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# Kids Brain Health Network jumps into lobbying to ensure MPs don't 'forget about children with disabilities'

NEWS, CAMPAIGNS AND ADVOCACY | STEPHEN JEFFERY  
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When **Kids Brain Health Network** (KBHN) ramped up its lobbying efforts late last year in a bid to secure access to a new government funding stream for its research grants, the organization found itself branching out into multiple streams of advocacy.

"We want to make sure the government doesn't forget about children with disabilities," said **Nicola Lewis**, CEO of the KBHN. "Raising our profile with MPs will help us raise the profile of the research work we fund, and how that research is helping children. We haven't done much of this [advocacy] before, but it's been very encouraging so far."

Based out of **Simon Fraser University** in Burnaby, B.C., KBHN funds neuroscience research, with a focus on neurodevelopmental disabilities in children aged 14 and under. The organization has funded approximately 150 research projects since 2010, through a mix of government grants and partnerships with other groups.

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*Nicola Lewis, CEO of the Kids Brain Health Network, has been meeting with parliamentarians recently, including Conservative health critic Stephen Ellis. (Photo courtesy of Kids Brain Health Network)*

KBHN registered to lobby for the first time on Nov. 29, 2022, hiring **Crestview Strategy** consultant **Laila Hawrylyshyn** to represent the organization. Hawrylyshyn was joined by Crestview colleague **Alexander Byrne-Krzycki** on Dec. 9, and **Alexa Sipeka** on Dec. 12.

The core purpose for registering was to discuss KBHN's application for funding from the Strategic Science Fund, run by Innovation, Science and Economic Development.

KBHN had previously received \$50.8 million in government funding through the Networks of Centres of Excellence (NCE) since 2010. However, the NCE announced in December 2018 that its funding would be gradually transferred to the New Frontiers in Research Fund (NFRF). KBHN received a final grant from the NCE worth \$11.7 million in May 2020, but is not eligible for NFRF funding due to its model as a not-for-profit organization and research network (the NFRF is designed for academics). Its current funding is due to run out in March 2024.

KBHN was one of 35 organizations chosen to progress to the full application stage for the Strategic Science Fund competition. "KBHN proposes to pursue three integrated and complementary objectives: improve outcomes for vulnerable children and families; accelerate the uptake of research innovations into practice; and strengthen Canada's research ecosystem," the [application](#) said.

### From listening to committees to addressing them

Since KBHN has registered to lobby, Lewis has visited Ottawa from her home in B.C. multiple times to meet with parliamentarians and attend committee meetings.

Lewis has met with **Andy Fillmore**, parliamentary secretary to Innovation Minister **François-Philippe Champagne**; Conservative health critic **Stephen Ellis**, addictions critic

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**Laila Goodridge**, and disability inclusion critic **Tracy Gray**; and NDP disability inclusion critic **Bonita Zarrillo**.

She has also had meetings with **Jordan Ames Sinclair**, senior special assistant to Health Minister **Jean-Yves Duclos**; **Joanna Lam**, Duclos's Western and Northern Canada adviser; **Shahad Khalladi**, science policy adviser to Innovation Minister Champagne; and **Sarah MacDonald**, special assistant to Champagne.

"The discussions have been very encouraging across parties," Lewis said. "There's been a lot of interest in the work we've been doing. There aren't many organizations like us, and it's been important for us to emphasize that."

Lewis attended a meeting of the House science and research committee on Feb. 2, during which Champagne spoke about international moonshot programs. A discussion with Fillmore following the meeting, about KBHN's "[Family Engagement in Research Course](#)", led to Lewis being invited to speak before the committee on Feb. 16 as part of its study of citizen scientists.

The 10-week course, run in partnership with **CanChild** and **McMaster University**, brings together families and researchers to help family members better understand research methods, and assist researchers with understanding the importance of engaging with families on projects.

"It's rooted in the shared values of co-creation, collaboration and respect for the different types of knowledge and experiences," Lewis said. "Canada has an opportunity to be a global thought leader in citizen engagement [for] conducting health research and implementation for the betterment of our children."

### Disability benefit and child care bills in sights

While the funding application remains the KBHN's priority, the organization has also turned its attention to bills that are likely to affect children with neurodevelopmental disabilities.

Bills of particular interest are Bill C-22, Canada Disability Benefit Act; Bill C-35, Canada Early Learning and Child Care Act; and Bill S-235, National Framework on Fetal Alcohol Spectrum Disorder Act.

KBHN and the Disability Policy Research Program (within the **University of Calgary's** School of Public Policy) made a [joint submission](#) to the House human resources committee for its study of Bill C-35. The organizations sought amendments to the bill that strengthen disability inclusion, specify funding commitments for disability-inclusive initiatives, and enhance monitoring, reporting and evaluation criteria.

"Having a [national child care program] would be so significant, but we want to make sure that they don't forget about kids with neurodevelopmental disabilities," she said.

Lewis expects that KBHN's advocacy efforts will increase through the year, culminating in the organization's annual conference in October.

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