

CHILD-BRIGHT NETWORK

REPORT TO COMMUNITY AS PER MARCH 31, 2017

Building the foundation for our network



CHILD-BRIGHT
Network

Strategy for Patient-Oriented Research

SPOR

Putting Patients First 



CONTENT

01	ABOUT CHILD-BRIGHT
05	LETTER FROM DR. ANNETTE MAJNEMER
08	LETTER FROM FRANK GAVIN
10	WHAT IS PATIENT-ORIENTED RESEARCH
12	RESEARCH
22	KNOWLEDGE TRANSLATION
24	TRAINING
26	CITIZEN ENGAGEMENT
28	DATA COORDINATING CENTRE
29	HEALTH ECONOMICS
30	COMMITTEES
31	OUR PARTNERS



ABOUT CHILD-BRIGHT

Who we are

The CHILD-BRIGHT Network is a pan-Canadian research network headquartered at the Research Institute of the McGill University Health Centre and co-directed by investigators at the BC Children's Hospital and The Hospital for Sick Children. 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.



ANNETTE MAJNEMER
Research Institute,
McGill University Health Centre



DAN GOLDOWITZ
BC Children's Hospital

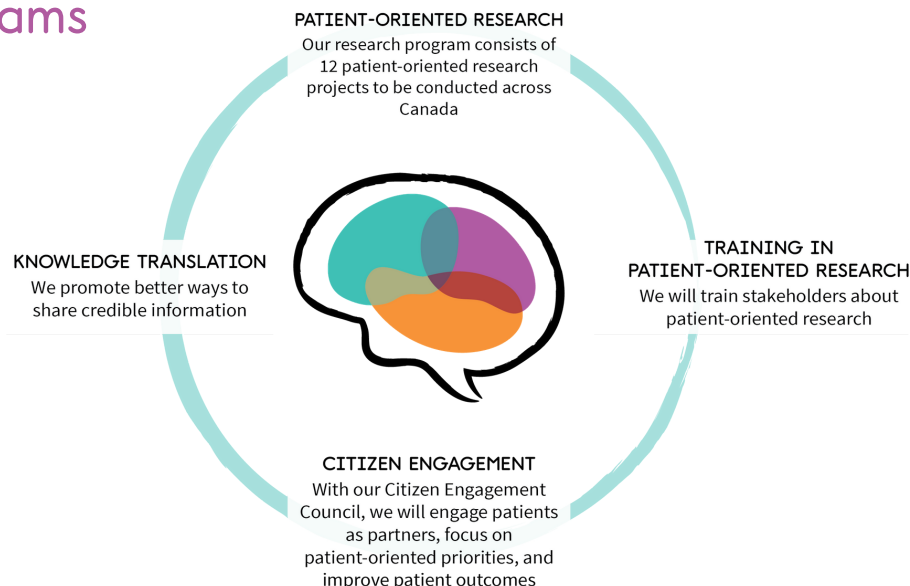


STEVEN MILLER
The Hospital for Sick Children

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 programs





OUR TARGET POPULATION

1 IN 10
children are born premature

1 IN 20
children have developmental disabilities

1 IN 13
children have learning disabilities

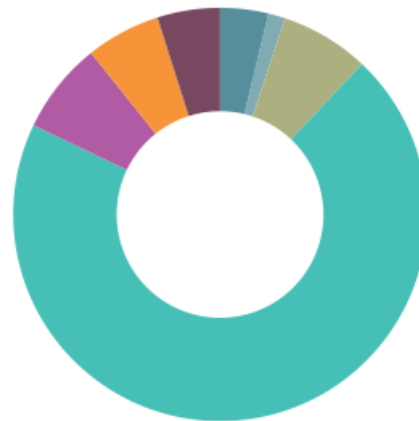
1 IN 68
children have autism spectrum disorder

1 IN 500
children have cerebral palsy



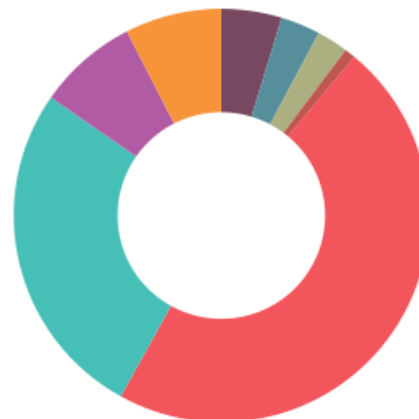
EVERY CHILD ALSO HAS A FAMILY

CHILD-BRIGHT 5-YEAR BUDGET ALLOCATION BY PROGRAM



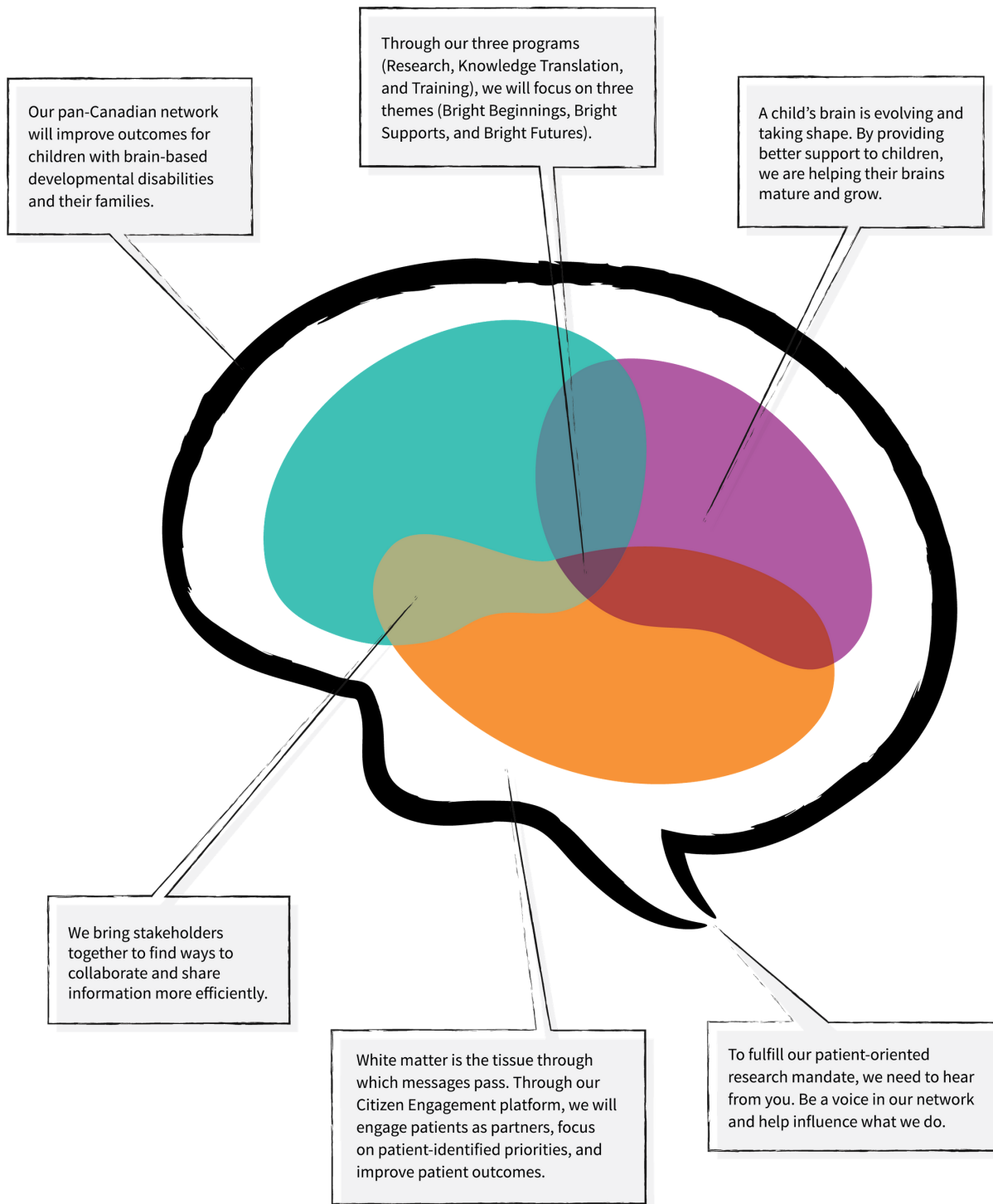
- Research 70.1%
- Knowledge Translation 7.2%
- Training 5.8%
- Citizen Engagement 4.9%
- Data Coordinating Centre 3.8%
- Health Economics 1.3%
- Administration 7.0%

CHILD-BRIGHT 5-YEAR FUNDS BY FUNDING PARTNER

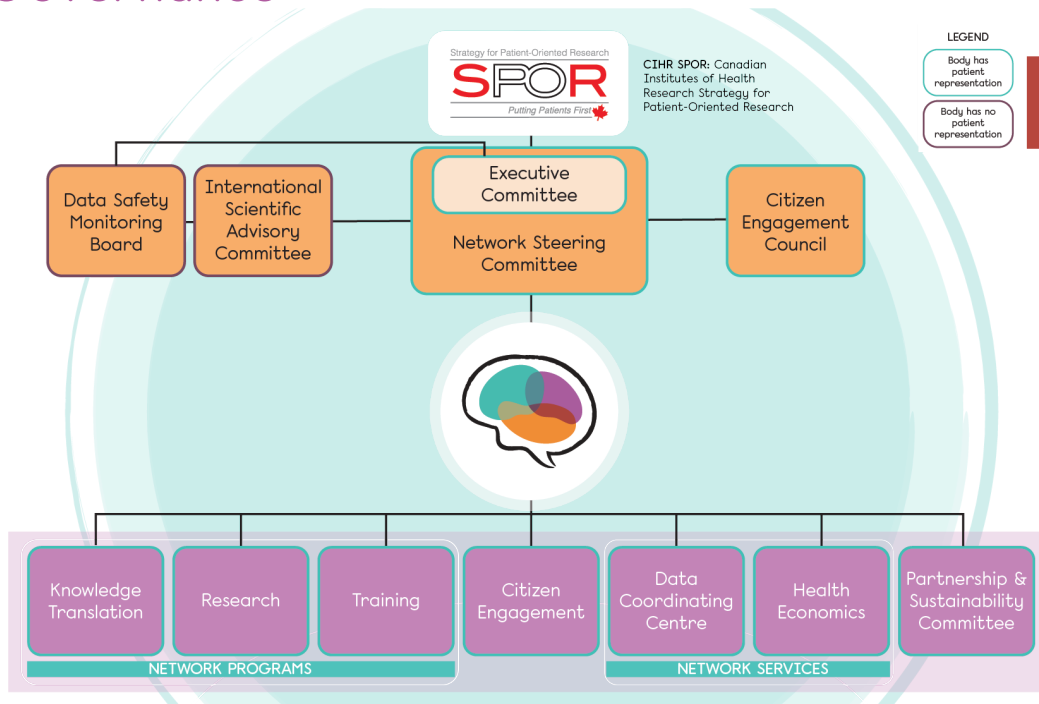


- CIHR 47.0%
- Hospital Foundations 26.6%
- Health Research Foundations 7.8%
- Health Systems 7.5%
- Not for Profit Organizations 4.7%
- Research Institutes 3.1%
- Universities 2.4%
- Private Organizations 0.8%

Our logo mark



Our Governance



International Scientific Advisory Committee (I-SAC)

The International Scientific Advisory Committee is composed of experts in patient-oriented strategies in chronic childhood disabilities. It will provide advice to the NSC on establishing priorities and executing a nation-wide agenda on patient-oriented research based on successful models from other countries.

Citizen Engagement Council (CEC)

The Citizen Engagement Council provides guidance on optimizing patient engagement activities to inform research development in areas of value to patients.

Network Steering Committee (NSC)

The Network Steering Committee, with the Executive Committee, has the highest decision-making authority in the network. It oversees and manages the network.

Executive Committee (EC)

The Executive Committee makes time-sensitive decisions as needed between NSC meetings.

Data Safety Monitoring Board (DSMB)

The Data Safety Monitoring Board is composed of clinical research experts from Canada and around the world. They monitor the safety of trials deemed to pose moderate to high risk.

Partnership and Sustainability Committee

Reporting to the NSC, the Partnership and Sustainability Committee (P&SC) will be responsible for the development and management of network partnerships to enhance collaboration and opportunities for future funding. This will include enhancing international collaborations and increasing engagement with other Canadian networks.

Letter from Dr. Annette Majnemer

CHILD-BRIGHT Network Director



Dear supporters,

What an exciting first year we've had at CHILD-BRIGHT, and what an honour it is to be sharing our first Report to Community with you! As I write this message, I can't help but be proud of how far we've come since the idea of launching a network like ours first came to light, all the way back in 2015.

At that time, after many discussions with researchers, health professionals and families, we all agreed that more needed to be done to help children with brain-based disabilities and their families, and that the first step was to involve the youth and families themselves in the process.

To better identify the issues at play, we sat down with a small group of 25 stakeholders (parents, young adults with a disability, health professionals, researchers, policymakers) and listened to their concerns and suggestions. We repeated the experience two months later with 55 more stakeholders from across Canada, and then sent out a targeted national survey. More than 900 families and youth responded and based on their input, we identified what now serves as the foundation of our research program.

We learned that patients and families are most concerned about three things:

- Optimizing brain development and developmental outcomes
- Integrating mental health into care
- Redesigning health care services to be more responsive to family needs.

We've made those our three research themes:
BRIGHT Beginnings, BRIGHT Supports, and BRIGHT Futures

We received direct feedback on what research questions patients and families wanted us to prioritize, and selected our 12 research projects based on this valuable input.

We also learned that it's important not only to support research teams, but to ensure that patients and families are guiding all aspects of our work; to learn from their lived experience and expertise in childhood disability; to study how to communicate information more effectively between all groups of people; and to train current and future generations to carry out patient-oriented work effectively.

For this, we structured our network around a Citizen Engagement platform and three programs: Research, Training, and Knowledge Translation.

Thanks to all this groundwork, the CHILD-BRIGHT Network was officially born on March 31, 2016 and is supported by a five-year grant by the Canadian Institutes of Health Research (CIHR) under Canada's Strategy for Patient-Oriented Research (SPOR), and the generous support of 27 funding partners from public and private sectors across Canada. We are thrilled to have this unique opportunity to tackle the challenge of meaningfully improving the lives of children with brain-based disabilities and their families.

We are proud of how far we've come, nonetheless the work is just starting. In this first year of operations, we learned that setting up a national network is no small challenge. Most of our time and resources went into setting up the network's administrative footing:

- We hired and trained passionate network, program, and project staff
- We set up a central office, work processes, and databases that enable our pan-Canadian network members to work efficiently together
- We branded our network with a name, logo, and visual identity
- We launched multiple communication channels in French and English
- We established a reporting framework with CIHR
- Our 12 research teams developed full research proposals, submitted their projects for scientific peer review, and ethics approvals
- We worked with institutions and funders to release funding to our 12 multi-centre research project teams, four network programs, and two network services
- We recruited members from all our stakeholder groups and formed a governance structure, to include network committees and workgroups
- We started working with youth and parent advisors and other stakeholders to build our training curriculum
- And we started building many new and important relationships.

Thank you to everyone who helped us lay this important foundation! We are very grateful to have such a loyal and committed pool of patients and families guiding our work already, but at the same time, we all agree that there is still much work to be done.



Diversity of opinions and experiences is important! The voices of children and youth with disabilities and their families is essential in ensuring that the research we do is relevant and will have important impacts on better health outcomes and better health care services.

We recognize that to consider all the challenges faced by Canadian families of children with brain-based developmental disabilities and by the children themselves, we need to hear from everyone, including those less often heard... those who live in more remote areas, those who face language barriers, those who don't typically share information about their experience due to lack of opportunity, fear of stigmas, financial concerns, or accessibility issues.

Learning how to reach all patients and families is one of our priorities for the coming years.

Another priority is to identify effective engagement strategies for patients. What is the best way to involve patients in research in Canada? How can their engagement translate into maximum impact? What approaches should we promote and encourage? How can all stakeholders—including patients, families, researchers, health care professionals, and policy makers—collaborate better to improve outcomes for children with disabilities?

Patients and families hold the precious answers to some of these questions.

So as you read this Report to Community and learn more about us and what we do, please give some thought to the issues you would like to bring up, to the families you know that our work may touch, and please reach out to us to learn how you can get involved.

Engage with us! We want to hear from you!

Very gratefully,

Annette Majnemer OT, PhD, FCAHS

Letter from Frank Gavin

Chair of the CHILD-BRIGHT Citizen Engagement Council



I am honoured and delighted, as the Chair of CHILD-BRIGHT's Citizen Engagement Council, to welcome you to our network. As the parent of a child with a brain-based developmental disability, now a terrific and accomplished young adult, I can attest to the importance of patient and family involvement in research. All of us have expertise grounded in our own experience, and our unique and indispensable contributions are helping to steer the work of research teams towards priorities and outcomes that matter to us.

I am therefore especially proud and heartened that at CHILD-BRIGHT, patients and parents hold leadership roles in all key committees and activities.

The Citizen Engagement Council, as CHILD-BRIGHT's main patient representation body, provides important guidance to the network on how to best engage the many individuals and communities who will (and should) be affected by CHILD-BRIGHT's work.

In our first year, we:

- Provided advice on ways to recruit patients and family members and match them to research projects and working groups
- Recommended speakers and important topics to address at CHILD-BRIGHT's first conference, the Brain-Child-Partners Conference 2017 (www.brainchildpartners.ca)
- Helped guide the design and content of the website
- Collaborated with network staff to develop compensation guidelines for patients and family members working on network teams
- Reviewed a variety of materials to ensure they reflected patient and family priorities and were written using patient-oriented language.

Our goal is to align all network programs, tools and resources to be patient oriented, to help accelerate the translation of research findings into better patient care and health care policy, and to find ways to encourage more patients and families to get involved in our work.

As one of only seven nationally funded Strategy for Patient-Oriented Research (SPOR) networks, we are striving to put in place a solid foundation that will serve as an example to others.

To best represent the wide variety of stakeholder groups we aim to represent and engage, we also built our Citizen Engagement Council to bring together people with distinctly different perspectives. We are composed of patients, parents, clinicians, a hospital CEO, the leader of a provincial child-health agency, the leader of a national organization of pediatric health centres, and CHILD-BRIGHT's Principal Investigator.

Our pan-Canadian team looks forward to convening in person for the first time at the Brain-Child-Partners Conference 2017 in Toronto this coming November. Here, we will review our first year's activities, identify priorities for the coming year, and consider how the network can engage new network members and deepen already established relationships.

We would love to meet you there.

Visit our event website to learn more :

www.brainchildpartners.ca

And please join us so we can put our voices together for children with brain-based developmental disabilities and their families!

Frank Gavin



What is patient-oriented research?

Patient-oriented research refers to a continuum of research that engages patients as partners, focuses on patient-identified priorities and improves patient outcomes. This research, conducted by interdisciplinary teams in partnership with relevant stakeholders, aims to apply the knowledge generated to improve health care systems and practices.

“I feel a sense of excitement at the end of teleconference meetings because I feel I'm a part of something that could truly make a change, make a difference. That momentum stays with me and fuels me to dive back into the daily ritual of therapy and appointments and schedules that support my son.”

Sasa Drover, patient representative & mother of a 4-year-old boy with ASD and VACTRYL association disorder

“Shelley has 20 years of experience as a counselor and I'm a Special Education teacher. We have three children, all with Fetal Alcohol Spectrum Disorder (FASD), Mild Intellectual Disability (MID), and Attention Deficit Hyperactivity Disorder (ADHD). We understand the challenges of finding support in a rural setting, and the importance of being strong advocate voices for those in need.”

Rob and Shelley More, Parent Advisors, Strongest Families

“I thought nothing could be harder than the NICU. Turns out the first year home is harder. We really struggled with appointments, services, and stress! We are thrilled that someone is doing something about this.”

Anonymous parent

“Accessibility and barriers are particularly pronounced for ‘invisible’ disabilities and delays - particularly for families without knowledge, language, or resources. Calling your program ‘Strongest Families’ is so suiting!”

Kari Welsh, Parent Advisor, Strongest Families

“I feel privileged to be part of an incredible team whose efforts and dedication have not only inspired me but have instilled hope within me, that a greater future exists for families touched by autism. My participation in the study has encouraged me to reflect on the journey and the challenges we have faced since our son's diagnosis, and given me the opportunity to use this experience to make a positive impact on the development of future services.”

Mother of a 4-year-old boy

“We are going to help children with chronic disease live longer, healthier, more successful lives. We will involve patients in the process, will listen to their needs, and will help ensure their voices are part of the conversations moving medicine forward and improving outcomes.”

Symon Hay, Patient and CHILD-BRIGHT Citizen Engagement Council Member



Research



“By strategically leveraging connections, and fostering engagement of families with researchers, we have the opportunity to make the Research Program greater than the sum of its parts.”

Dr. Steven Miller

CHILD-BRIGHT’s pan-Canadian research program team will study 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.

Building a Network That is Greater Than the Sum of its Parts

CHILD-BRIGHT's Research Program brings together 12 research project teams and 24 Principal Investigators from across the country around one common goal: improving the lives of children with brain-based developmental disabilities and their families through patient-oriented research.

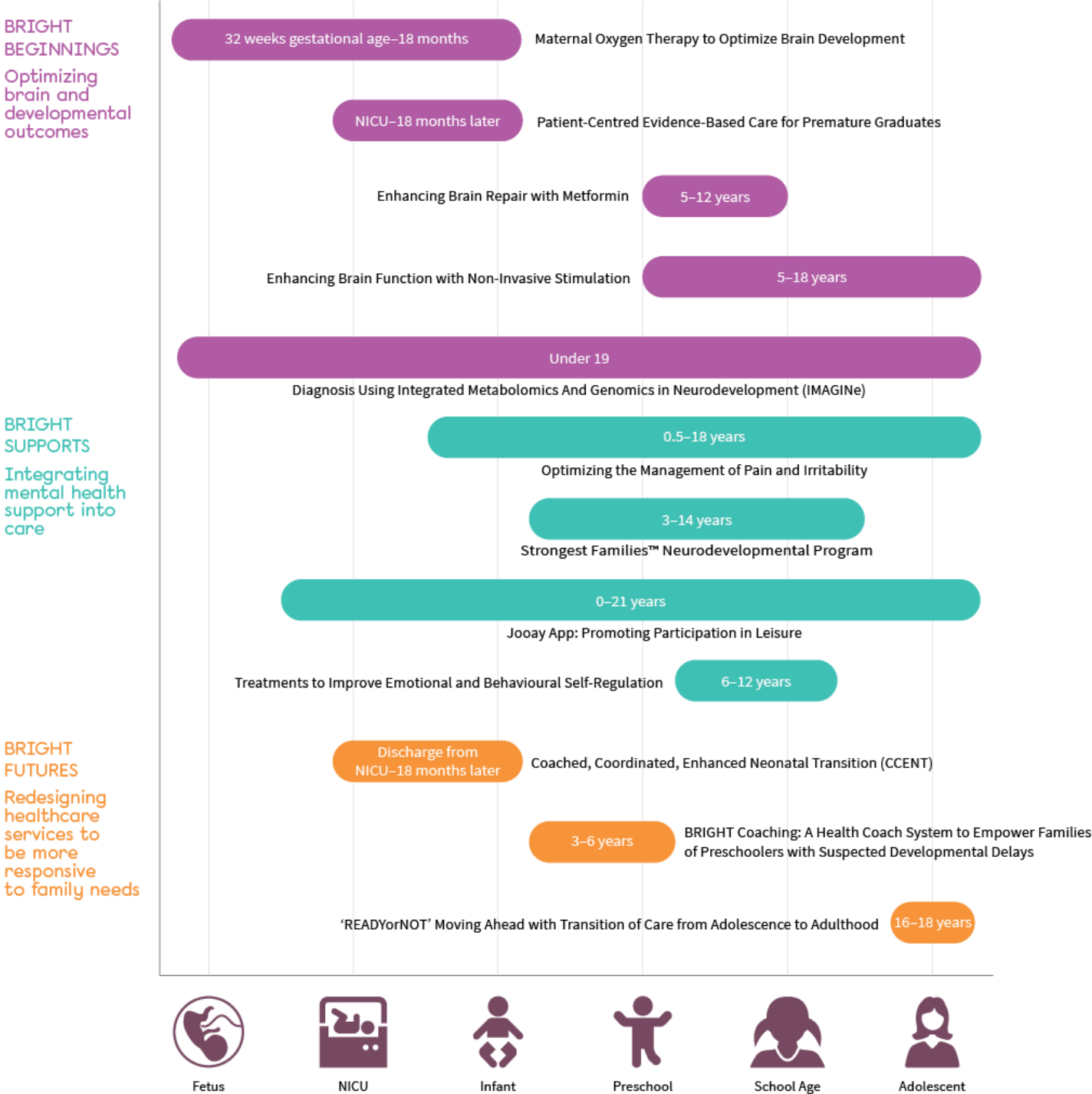
To best accomplish this goal, teams work collaboratively within research themes (BRIGHT Beginnings, BRIGHT Supports, and BRIGHT Futures). This collaborative approach helps maximize efficiencies and allows teams to leverage each other’s expertise, and resources. Together, in this first year of collaborative work, the teams:

- Put in place a peer review process that enhanced each project
- Hosted theme-wide teleconferences to discuss common research priorities and established procedures for working together within themes
- Worked to optimize the language used in ethics applications to help projects move forward more efficiently in their research ethics board applications and approval processes
- Identified and discussed project measures shared among different projects and best practices for patient engagement in pediatric research, which are a common focus for each of our interactions.

A Research Program Committee, composed of 7 dedicated members, helps oversee and provide direction to all research teams.

CHILD-BRIGHT Research Themes & Projects

CHILD-BRIGHT’s 12 research projects fall under three themes and focus on critical issues surrounding brain-based developmental disabilities across the pediatric age range.





RESEARCH THEME 1:

BRIGHT Beginnings

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 will 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 that will promote resilience, improve the child's physical and mental health, and enhance overall well-being.

Maternal Oxygen Therapy to Optimize Brain Development

Principal Investigators: Dr. Mike Seed and Dr. Steven Miller (SickKids)

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.



Parent-Centred Evidence-Based Care for Premature Graduates

Principal Investigators: Dr. Anne Synnes (BC Women's Hospital) and Dr. Prakeshkumar Shah (Mount Sinai Hospital)

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.



Enhancing Brain Repair with Metformin

Principal Investigators: Dr. Donald J. Mabbott (SickKids) and Dr. Darcy Fehlings (Holland Bloorview Kids Rehabilitation Hospital)

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.



Enhancing Brain Function with Non-Invasive Stimulation

Principal Investigator: Dr. Adam Kirton (University of Calgary)

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.



Diagnosis Using Integrated Metabolomics And Genomics In Neurodevelopment (IMAGINE)

Principal Investigators: Dr. Jan M. Friedman and Dr. Clara van Karnebeek (University of British Columbia)

Brain injuries in early life are commonly thought to cause many cases of cerebral palsy, but in some children, cerebral palsy-like conditions are caused by genetic or metabolic abnormalities. 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.





RESEARCH THEME 2:

BRIGHT Supports

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 will be evaluated in children with a wide range of developmental disabilities. Health promotion strategies that foster fitness and social participation will also be developed. The four BRIGHT Supports projects will also fill a critical gap by offering family-centred ‘help-giving’ practices to support parents in their role as caregivers.

“We are implementing exciting patient-oriented research trials to bring us towards the day when every child has a healthy start, strong mind, and bright future.”

Dr. Steven Miller
Co-Director, CHILD-BRIGHT Network

Optimizing the Management of Pain and Irritability

Principal Investigators: Dr. Hal Siden and Dr. Tim Oberlander (BC Children's Hospital / University of British Columbia)

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.



Strongest Families™ Neurodevelopmental Program

Principal Investigators: Dr. Patrick J. McGrath (IWK and Nova Scotia Health Authority) and Dr. Lucyna Lach (McGill University Health Centre)

Children with brain-based developmental disorders 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 brain-based disorders through parenting programs that include education, telephone support, and parent-to-parent connections.



Jooay App: Promoting Participation in Leisure

Principal Investigator: Dr. Keiko Shikako-Thomas (McGill University)

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.



Treatments to Improve Emotional and Behavioural Self-Regulation

Principal Investigator: Dr. Jennifer Crosbie (SickKids)

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.





RESEARCH THEME 3:

BRIGHT Futures

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 will focus 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.

“My hope is that the knowledge we generate will lead to better health care experiences and will transform the lives of youth with brain-based disabilities as they journey into adulthood.”

Dr. Jan Willem Gorter
CHILD-BRIGHT Principal Investigator

Coached, Coordinated, Enhanced Neonatal Transition (CCENT)

Principal Investigators: Dr. Eyal Cohen (SickKids), Dr. Julia Orkin (SickKids), Dr. Nathalie Major (CHEO), and Dr. Paige Church (Sunnybrook Health Sciences Centre)

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, who will provide ongoing support in the community to help care for their child using an acceptance and commitment therapy framework, and we will compare the experience, stress, and health to the experience of families who receive standard care consisting of regular neonatal follow-up without this level of support.



BRIGHT Coaching: A Developmental Coach System to Empower Families of Preschoolers with Developmental Delays

Principal Investigators: Dr. Annette Majnemer (McGill University Health Centre) and Dr. Maureen O'Donnell (Child Health BC)

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.



'READYorNOT' Moving Ahead with Transition of Care from Adolescence to Adulthood

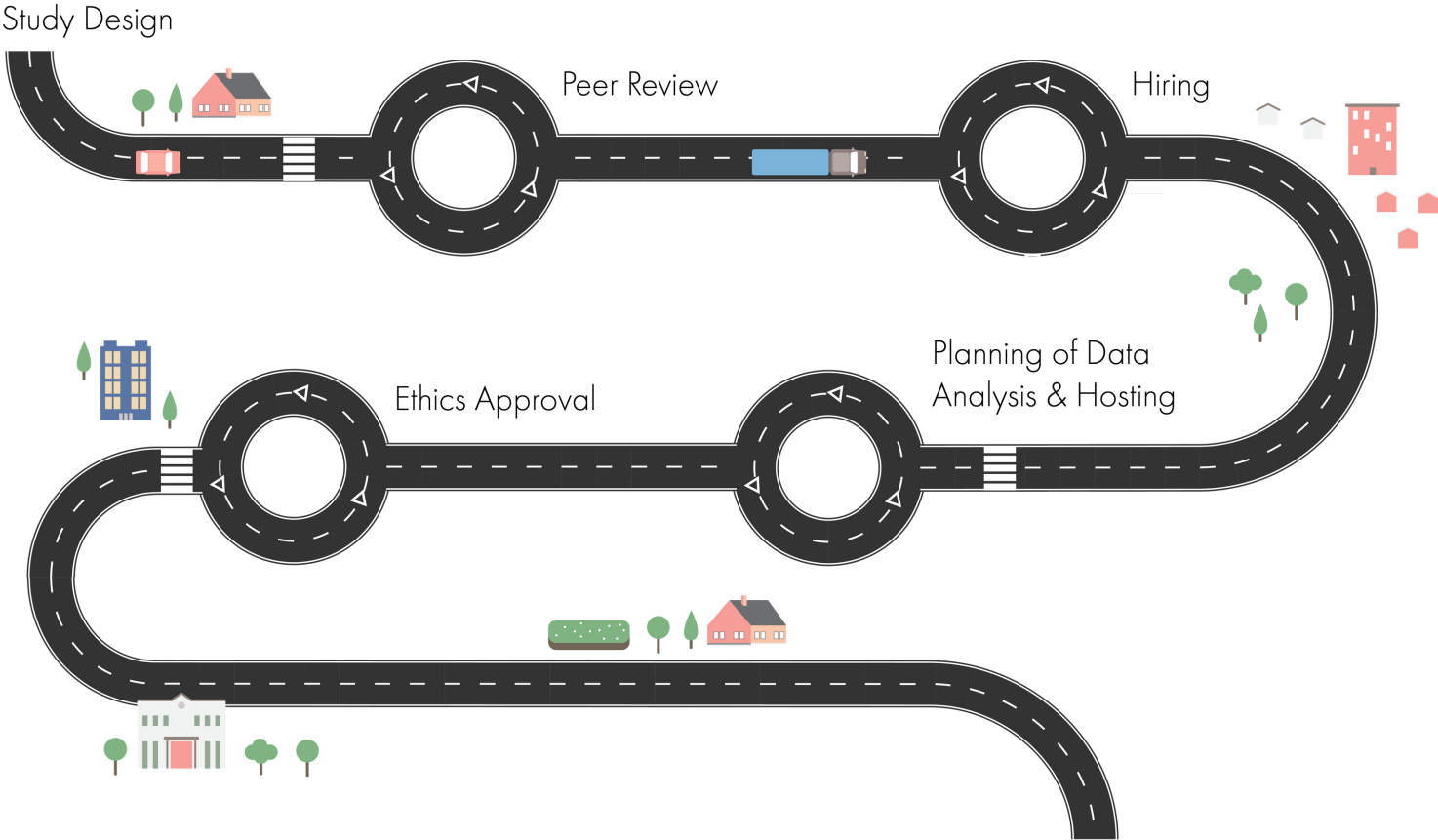
Principal Investigators: Dr. Ariane Marelli (McGill University Health Centre), Dr. Jan Willem Gorter (McMaster University), and Dr. Khush Amaria (SickKids)

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.



The Road to Research Success

STUDY START-UP



Clinical research is complex and involves many regulatory stages. This chart illustrates the multiple steps required to initiate a clinical research project or study, and the progress made by each of CHILD-BRIGHT’s 12 research projects in Year 1.

[MORE ABOUT EACH STEP](#) 

STUDY START-UP

1

STUDY DESIGN

Researchers combine their existing expertise with novel ideas put forward by their team to design a protocol, intervention, and outcome measures for their study.

CHILD-BRIGHT researchers and patient representatives collaborated to design 12 patient-oriented studies for the network.

2

PEER REVIEW

Proposed studies are anonymously reviewed and enhanced by subject matter experts.

Each CHILD-BRIGHT project was reviewed by at least two individuals during Year 1.

3

HIRING

During Year 1, 10 of 12 CHILD-BRIGHT project teams hired staff to initiate their study.

4

PLANNING OF DATA ANALYSIS AND HOSTING

Plans to analyze and host data collected by researchers require substantial preparation before studies begin.

During Year 1, members from 8 CHILD-BRIGHT studies consulted with our Data Coordinating Centre to discuss database management and the legal processes that are required for safely hosting data.

5

ETHICS APPROVAL

Research institutions have ethics boards that rigorously review study designs to ensure that participants will be treated fairly. Applications to research ethics boards include the study protocol, consent forms, data collection forms, recruitment pamphlets among other documents.

During Year 1, 3 CHILD-BRIGHT studies received approval from their research ethics board and 3 more submitted their applications and are awaiting responses from their research ethics board.

The start-up phase of clinical studies includes substantial scientific, ethical, and legal review processes that take time. After these processes are complete, researchers move toward pilot testing or recruitment of subjects.

Knowledge Translation



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

Establishing our Committee

In our first year, our program team made up of three co-chairs and one program officer put together and mobilized a group of 11 dedicated committee members, all individuals who strive to advance the science of Knowledge Translation (KT) at a national level. Our newly formed committee convened six times in Year 1 to brainstorm ways to advance KT of research.

Establishing Patient Leadership

In January 2017, we welcomed Connie Putterman, the parent of a child with a brain-based disability, as our program's Parent Lead. She co-chairs the KT Program alongside Drs. Keiko Shikako-Thomas and Jonathan Weiss and contributes an essential parent perspective on all our decisions. With her input, we have already improved our program communications, increased stakeholder diversity representation, and broadened our engagement initiatives to engage with greater impact.



Forming New Partnerships

In collaboration with the Quebec SPOR Support Unit, we are adapting a stakeholder engagement questionnaire for francophone stakeholders across Canada. This process is called a transcultural adaptation. The purpose of the questionnaire is to measure the level of stakeholder engagement at the beginning of the CHILD-BRIGHT research project development, and then track the progression of stakeholder engagement activities and its outcomes in the long-term.

Learning How CHILD-BRIGHT Research Can Support Political Agendas

The KT program team worked closely with network researchers and health care practitioners in childhood disabilities this year to expand our understanding and expertise in Canadian emerging policy considerations. We produced three policy briefs on issues and policy considerations that we presented to the appropriate Ministries, in the hopes of introducing CHILD-BRIGHT as a national source of evidence-based knowledge on topics currently on the political agenda such as the new federal accessibility legislation.

Developing a New Pan-Canadian KT Initiative

As part of our activities, we are gearing up to launch a new pan-Canadian initiative called the Knowledge Translation Innovation Incubator, an initiative that will create a setting where researchers, patients, and other stakeholders can talk together about a KT research idea that can advance stakeholder engagement, and leverage our network's expertise to develop it. The initiative will be launched at our Brain-Child-Partners Conference 2017.



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, 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.

Identifying Needs and Resources

To help establish our program's strategic direction, we disseminated a survey to identify the needs and expectations of network members. We also performed an environmental scan of pediatric research training opportunities already offered in Canada to avoid duplicating their efforts, and to identify potential collaborations for the future.

Establishing our Committee Membership

In our first year, we formed a committee composed of nine dedicated individuals, all committed to helping advance patient-oriented research in Canada for all stakeholder groups, including youth, families and researchers. Our newly formed committee convened seven times this year.



Piloting New Workshops

In September 2016, members of our team attended “Train-the-Trainer” sessions in Ottawa to learn more about CIHR’s National Pilot Curriculum on Patient-Oriented Research, a curriculum geared to teaching research teams (including patients) about patient-oriented research. Following our training, we collaborated with two other SPOR Networks, IMAGINE and Can-SOLVE CKD, as well as the BC SUPPORT Unit to roll out this curriculum five times in British Columbia during the current reporting period.

Laying the Foundation for Involving Youth in Research

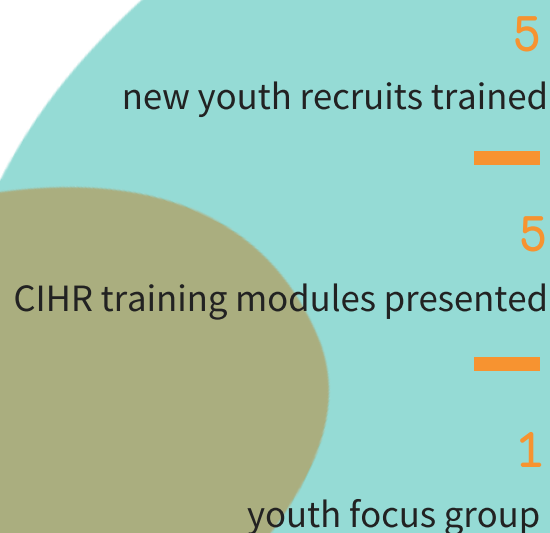
To build a more pediatric-focused training program and give youth an advisory role in CHILD-BRIGHT projects, we partnered with KidsCan, a Young Person’s Advisory Group based out of the British Columbia Children’s Hospital Research Institute. Teen KidsCan advisors will help us adapt our training material and approach to be more accessible to youth aged 13 to 18. In Year 1, after piloting CIHR’s Patient-Oriented Research workshop titled *Introduction to Health Research in Canada* to a current set of KidsCan advisors, we solicited their feedback and set out to design a workshop that was more accessible to youth. Our goal is to use this module to better educate youth about how research projects unfold, how basic biomedical research differs from clinical research, and to teach them about the role and processes of ethics and peer review, so they can better engage with us and other research teams as partners and influencers in the future.

Establishing Patient-Oriented Summer Studentship Opportunities

In March 2017, we rolled out a framework to help researchers hire undergraduate students and meaningfully engage them to advance awareness of patient-oriented research, and its benefits, during the summer period.

Building Strategic Partnerships

We identified and pursued partnerships this year with other SPOR-funded entities that will help us build pediatric and family friendly training curriculums.



Citizen Engagement



As a network working under Canada's Strategy for Patient-Oriented Research, 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 is leading this effort.

Building a Council to Represent Patients

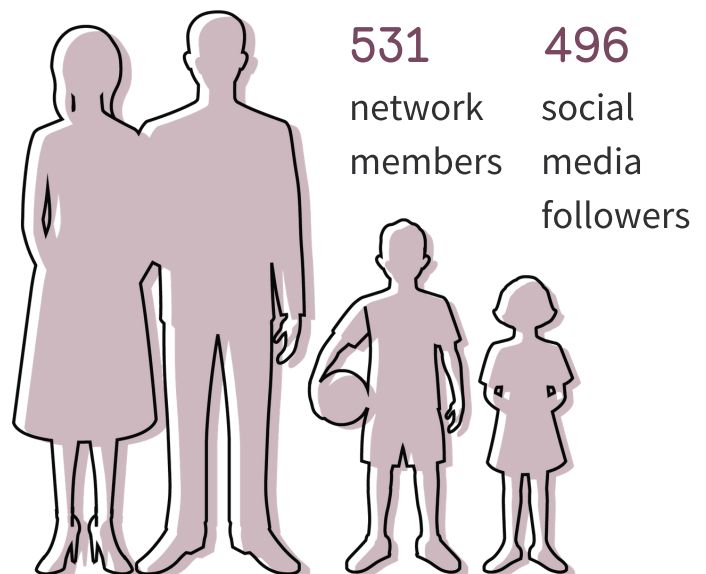
To orient all network programs, tools, and resources around the patient, we formed a Citizen Engagement Council. Our 11 council members help ensure that patients and families engage and hold leadership roles in our network, influence our work, and help accelerate the translation of research findings into patient care and health care policy.

Developing a Matching Process & Compensation Guidelines

In collaboration with the Knowledge Translation program team co-chairs, we are developing a network tool that will help us advertise opportunities for patient involvement in our network and research projects, and subsequently match interested citizens to these opportunities. We also developed compensation guidelines to support the contribution of patients and families in research, governance and other significant activities in our network.

Establishing an Engagement Framework & Measurement Tools

In collaboration with our Data Coordinating Centre, we are developing tracking tools that will help us measure patient and citizen engagement throughout our five-year mandate.





Supporting Research Program and Teams

Over the course of our first year, we met with research and project leads to share patient engagement strategies and help these teams set up their projects to comply to Canada's Strategy for Patient-Oriented Research (SPOR) model and requirements. We are also contributing to the selection of an online platform to support the development of a community of practice for parents.

Growing Awareness

Members of our network participated in a number of speaking engagements over the year and represented the network at SPOR events, to help grow awareness of our work and promote patient involvement. For example, two of CHILD-BRIGHT's directors, as well as some administrative staff, project team representatives, funding partner representatives, and patient representatives attended CIHR's Strategy for Patient-Oriented Research (SPOR) Summit in Ottawa from October 25-27, 2016. This event brought together 300 SPOR stakeholders, including patients, federal/provincial/territorial ministries, partners, researchers and clinicians, and allowed CHILD-BRIGHT team members to exchange with other attendees about our network's mission and vision, and also host a widely visited booth at the event's marketplace.

Branding our Network & Launching Communication Channels

To promote our network to pan-Canadian audiences and attempt to reach all stakeholders touched by brain-based developmental disabilities, we branded our new network with a logo and distinct visual identity. We also initiated several communication channels including a network website, internal and external newsletters, social media feeds (Twitter and Facebook), an intranet, and various printed publications such as a brochure and project description sheets, most in both English and French.



BRAIN-CHILD-PARTNERS CONFERENCE

NOVEMBER 6-8, 2017 | TORONTO, CANADA



Planning our First Conference

In partnership with Kids Brain Health Network, and in close collaboration with our Citizen Engagement Council, we started planning our first annual meeting, the Brain-Child-Partners Conference 2017, which will be held from November 6-8, 2017 in Toronto. Learn more at:

www.brainchildpartners.ca

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.

A Study is Only as Good as its Data

To provide the evidence needed to create brighter futures for children with brain-based developmental disabilities, researchers need well-developed, secure, easy-to-use systems to capture and manage their study data. The DCC helps ensure that CHILD-BRIGHT research teams have data systems that are tailored to their needs.

Located at the Women and Children's Health Research Institute (WCHRI), University of Alberta, the DCC team provides a wide range of services to the CHILD-BRIGHT network including research database setup, data management, data analysis and interpretation, data reporting and visualization. In the past year, we:

- Established our DCC service platform
- Developed materials, documents, and guidelines to facilitate efficient database setup
- Met with 8 of the 12 network project teams to better understand their data needs, to develop relevant work plans
- Explored options for standardizing data to facilitate data sharing and future secondary use within the network
- Provided statistical planning support to four project teams
- Initiated database build with three project teams
- Hired a data scientist.

“Our work will ensure that the research data contributed by patients, parents and families is well managed, kept private and secure, and used to maximum effect.”

Tanya Voth, Co-Lead, Data Coordinating Centre

Health Economics

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. They provide expertise on choosing valid outcome measures for resource use and quality of life,



and assist with customization for particular studies. We work closely with each project team and the Data Coordinating Centre to enable and promote the conduct of high-quality economic evaluations alongside relevant projects.

Understanding the Value and Impact of Emerging Technologies

Children with a brain-based developmental disability and their families often experience challenges in getting access to optimal care, and sometimes also encounter economic challenges. At the same time, the health care system faces growing economic pressure to deliver cost-effective care. Understanding the value for money of emerging technologies and their impact on the quality of life of children and caregivers is essential evidence to informing adoption decisions. The Health Economics team is working closely with individual CHILD-BRIGHT teams to design and collect the data required to generate this evidence. This work will also propel forward our knowledge regarding the costs of brain-based disabilities to families, to the health care system, and to society. In the past year, we:

- Met with CHILD-BRIGHT’s 12 project teams
- Provided detailed resource use questionnaires
- Consulted on the use of quality-of-life and caregiver burden instruments
- Coordinated activities with the Data Coordinating Centre
- Secured a network-wide Health Utilities Index (HUI) license.

“The integration of common evaluation measures into each of the research projects will be essential in demonstrating the impact of CHILD-BRIGHT research and informing policy to improve the lives of children and families with a brain-based disability.”

Jennifer Zwicker, Co-Lead, Health Economics Platform



Committees

** Non-voting members*

Executive Committee

Annette Majnemer (Chair) - Frank Gavin - Daniel Goldowitz - Steven Miller - To Nhu Nguyen

International Scientific Advisory Committee

Deborah Hirtz (Chair) - Nadia Badawi - Diane Damiano - Amy Houtrow - Beatrice Latal - Steven Miller*
Christopher Morris - Stephen Scherer

Network Steering Committee

Annette Majnemer (Chair) - Steven Miller (Vice-Chair) - Alan Cooper* - Allison Eddy - Frank Gavin - Daniel Goldowitz
Astrid Guttmann - Adam Kirton - Nathalie Major-Cook - Michelle Marquis* - Nancy Mason-MacLellan*
Patrick McGrath - To Nhu Nguyen* - Nancy Poole - Michael Shevell - Donna Thomson - Pierre Zwiegers*

Partnership and Sustainability Committee

Michael Shevell (Chair)

Research Committee

Steven Miller (Chair) - Alan Cooper - Lucyna Lach - To Nhu Nguyen - Julia Orkin - Kate Robson - Keiko Shikako-Thomas

Knowledge Translation Committee

Keiko Shikako-Thomas (Co-Chair) - Jonathan Weiss (Co-Chair) - Connie Putterman (Co-Chair) - Chantal Camden
Julie Caron - Noemi Dahan-Oliel - Mayada Elsabbagh - Aryeh Gitterman - Stephanie Glegg - Janet Jull - Ariane Marelli
Christine Marcotte - Michelle Marquis - Natalie Murdock - Jennifer Sprung

Training Committee

Dan Goldowitz (Chair) - Nancy Feeley - Marie Brossard-Racine - Frank Gavin - Janet McCabe - Tim Oberlander
Amy Outschoorn - Pierre Zwiegers - 1 member who wishes to remain unnamed

Citizen Engagement Council

Frank Gavin (Chair) - Maureen O'Donnell - Symon Hay - Tracy Kitch - Annette Majnemer* - Maryam Oskoui
Sue Robins - Kate Robson - Donna Thomson - 2 members who wish to remain unnamed

Our 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.

Platinum Partners (\$1M +)



Gold Partners (\$500,000 to \$999,000)



Silver Partners (\$100,000 to \$499,000)



Bronze Partners (\$1 to \$99,999)



YOUR VOICE IS THE ONE THAT MATTERS!

Join us & influence our decisions



On our website:

www.child-bright.ca

At our conference:

www.BrainChildPartners.ca



CHILD-BRIGHT
Network

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