN'S HOSPITAL+ HEALTH CENTRE FOUNDATION
- DESIGN SHOPP
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Canadian Association of Occupational Therapists
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Nunavut SPOR SUPPORT Unit
Ontario SPOR SUPPORT Unit
Primary and Integrated Health Care Innovations (PIHCI)
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Saskatchewan SPOR SUPPORT Unit
Yukon SPOR SUPPORT Unit

> “We’re learning to train future researchers.”
>
> Dan Goldowitz,
> CHILD-BRIGHT Co-Director
> & Training Program Lead

Get Involved!

CHILD-BRIGHT
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Strategy for Patient-Oriented Research
SPOR
Putting Patients First

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