BRIGHT BEGINNINGS

Optimizing brain and developmental outcomes

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 preterm. 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 motor learning in healthy children and adults with stroke but we don't yet know how much it can help children with stroke achieve better function. Here, we will conduct a clinical trial across Canada to test whether non-invasive brain stimulation improves motor learning in children with motor difficulties (cerebral palsy) and, if so, how.

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.

BRIGHT SUPPORTS

Integrating mental health support into care

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 daily function for the child and family, and simplifying treatment options for clinicians.

Strongest Families™ Neurodevelopmental Program

Principal Investigators: Dr. Patrick J. McGrath (IWK) 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.

BRIGHT FUTURES

Redesigning healthcare services to be more responsive to family needs

Coached, Coordinated, Enhanced Neonatal Transition (CCENT)

Principal Investigators: Dr. Nathalie Major (CHEO), Dr. Julia Orkin (SickKids), and Dr. Eyal Cohen (SickKids)

Better medical care has helped many women with challenging pregnancies deliver babies however, some babies are born with serious and chronic conditions. These 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, and will compare their experience to the experience of families who receive standard care consisting of regular medical checkups without continued support between appointments.

BRIGHT Coaching: A Health 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 whereas children with brain-based developmental disabilities may struggle in the development of such skills. Accessing the best diagnostic and interventional care, and the best services during this important period of their child's development may be challenging. This study asks whether a standardized and nationally available online health tool and coaching resource is feasible and helpful to parents as their 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.