

CASE FOR SUPPORT

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Families of children living with a neurodevelopmental disability want them to flourish, but they often lack the tools for success. We have ways to help, from early identification to evidence-based intervention and family support.

Please join us.

“Promise me you’ll always remember... you’re braver than you believe, stronger than you seem, smarter than you think, and loved more than you know.”

*~ Christopher Robin
(From Winnie the Pooh, by A.A. Milne)*



◀ Ben and his son David together at a park.

Ten-year old David adored his four furry feline companions. A great communicator, he enjoyed chatting with adults. Unfortunately, for David, going to sleep was no easy task. According to his father Ben, David had difficulties falling asleep and even when he managed to, he never woke up well rested.

Ben says his family had reached a crisis point. His son's inability to fall asleep or stay asleep affected most aspects of his life, including school, where David had challenges focusing and learning. When he received a diagnosis of attention-deficit/hyperactivity disorder (ADHD), it helped to explain some of his struggles.

Like David, many children living with neurodevelopmental disabilities struggle with sleep. These disabilities mostly affect the growth and development of the brain and central nervous system, in unique ways for each child. Research suggests more than 85 per cent of children with a neurodevelopmental disability will struggle with falling asleep, staying asleep, and achieving high quality sleep. (Corkum, Penny et al; 2014)

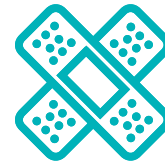
THE CHALLENGES WE FACE



Children and youth with a neurodevelopmental disability comprise

75% of young people

with a disability in Canada (an estimated 5-9% prevalence). Examples include autism spectrum (AS), fetal alcohol spectrum disorder (FASD), intellectual disabilities, and cerebral palsy. As diagnostic tools improve, the number of children identified with such disabilities will rise.



There are no cures for these disabilities,

and opportunities for prevention are limited or non-existent. They are a fact of life.

But that is not the end of the story. Together, we can help children of all abilities to thrive.

The science of children's brain health is making incredible progress.

Researchers are discovering new ways to help kids with neurodevelopmental disabilities lead their best lives. Parents, family members, and caregivers have new opportunities to participate in care and improve family life. Organizations across the country are connecting to share new knowledge and bring solutions to those who need them most.

There is a movement taking place and we want you to be part of it.



Partners and Champions

Since I started the program, I feel much more confident, and my daughter's achievements make us so happy. Each new word, each new action is the greatest happiness in the world, and I was part of it."

Jina, a parent who participated in the Social ABCs program (a program that helps children showing early signs of autism and communication challenges develop communication skills)



▲ Social ABCs coach Sara Daoud works with Jina and her daughter Mimi who is autistic. Photo: Morro Creative.



KIDS BRAIN HEALTH NETWORK

Founded in 2010, the Kids Brain Health Network (KBHN) was created as part of the *Networks of Centres of Excellence Program* – an initiative of the Government of Canada to fund partnerships between universities, hospitals, industry, government, and not-for-profit organizations. We engage front-line service providers, researchers, clinicians, families, and caregivers in our work.

KBHN is a national organization with a bold mission: *Through catalyzing collective action across sectors, KBHN strives to ensure optimal care and better outcomes for children with neurodevelopmental disabilities and their families.*

We achieve our mission by:

- **Identifying and supporting the most promising new research in neurodevelopmental disabilities.**
- **Integrating parents and family members into the research process.**
- **Turning research into practical interventions that parents, children, and professionals can use every day.**
- **Overcoming barriers to access.**
- **Training the next generation of neurodevelopmental professionals.**
- **Bringing together partners and collaborators into a highly effective network.**
- **Working with healthcare systems and policy makers to integrate evidence-based programs to produce better outcomes across the country.**

OUR WORK

Since 2010, KBHN, along with government and partner support, has invested over **\$77M into more than 200 projects** and research initiatives. These funded projects have enabled thousands of Canadian families to access timelier and more personalized care within their communities.

Our work can benefit all Canadians by enhancing supports for thousands of children and their families, improving their employment and economic prospects, and reducing health care needs and costs in the long term. Most importantly, we improve children's quality of life, starting from the early years.

Our research validates the effectiveness of our interventions.

Using community delivery of parent-led interventions to support toddlers with autism.

RESULT

Clinically meaningful gains in toddlers' language, communication, and social skills.
(Brian et al; 2022)

Supporting parents to help them and their children get a better night's sleep.

RESULT

Evidence-based sleep interventions with benefits for health and well-being of children.
(Tan-McNeill et al; 2020)

Providing personal and social support for mothers of children with autism spectrum disorder.

RESULT

Better coping strategies and lower levels of parenting stress.
(Zaidman-Zait et al; 2017)



OUR MEASURES OF SUCCESS

Our funded research-to-practice initiatives are making a meaningful difference in the lives of thousands of children. With the right resources and opportunities, children with neurodevelopmental disabilities can access and share their strengths. Together with our network members, implementing partners, and families engaged in research, we have accomplished so much. Here are some highlights:

No other organization in Canada does what the Kids Brain Health Network does, and we could do so much more with your help.



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- *Infant and Early Mental Health Promotion* is a national organization which improves outcomes across the lifespan through translating and promoting the science of early mental health into practice with families during pregnancy, infancy, and early childhood. The program has **built meaningful relationships with many Indigenous communities;** alongside other groups/communities across Canada. Together, they are supporting practitioners, young children, and their families to improve mental health outcomes across the lifespan.

- Termed a 'serious game', *Dino Island* improves attention, working memory, and executive function in children with neurodevelopmental disabilities. *Dino Island* (and its earlier configurations) has **engaged more than 2,000 children across Canada** as part of its development and we continue to expand the reach of the program nationally and internationally. One young boy learned a valuable skill while playing *Dino Island*. Rather than hiding under his desk whenever he made a mistake, he would say, "Oops!" instead and continue with his school work.



- Parents of a child recently diagnosed with autism may feel overwhelmed, and not know where or how to access help.

More than 900 families in British Columbia have accessed improved service delivery for children newly diagnosed with autism,

through our *Integrated Navigational Resources Program*. This program piloted in three sites across Canada has also trained 285 parent-peer mentors in Alberta to support families' navigational journeys.

- We have **helped more than 800 families to support their children's communication development and engagement in positive social interactions with their caregivers,**

through the *Social ABCs* program. For example, toddlers used significantly more words after participating in the six-week program.

- We have **provided more than 1,400 families and individuals with direct clinical services, system navigation, and family support through the Fetal Alcohol Resource Program,**

and delivered training on practical supports for individuals with FASD to over 5,500 professionals and frontline workers.



INCLUDING FAMILY VOICES AS PARTNERS IN RESEARCH

We connect families
and researchers
with community,
government, and
industry partners to
work together.

We respect that many families of children with a neurodevelopmental disability want to be active research partners. Additionally, we understand that successful research initiatives can have greater relevance when they include family perspectives alongside the expertise of researchers and their funders. In 2018, the *Family Engagement in Research Certificate program* was created to bring together researchers (graduate students, research coordinators, investigators) and family members (parents, siblings, grandparents, caregivers).

The program creates a cohort of family members and researchers who are:

- Invested in contributing to neurodevelopmental disabilities research.
 - Knowledgeable about family engagement in research.
 - Capable and confident in engaging at various stages of the research process.
-

NURTURING THE NEXT GENERATION OF NEUROSCIENCE PROFESSIONALS

KBHN supports the professional development of new researchers and scientists.

Launched in 2010, our globally recognized trainee program is the only national developmental neurosciences training program in Canada. The program attracts participants from across Canada and around the world.

OUR COMMUNITY

A key factor in our record of unequivocal impact is our diverse national network of more than 270 partners, funders, and supporters including family members. We are a strong community of deeply engaged partners and talented individuals dedicated to neurodevelopmental research. Our shared passion for helping kids of all abilities to live their best lives is what drives our work.

Our community includes:

- Leading Canadian hospitals
- Researchers at Canada's top universities
- Organizations that focus on program delivery
- Provincial ministries, regional health authorities, and policy makers
- Indigenous communities
- Families and caregivers

Every year, we bring our community together at a national conference to gather, network, share ideas, and learn from each other with a focus on achieving better outcomes for children with neurodevelopmental disabilities.

By coming together as a community to support KBHN's work, we are helping thousands of children to thrive.

Ben registered for the Better Nights Better Days (sleep intervention) program and started his first session with David in the summer of 2019.

"I discussed with my son that this was a summer project we would work on together—it wasn't just something for me or just something for him, it was for both of us," says Ben. "It's a great program and so well structured; it gave us the opportunity to track progress and see everything we achieved together."

For 10 weeks, the duo sat together nightly and worked through the modules, with the goals of improving David's quality of sleep and increasing his energy levels during the day.



For Ben and David, the program has been transformational. David is sleeping better and enjoying better days at school, and at home where he loves doing art.

The program's benefits were evident when the duo took a father-son trip to Berlin in the fall of 2019. In one week, the pair took eight flights and stayed in four hotels. If David's sleep was going to regress, Ben figured this would be the time. But it didn't. It was a wonderful opportunity for bonding time as they created lasting memories on this amazing adventure. They arrived home on Saturday and David was well rested and back in school and ready for learning on Monday.

◀ *David, age 10, photo taken in Berlin.*



CREATING TRANSFORMATIONAL IMPACT ACROSS CANADA

Our priority is to scale up our success so that we can support as many children and their families as possible.



Turn today's science into tomorrow's tools. As new research findings offer hope to more kids and their families, KBHN's work is more important than ever. Help us continue translating scientific discovery into practical tools that help families and children grow and learn.

Help us reach families lacking programs and services, especially those in remote areas. Unless we can do more, the gap will grow between scientific innovations and families experiencing inequities. With your support, we can ensure that children have access to education and positive social experiences and that families can access resources and supports to be successful.

◀ *Alex participates in equine therapy at Kindred Farm Rescue, a resource he has been able to access thanks to the FARP program. Photo: Morro Creative.*

You can help us transform the lives of children with neurodevelopmental disabilities and their families, and to reduce the impact on Canada's health, education, and social services systems.



Increase our equity, diversity, and inclusion. KBHN is working closely with Indigenous communities to implement *Nurturing the Seed* and other indigenous-led programs. We are determined to help end systemic racism and discrimination, which causes historic and continuing harm to Indigenous, Black, and racialized people and communities, and LGBTQ2S+ families and children in Canada. Recently, the KBHN Board made significant changes to its management structure and governance practices. This included developing a strategy to ensure Equity, Diversity and Inclusion at all levels across the governance and operations of the Network.

Help kids and families continue to overcome the immediate and longer-term impacts of the COVID-19 pandemic. Thousands of children with neurodevelopmental disabilities suffered significant setbacks in their progress during the pandemic. Let's seize the moment to offer support for their growth and development, potentially changing the trajectory of their lives. In addition, we can reduce the strain on Canada's health, education, and social services systems for decades to come.





HELP US REACH EVERY CHILD

Imagine a world where children of all abilities can thrive and be happy. Picture a world where families have the tools, resources and support they need to confidently nurture and raise all their children including those with a neurodevelopmental disability.

Together with your support, we can make this dream a reality with a national, comprehensive solution.

Our Network provides science-based collective action, and we are growing in impact. Supporting KBHN through our Foundation will help hundreds of thousands of children and their families, across Canada.

Our reach is limited only by our current funding levels. With your support, together we can expand our most successful programs to reach every Canadian family needing our help.

Help us reach every child and family.





Partners and Champions

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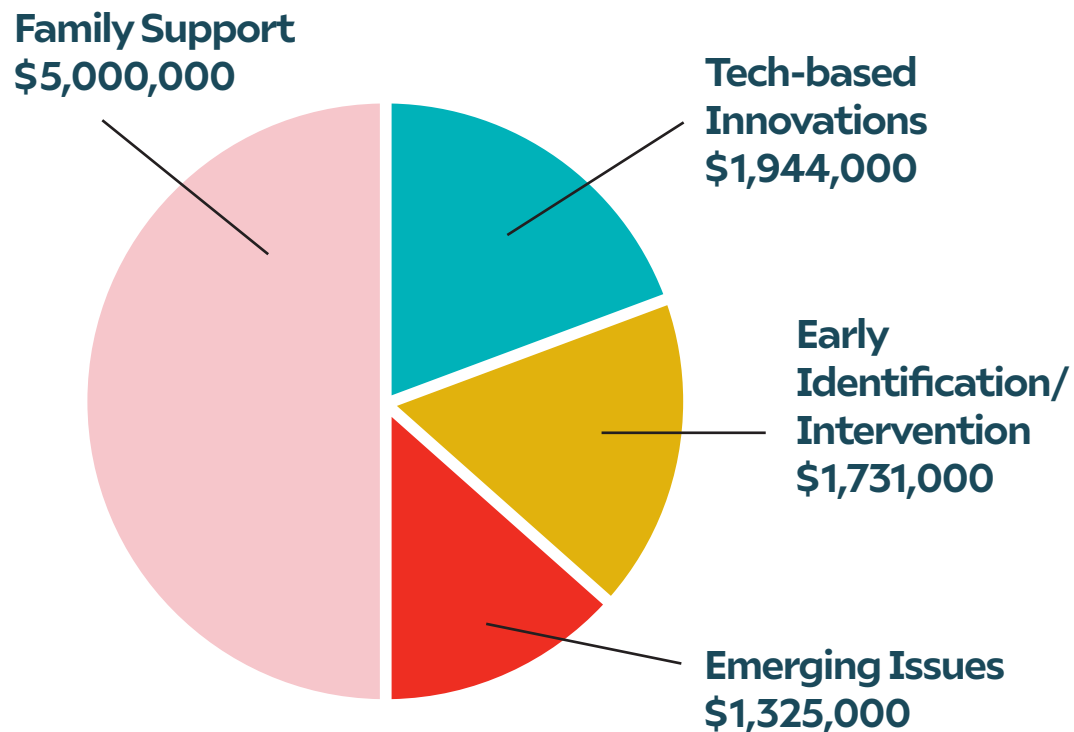
The Fetal Alcohol Resource Program has by far been the most valuable resource since we first began to wonder if our daughter had FASD. They have helped us educate our daughter's school about her brain injury and how they can best support her. They have come to school meetings and directed us to resources; they have offered a support group where we can truly be understood! And most of all they have made us feel less alone in walking what can be an extraordinarily difficult journey.”

A PARENT OF A CHILD WITH FETAL-ALCOHOL SPECTRUM DISORDER

JOIN THE MOVEMENT!

Donate to the Kids Brain Health Foundation today!

Help us reach our goal of raising \$10M over 5 years to create transformational impact across Canada.



Partners and Champions



Helping children with neurodevelopmental disabilities is often an incremental process. But even the smallest step forward holds a lot of meaning for the child, the parents, the other family members, and the community at large. KBHN links researchers and organizations across the country, and brings parents, families and caregivers into the conversation. By putting these pieces together, they help to make amazing change happen.”

**EMILY GRUENWOLDT, PRESIDENT & CEO
CHILDREN'S HEALTHCARE CANADA**

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Kids Brain Health Foundation

Simon Fraser University, Burnaby Campus
Discovery 2, 204-8900 Nelson Way
Burnaby, BC, V5A 4W9

kidsbrainhealth.ca



Charitable registration #: 789819125 RR 0001

OUR VISION

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

CONTACT US

Jane Dafoe,
Senior Director of Philanthropy
1-368-999-4282
jdafoe@kidsbrainhealth.ca

Nicky Lewis,
Chief Executive Officer
nlewis@kidsbrainhealth.ca

Kids Brain Health Network, situated at SFU Burnaby, respectfully acknowledges the unceded traditional territories of the Coast Salish peoples, including the sə́ilwətaʔ (Tseil-Waututh), kʷikʷə́ləm (Kwikwetlem), Sk̓w̓x̓wú7mesh Úxwumixw (Squamish), and xʷməθkʷəy̓əm (Musqueam) Nations.