

2022-23

## IMPACT REPORT





### **OUR VISION**

All children living with neurodevelopmental disabilities enjoy a good quality of life, inclusion in all aspects of society and the attainment of their full potential.

### **OUR MISSION**

Through catalyzing collective action across sectors, Kids Brain Health Network ensures optimal care and better outcomes for children with neurodevelopmental disabilities and their families.

### **EXECUTIVE MESSAGE**

### SOLUTIONS FOR A HEALTHY FUTURE



**Nicky Lewis**Chief Executive Officer, KBHN



**Dr. James Reynolds**Chief Scientific Officer, KBHN

To summarize everything Kids Brain Health Network accomplished in 2022-23 is a challenge, and that speaks to the wide-ranging collective efforts made to make meaningful change for children with neurodevelopmental disabilities (NDDs) and their families. Thousands of people from many sectors—including families themselves—contributed to the network's initiatives, which spanned scientific innovations, training programs, a global conference, implementation projects and policy recommendations.

Encouragingly, Canada made a formal commitment this year to financial security for people with disabilities (with Bill C-22, the Canada Disability Benefit Act) and Canada-wide affordable childcare services (with Bill C-35, the Canada Early Learning and Childcare Act). In both cases, KBHN executive management and affiliated experts worked to ensure that children with disabilities would be included among those who would benefit.

We engaged with the federal government in other ways as well. For instance, KBHN made disability-inclusive recommendations for the federal COVID-19 recovery plan, to reduce the risk of long-lasting pandemic-related harm to the physical and mental health of families living with NDDs. By invitation, KBHN's CEO also presented to the Standing Committee on Science and Research on the importance of co-producing research with families, so that they will have more opportunities to inform and fully engage with research that concerns them going forward. And we contributed further to Canada's national autism strategy through a third year of policy-development practicums and a new policy-to-data fellowship.

Finally, we applied to the inaugural competition of the Strategic Science Fund. New investments are crucial to our ability to continue advancing the well-being of some of Canada's most vulnerable kids for years to come.

The solutions that KBHN has developed over the past 13 years are already making a difference. To name a few, these include function-based interventions that can begin even before a formal diagnosis is available, tools for addressing health challenges that disproportionately affect kids with NDDs, and systems of support that are easier for families to navigate.



KBHN CEO Nicky Lewis meets with Members of Parliament Charles Sousa and Lena Metlege Diab, accompanied by Dr. Andrea Cross and Connie Putterman from the Family Engagement in Research program.

To enable some of our most successful solutions to reach as many people as possible, we are supporting 12 evidence-informed implementation projects as they spread and scale across Canada's broad geography and diverse communities. Some of the families who've benefitted from them have graciously agreed to share their stories in inspiring videos that will help KBHN to connect with even more implementation partners going forward.

We're not stopping there: five new projects recently got underway through the Strategic Investment Fund. This pipeline of innovations, established by KBHN in partnership with Brain Canada, aims to improve quality of life for children with NDDs and their families in the near term. We specifically targeted projects with an established evidence base that are designed to spark positive changes in practice or policy, develop new applications for existing technologies or expand solutions in KBHN's three focus areas: early diagnosis, effective interventions and family support.

As a network, we serve as a nexus for people and organizations across diverse sectors to join forces for a common goal. We thank our many partners for their immense and invaluable contributions to our collective work together, and we welcome the prospect of collaborating with all others who want to help shape the flourishing future that every child deserves.

# AN UPDATE FROM OUR FOUNDATION

Kids Brain Health Foundation raises funds to allow KBHN to expand the reach and sustainability of its transformative solutions for children with neurodevelopmental disabilities and their families.

In late 2022, we hired our first director of fundraising, Jane Dafoe, who brings over 20 years of diverse experiences to the role. She has been working closely with the foundation's board and KBHN's CEO in areas such as governance, operational support and priorities. The board has adopted an ambitious goal of raising \$10 million over five years. It is focused on sustaining the legacy of KBHN's most impactful projects that bring meaningful benefits to kids, families and communities.

To initiate our fundraising efforts, we invited network/foundation board members and staff to contribute an amount that was meaningful to them. This gave the Foundation some positive momentum to build on.

We are continuously focused on building and nurturing relationships with donors who share our vision of a world where children of all abilities can thrive. We hope to make some gift announcements shortly and look forward to building upon this encouraging momentum in the years to come.

Thank you once again to our generous donors! We encourage you to join them.



**Sheila Laredo**Chair, Kids Brain
Health Foundation

# **A SNAPSHOT OF 2022-2023**



People

207

Trainees developed their capacity in both research and practice

114

Partner organizations contributed to research and implementation projects

9,876

Stakeholders participated in **386** engagement events



**Knowledge and Innovation** 

17

Research and implementation projects

32

New academic publications

33

Academic training events



**Implementation** 

4

New clinical-practice guidelines

11

New policy documents

4

Commercial products in development

36

New training resources and tools for parents and frontline professionals

# OUR OBJECTIVES AND IMPACT

KBHN trainee Maude Champagne's work addressing child/teen aggression toward family or caregivers won a national Mitacs Award for Outstanding Innovation.

So far, over **800** families have benefitted from Social ABCs, a program that fosters socialcommunication skills in toddlers with suspected autism. KBHN formed a new partnership with SFU Venture Labs to help its researchers bring their products and solutions to market.









Conduct highquality, relevant research



Translate knowledge into practice



Develop highly qualified personnel who can excel at research or meeting the needs of children with NDDs and their families



Improve outcomes for children with NDDs and their families



KBHN researchers trained over **3,239** frontline service-delivery personnel in evidence-based interventions and programs.



**61** former KBHN trainees now hold positions in universities and research institutes. **150** work in health and medicine.



To date, KBHN's peerreviewed articles have been cited **14,578** times, an average of **34** times each.



# OUR THREE FOCUS AREAS

### **Early Identification**

Too often, children with NDDs are not identified during the critical early periods of brain development when interventions have the greatest impact. Research funded by KBHN is breaking down barriers to assessment and pushing diagnostic capacity into infancy.

### **Early Intervention and Effective Treatment**

Childhood interventions for neurodevelopmental disabilities open opportunities for very real progress, which means they must be accessible in all parts of the country and to diverse cultural and linguistic groups. KBHN is working at the cutting edge of treatment, to ensure that all families can benefit early on.

### **Family Support**

Families raising children with neurodevelopmental disabilities face challenges that affect most aspects of their lives. Our research is identifying the most effective solutions to help families reduce stress and give their children what they need to live their best lives.



### **OUR SOLUTIONS**

### **EARLY-IDENTIFICATION PROJECTS**



### Early Detection and Intervention Toolkit for Children With Cerebral Palsy (EDIT-CP)

#### **Principal investigators:**

Dr. Darcy Fehlings, Holland Bloorview Kids Rehabilitation Hospital

Dr. Annette Majnemer, McGill University

Dr. Tatiana Ogourtsova, McGill University

According to international guidelines, doctors should ideally diagnose cerebral palsy (CP) before a baby's first birthday. This way, the child can access early interventions that will help them reach their fullest potential for movement and function. However, the average age for a CP diagnosis in Canada is 18.9 months.

To address this shortcoming, the EDIT-CP project is supporting the integration of early-detection tools in both family doctors' offices and neonatal follow-up programs, which monitor infants who are at high risk of developmental conditions. They're also helping to build capacity for early interventions, with a particular emphasis on Baby CIMT, a treatment that is often helpful for a common kind of CP.



### **Genetic Screening for FASD Risk**

### **Principal investigators:**

Dr. Geoff Hicks, University of Manitoba

Dr. Brenda Elias, University of Manitoba

Dr. Paul Pavlidis, University of British Columbia

Frank Turner, Cree Nation Tribal Health Services

These researchers are developing a screening method called FASD Code. It involves cheek swabbing and saliva sampling to test for changes that may occur throughout the genome after prenatal alcohol exposure. This makes it a simple, cost-effective way to identify young children who may turn out to have fetal alcohol syndrome disorder. Given that children are usually school-aged before they get a diagnosis, this innovation could allow families and service providers to understand and address a child's challenges sooner.



### The Infant and Early Mental Health (IEMH) Hub for Training, Resources, & **Tools**

### **Principal investigators:**

Dr. James Reynolds, Queen's University

Dr. Chaya Kulkarni, The Hospital for Sick Children

Mental health is crucial for people of all ages, and especially young children, because their brain development is the most active by far. The web-based Infant and Early Mental Health Hub aims to improve young kids' socioemotional development by enhancing the skills and knowledge of the practitioners who work with them, including social workers, early-childhood educators, home visitors and medical staff.

The IEMH Hub's rich and growing pool of resources include a free webinar that introduces the basic concepts of infant mental health, "pathways of care" that allow families and practitioners to find appropriate children's mental-health services in their geographic areas, and Nurturing the Seed, a culturally sensitive developmental-support program created in consultation with Indigenous communities across Canada.

### EARLY INTERVENTION AND EFFECTIVE TREATMENT PROJECTS



### The Babbly Application

### **Principal investigators:**

Dr. Anna McCormick, Children's Hospital of Eastern Ontario

Dr. Christopher Fennell, University of Ottawa

The Babbly app uses machine learning to analyze recordings of a child's voice and to assess their speech and language development. It also provides targeted speech-promoting activity suggestions. Designed to be fun and easy to fit into everyday routines, these activities give parents the chance to participate in their child's learning. KBHN's research is focused on finding out whether Babbly could help families who are waiting for speech and language evaluation and services, which can take up to a year or more to access in Canada.



### **Brain-Computer Interface (BCi) Move**

### **Principal investigators:**

Dr. Adam Kirton, University of Calgary

Brain-computer interfaces (BCIs) recognize changes in thought patterns through a non-invasive headset and transmit those signals to electronic devices. A child could think the word "go," for example, to move a scooter forward. The BCi-Move project aims to determine if children with severely limiting physical disabilities can use this cutting-edge technology to achieve personalized mobility goals. Its findings could lay the groundwork for independent play and the use of electric wheelchairs in everyday life.



### **Dino Island**

### **Principal investigators:**

Dr. Sarah J. Macoun, University of Victoria

Dino Island is a tablet-based game designed specifically for children with neuro-developmental disabilities (NDDs). Studies in children with autism, fetal alcohol syndrome disorder and attention-deficit/hyperactivity disorder have shown that it helps with attention, memory, self-regulation, emotional and behavioural control, self-confidence, problem-solving strategies and academic performance. A companion website trains therapists, teachers or parents to support children in playing the game and applying the skills it strengthens to other areas of life.

Through several studies involving hundreds of children in total, this project is expanding Dino Island's impact in home, community, clinical and school settings across Canada and internationally.



### eHealth for Neurodevelopmental **Disorders**

### **Principal investigators:**

Dr. Penny Corkum, Dalhousie University

Dr. Shelly Weiss, University of Toronto

This team is developing and implementing two online programs. The first addresses the fact that children with NDDs are at high risk of struggling to fall and stay asleep. This sleep disruption can affect their ability to feel well and do their best during the day. Better Nights, Better Days for Children with Neurodevelopmental Disorders (BNBD-NDD) is an e-health intervention that helps parents to improve kids' insomnia.

ASSIST (Accessible Strategies Supporting Inclusion for Students by Teachers) helps teachers to support students with NDDs. This meets a crucial need: most mainstream classroom teachers report they don't have adequate training to work effectively with this group of kids, despite growing demands upon them to do so.



### **Intelligent Device for Sound Sensitivity**

#### **Principal investigators:**

Dr. Elina Birmingham, Simon Fraser University

Dr. Siamak Arzanpour, Simon Fraser University

Many children living with autism are hypersensitive to certain sounds. Schools' approaches for accommodating sound sensitivity include letting students wear earplugs or earmuffs or allowing them to take breaks in a quiet area. Because such strategies block or avoid all sounds indiscriminately, they interfere with the child's full participation in class and other activities.

This team of researchers is developing a device that selectively filters or reduces specific noises that a child finds distressing (e.g., dogs barking, sirens, jackhammers) while allowing them to hear other sounds, such as the teacher's voice. This project's current goals are to test prototypes in virtual and in-person settings, to make improvements based on feedback and to plan for widescale commercialization.



### **KidsAction Coaching**

### **Principal investigators:**

Dr. Jean-Paul Collet, University of British Columbia

Participating in sports and recreation brings a whole host of benefits to kids with NDDs, including the development of healthy lifestyle habits, self-esteem, selfcontrol, physical abilities and social skills. However, community programs are often designed without them in mind.

KidsAction Coaching (KAC) helps programs become more accessible to all. It's an approach that involves understanding each child's specific abilities, adapting activities as needed and highlighting progress. KidsAction Coaching also engages children's families: coaches give parents a personalized list of activities they can practice with their child at home, along with access to instructions and videos.

This project's team is developing KAC resources and building partnerships with physical-activity programs across the country.



### The Math Interactive Learning **Experience (MILE) for the Classroom**

#### **Principal investigators:**

Dr. Jacqueline Pei, University of Alberta

Dr. Carmen Rasmussen, University of Alberta

Originally developed for children with fetal alcohol syndrome disorder, MILE is an evidence-based intervention geared toward building the underlying cognitive skills that are critical to math. Not only do math skills improve, but also behavioural functioning in the classroom. This creates a foundation for later success in math and school more generally.

MILE was originally a tutoring program that relied on individual or small-group instruction, which can be a tall order for schools with limited resources. To make MILE less costly to adopt, and to provide a more inclusive classroom experience, this research team adapted it for teachers to use with all the children in their class. They are now implementing this version of MILE in participating school divisions across Alberta and measuring its effectiveness.



### **Secret Agent Society**

### **Principal investigators:**

Dr. Vivian Lee, Carleton University

The Secret Agent Society: Small Group Program (SAS: SG) digital software provides fun espionage-themed activities and tools including a digital board game, role playing and a computer game. It targets core areas of difficulty for kids with autism, such as developing desired friendships, working in teams and problem-solving. SAS:SG also helps children recognize emotions, express them in helpful ways and cope with challenging ones.

Previously, this team had shown that SAS:SG is feasible and useful when delivered by autism-focused service providers. However, to reach all the kids who need programs like Secret Agent Society, not only autism centres but also publicly funded mental-health centres should be able to offer them. Therefore, the researchers are leading a study evaluating whether and how mental-health therapists could use the program to improve the well-being of autistic children.



### Social ABCs

### **Principal investigators:**

Dr. Jessica Brian, University of Toronto and Holland Bloorview Kids Rehabilitation Hospital

Social ABCs is a program for toddlers with diagnosed or suspected autism and those showing signs of delayed social communication. Given that evidence-based interventions for kids under age three have not been widely available, Social ABCs is filling a service gap at a key stage of brain development when kids may benefit the most. Trained coaches work with parents one-on-one or in a group setting, teaching them strategies for helping their toddlers to communicate and interact socially. KBHN-funded researchers are establishing the evidence base for Social ABCs and helping it to spread.

### **FAMILY SUPPORT PROJECTS**



### **Acceptance and Commitment Training** (ACT) for Family Caregivers

### **Principal investigators:**

Dr. Johanna Lake, Centre for Addiction and Mental Health

Dr. Yona Lunsky, Centre for Addiction and Mental Health

Dr. Kenneth Fung, University Health Network

ACT is an intervention that helps people improve their mental well-being by accepting their thoughts and feelings—even those that are painful—and living an engaged, meaningful life aligned with their values. This research team has helped to develop ACT-based workshops that are co-led by clinicians and caregivers together. Caregivers of people with autism and fetal alcohol spectrum disorder (FASD) who've participated in these workshops have reported feeling less depressed, stressed and isolated. The researchers are now training new facilitators across Canada to deliver ACT workshops, both in person and online.



### The Family Check-Up

#### **Principal investigators:**

Dr. Teresa Bennett, McMaster University and McMaster Children's Hospital Dr. Irene Drmic, McMaster Children's Hospital

In the Family Check-Up program, parents complete an assessment that helps a clinician to provide non-judgmental information about strengths and areas for improvement in parenting, as well as services in the community that could help the family. In addition, short sessions are available to help parents gain practical skills to address the specific challenges they're facing.

Studies have found that the Family Check-Up often improves long-term child and caregiver mental health in families with non-autistic children, but we don't yet know if it can be delivered effectively within an autism-service setting. To find out, this research team helped to establish a Family Check-Up clinical team within the McMaster Children's Hospital Autism Program. They're now studying whether the program reduces emotional and behavioural problems in autistic children and improves parent well-being.



### **Client-Oriented Mapping for Point of Care Access to Supports and Services** (COMPASS)

### **Principal investigators:**

Dr. Jocelynn Cook, University of Ottawa

Dr. Jacqueline Pei, University of Alberta

Dr. Kaitlyn McLachlan, University of Guelph

Every person with fetal alcohol syndrome disorder (FASD) has their own strengths and challenges. That means there's no one-size-fits-all pathway through the available supports and services. Instead, families have to figure out what makes the most sense given their child's needs, age, goals and context.

Client-Oriented Mapping for Point of Care Access to Supports and Services (COMPASS) is a resource informed by nationwide data about the characteristics of individuals with FASD, their experiences, and the supports they've used at different stages of their lives (e.g. academic coaching, mental-health services, social-skills training, etc.) COMPASS aims to apply past learnings to new patients, so that FASD clinics can give meaningful, evidence-based recommendations to families when their child gets a diagnosis.



### The Fetal Alcohol Resource Program (FARP)

### **Principal investigators:**

Dr. James Reynolds, Queen's University Michael Song, ABLE2

FARP began as a navigation service, helping to connect people living with fetal alcohol spectrum disorder (FASD) and their families to existing programs in their communities. Now it supports families in three Ontario regions in other ways as well, such as providing them with FASD workers who can help them to get a diagnosis, understand the medical system, advocate for their children at school, and more.

In the wider community, FARP raises awareness of FASD and trains professionals from a variety of sectors (e.g. education, healthcare, mental health, criminal justice, child welfare and housing) about the disorder and how to improve the ways they serve people with FASD.



### **F-Words Foundations**

### **Principal investigators:**

Dr. Peter Rosenbaum, McMaster University

Dr. Andrea Cross, McMaster University

Dr. Rachel Teplicky, McMaster University

The F-words (Functioning, Family, Fitness, Fun, Friends and Future) are six key areas that this research team promotes as the main focus in childhood disability. Built upon the World Health Organization's International Classification of Functioning, Disability and Health framework, they encourage everyone to think about factors that are important to any child's development and well-being, such as their activities and environment. Introducing this way of thinking to families and service providers can result in measurable changes to self-reported family empowerment, parenting confidence, and experiences of family-centred service.

This project has made <u>foundational F-Words training</u> freely available across Canada by creating a self-paced online course in English and French. Over 1,000 people have accessed it so far.



### OUR IMPACT

IN THE WORDS
OF FAMILIES AND
PARTNERS



In our small community, there are no resources to refer families to unless they travel a far distance (which, for most of these families, isn't an option), so having the Nurturing the Seed developmental support programs gives me the tools to fill those gaps ... I can see the benefit on not only the child's development but also the parent-child relationship."

TRACY BROWN, HOME VISITOR, KIDSFIRST NORTH





One participant [with severely limited mobility] enjoyed playing a game of modified Quidditch from Harry Potter with his assistant, while another was able to chase with her siblings down the hall, leading to them beaming from ear to ear."

**INVESTIGATOR FOR THE BCI-MOVE STUDY** 



Kai gained a lot of selfawareness through Secret Agent Society, like recognizing the physiological changes he experiences when he's stressed or feeling anxious or uncomfortable. He also learned techniques that helped him cope with these types of stressors."

PARENT OF A CHILD WITH AUTISM



There is a sense of joy I find after each workshop ends. They remind me that I am not alone, and that despite ethnic, cultural or age differences, as parents we are all striving to help our children lead their best lives possible."

LEE STEEL, CAREGIVER FACILITATOR FOR ACCEPTANCE AND COMMITMENT TRAINING (ACT) FOR FAMILY CAREGIVERS



We are excited about what the Fetal Alcohol Resource Program offers and their on-going efforts to educate people. It's a comfort knowing we are not alone and this organization is there to support and advocate for those affected who, sadly, are often misunderstood."

PARENT



# OUR TRAINING INITIATIVES

Kids Brain Health Network is strengthening knowledge and skills in Canada's neurodevelopmental research community—including family participants in research—and among people serving families directly.

**904 researchers, 375 family advocates, and 3,239 frontline workers** were trained in KBHN-sponsored programs and interventions this year.

### THE NATIONAL TRAINING PROGRAM

Aimed at students and researchers, KBHN's national training program offers:

- Hands-on experience in KBHN's research and implementation projects
- Workshops and webinars on topics that help to develop the core competencies that are crucial to KBHN's mission and vision
- A rich variety of awards and internships
- Networking, learning and presentation opportunities at KBHN's annual conference

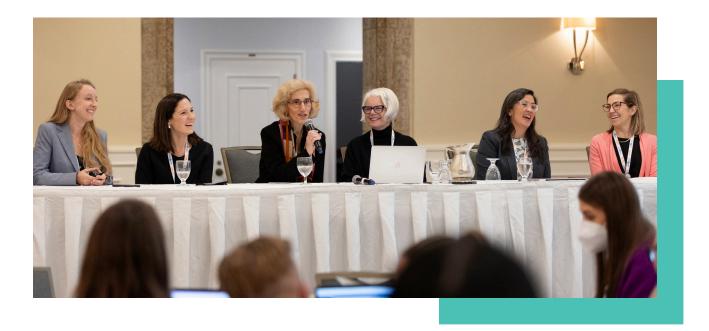
This year, **207** trainees took part in KBHN-supported research projects and internships. **84** of them were new to the network. Meanwhile, KBHN launched a new partnership with The Centre for Implementation to teach trainees and investigators how to design, implement, spread and scale change. So far, **15** people have earned an Implementation Support Specialist certificate through this initiative.

### THE FAMILY ENGAGEMENT IN RESEARCH PROGRAM

Sponsored by KBHN and administered by CanChild in partnership with the McMaster Institute of Continuing Education, a 10-week online course called the Family Engagement in Research (FER) Course brings families and researchers together to learn from each other about how to build a productive partnership. By doing so, it aims to shape the future of Canadian neurodevelopmental research, anchoring it in the real-life needs of children and their families.

FER-course graduates who want to not only partner in research but also become FER leaders and advocates in their communities and organizations can proceed to the FER Leadership Academy, which uses small-group discussions, projects and mentorship sessions to help them build upon their skills.

The year 2022-23, saw 79 researchers and 58 family members complete the FER Course, while eight researchers and 13 family members graduated from Leadership Academy.



### Team

Dr. Andrea Cross, Connie Putterman, Donna Thomson, Dr. Samantha Micsinszki, Rachel Martens, Alice Kelen Soper, Dayle McCauley, Dr. Kinga Pozniak, Sara Pot and Dr. Jan Willem Gorter, all of the CanChild research centre at McMaster University

### INTERNSHIPS, AWARDS, PRACTICUMS AND FELLOWSHIPS

### **Early Career Investigator** & Mentorship Awards

These awards strengthen the research programs of early-career professors and investigators at universities or institutes. It allows them to recruit excellent trainees, foster their connections to community partners and build their capacity as researchers in the field of neurodevelopmental disabilities (NDDs).

### **2022-23 AWARDEES**



Dr. Elizabeth Condliffe (University of Calgary) Biomedical engineer and physiatrist



Dr. Tatiana Ogourtsova (McGill University) Occupational therapist and pediatric researcher

### **KBHN-Mitacs Awards**

These awards fund projects that enhance services and supports for children with neurodevelopmental disabilities and their families across Canada. Trainees and their academic supervisors collaborate with a nonacademic organization to make progress on real-world challenge areas.

### **2022-23 AWARDEES**



Carly Magnacca

In partnership with the Centre for Addiction and Mental Health, Magnacca is co-developing an Acceptance and Commitment Training intervention for and with autistic youth who are transitioning into adulthood. This is a stage of life when mental-health supports—and supports in general—tend to drop off for people with autism, so the project could help fill a major service gap.

### **Autism Alliance of** Canada-KBHN Data-to-**Policy Fellowships**

These awards fund projects that enhance services and supports for children with neurodevelopmental disabilities and their families across Canada. Trainees and their academic supervisors collaborate with a nonacademic organization to make progress on real-world challenge areas.

### **2022-23 AWARDEES**



Angela MacDonald-Prégent (McGill University)

MacDonald-Prégent is co-leading the National Autism Waitlist Initiative, which aims to standardize the metrics we use to measure how long families wait to access autism assessments and diagnoses. From there, it will become possible to compare wait times between jurisdictions, highlight the urgency of reducing their length, establish standards, monitor progress and allocate resources to the places where they're needed the most.



Dr. Amber Rieder (Duke University)

Rieder is supporting the development of a National Autism Lived Experience Advisory Group, which will improve the active involvement of autistic people and their families in research and policy initiatives.

### **Autism Alliance of** Canada-KBHN Policy **Development Practicum Award**

This practicum gives KBHN trainees experience in policy development, writing for an audience of policymakers, and facilitating engagement with community partners.

### **2022-23 AWARDEES**



Alexandra Minuk (Queen's University)



Christiane Gwendolin Roth (University of Calgary)



Dr. Preeti Kar (University of British Columbia)

The 2022-23 cohort of fellows conducted a scoping review of the national-level autism policies of all the countries that have signed or ratified the United Nations Convention on the Rights of People with Disabilities (UNCRPD). They assessed whether these policies are aligned with the UNCRPD and identified strengths and shortcomings that will inform future autism-policy development.

### **KIDS BRAIN HEALTH CONGRESS 2022**

### A GLOBAL GATHERING **FOR HEALTHY DEVELOPMENT**



A thriving early childhood is not only valuable in its own right, it also sets the stage for a healthier trajectory through the entire lifespan. Therefore, it was a natural fit when KBHN — a network dedicated to enabling better outcomes for children with NDDs and their families partnered with DOHaD Canada and the International Society for DOHaD to bring the DOHaD World Congress 2022 to Vancouver. DOHaD (developmental origins of health and disease) is a field of research that examines how each person's childhood environment influences their well-being throughout life.

In this context, the "environment" includes not only physical factors such as air quality, nutrition and prenatal exposures, but also intangible ones such as family stress

and access to supports. Much of KBHN's work revolves around improving these factors for kids with NDDs, a group whose needs have often been poorly understood and underserved.

The DOHaD World Congress, titled "Social and Environmental Disruptions in DOHaD; Successful Interventions for a Healthy Future," was an opportunity for KBHN to share its work on a global stage while learning from diverse voices, including world-class experts from multiple disciplines. The event assembled over 1,000 attendees from 52 countries, all of them passionate about building a healthy future by giving every child a good start in life.



Spakwus Slolem ("Eagle Song Dancers") from the Squamish nation welcomed attendees with a performance.



Dr. Vikram Patel addressing a room full of attendees for the annual KBHN-Fraser Mustard lecture, 2022

### **Worldwide Hope for Mental Health**

KBHN awarded its annual Fraser Mustard Lecture to Dr. Vikram Patel, an advocate for global mental health based at Harvard Medical School. "Mental illness is one of the most intractable health challenges every country has been facing," Patel said during his address, which attracted a full house. "We've often thought there's nothing we can do for prevention. But I think that's completely wrong."

Half of all mental-health challenges emerge by the age of 18, and two thirds before age 25. This means that childhood and adolescence are prime times for preventing them. No single intervention can end the mental-health crisis alone, Patel explained. But there are measures that could shift the needle when used in combination. What's more, these measures are scalable, even to low-resource settings such as the communities where Patel and others have helped to implement them in India.

KBHN's own research and implementation efforts complement the work of scholars like Patel by tackling the disproportionately high incidence of mental-health challenges among children and youth with NDDs. For instance, the network is currently supporting the implementation of Secret Agent Society, a program that helps kids with autism to improve their social and emotional-regulation skills.

### **Disruptions and Solutions**

As the world attempts to recover from the COVID-19 pandemic, families and scientists continue to see its impact on developmental health. War, famine and inequities can disrupt optimal development as well. In a panel that was open and free to the general public, Dr. Margo Greenwood, scientific director of the CIHR Institute of Indigenous Peoples' Health, described the devastating, intergenerational impacts of the cultural genocide committed against Indigenous communities through the colonization of Canada. She also shared some of the ways that Indigenous people today are bringing cultural knowledge and strengths to lead healing initiatives.

The approach they are refining could also benefit other kids facing adversity and challenges, such as those in foster care and those living with fetal alcohol syndrome disorder. "Indigenous peoples are the ones changing the mental-health conversation in Canada," Kulkarni emphasized.



KBHN sponsored three symposia focused on areas of particular interest in neurodevelopmental research, namely: Early brain development and the origins of infant mental health; Social determinants of DOHaD; and Applications of artificial intelligence (AI) to improve health outcomes across the lifespan

### **Training and Supporting Future Generations**

KBHN's annual conference is always rich in professional-development opportunities for network trainees. This year, 50 promising early-career scientists and professionals participated in two days' worth of pre-congress workshops, which spanned topics ranging from communicating with non-scientist audiences to using big data in research. Among them were seven trainees that KBHN sponsored to attend from low- and middle-income countries.

The group also participated in networking and learning events organized by KBHN's Policy Advisory Research Training (PART) Committee, a subset of trainees elected to enhance their peers' experiences.



Dozens of KBHN trainees made poster presentations at the congress. One of them, Alice Soper, won a Presidential Plenary Award, given to the highest ranked abstracts judged by an international panel. Soper shared strategies for involving family members as equal partners throughout the research process, to help ensure it makes a real and relevant difference to families' needs.

The urgency of translating research into impact was a recurring theme at the congress. After all, the DOHaD model emphasizes the transformative power of evidence-based early interventions. KBHN Board Chair Geoff Pradella anticipated this during his remarks at the opening ceremony. "By gathering as a global community," he said, "we give ourselves the power to imagine and achieve real change for children and families, for many generations to come."

### **FINANCIALS**



# 2023

Receipts	
Contributions from Networks of Centres of Excellence (NCE)	\$4,032,030
Contributions from Institute for Ministry of Health (MOH)	\$196,555
Contributions from Kids Brain Health Foundation (KBHF)	\$150,839
Conference registration fees and other support	\$25,000
Amortization of deferred capital contributions	\$2,963
	\$4,407,387
Expenditures	
Research and knowledge mobilization grants and training	\$2,652,859
Operating and Administration	\$897,265
Travel, meetings and networking	\$313,134
Professional and consulting fees	\$308,782
Communications	\$97,808
Insurance	\$15,862
	\$3,285,710

**Audited Statements >>** 



### **OUR THANKS**

Kids Brain Health Network's achievements rely on the skills and contributions of hundreds of people and organizations, all of whom deserve our heartfelt thanks. We'd like to specifically thank families and caregivers for working with us. We could not do this work without them.

### **Network members**

Kids Brain Health Network collaborates with 22 leading academic and research institutions. We thank these groundbreaking organizations that are the homes of our principal investigators and researchers.

- Carleton University
- CAMH
- CHEO
- CHU Sainte-Justine
- Dalhousie University
- Holland Bloorview Kids Rehabilitation Hospital
- McGill University

- McGill University Health Centre Research Institute
- McMaster University
- Queen's University
- SickKids
- Simon Fraser University
- University Health Network
- University of Alberta

- University of British Columbia
- University of Calgary
- University of Guelph
- University of Manitoba
- University of Ottawa
- University of Victoria
- Western University
- York University



### **KBHN** is funded under **Networks of Centres of Excellence (NCE)**

We are deeply grateful to the Network of Centres of Excellence for their longstanding support to KBHN as we continue our third and final cycle of funding under their program.



### **Host institution**

We extend thanks to our host institution, Simon Fraser University (SFU), for their continued collaboration.



### Thank you to our partners

We'd like to underline the great contributions of our partners, who bring innovations to life for the benefit of children with neurodevelopmental disabilities and their families. A full list is available at: kidsbrainhealth.ca/impact/annualreports/year-in-review-2022-2023/

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Executive Director, The Center for Implementation



### LOOKING AHEAD

### Thank you to our partners

The next five years will see KBHN pursuing three complementary objectives:

Improve outcomes for children with neurodevelopmental disabilities and their families by selecting and supporting research projects that meet their needs. These will include projects that are developing new solutions, projects that bridge gaps between innovation and implementation, and projects that increase the accessibility of solutions to every child and family who might benefit from them.

Accelerate the real-world impact of research innovations by building capacity within KBHN to support their scale and spread. Each project will develop an implementation, business, social enterprise or commercialization plan with the help of network-sponsored resources such as mentorship, access to experienced advisors, workshops, socioeconomic-impact evaluation services.

**Strengthen Canada's research ecosystem** by providing inclusive training programs for the next generation of researchers, family and community members, frontline practitioners and healthcare providers. Learning opportunities will extend beyond traditional academic training to include entrepreneurship, implementation science and family engagement in research.

### We welcome supporters and partners to join us!



The path ahead is one of transformative growth, focusing on the implementation, acceleration and scale and spread of our groundbreaking research through a variety of project-appropriate delivery and business models that can attract new partnerships and investments, and increase national access. By doing this, we are committed to further positioning the Kids Brain Health Network mission and team to achieve the exceptional outcomes we envision for our future, expanding our network, and building out our role as Canada's 'implementation hub', contributing ongoing value to the sector."



**Geoff Pradella. KBHN Board Chair** (2022-2023)



### **Contact Us**

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