

Just 4 kids

FALL 2021

World-first Research



Learn how Brain Computer Interface is helping kids like Danial “bypass their broken bodies”

Alberta
Children's
HOSPITAL 
FOUNDATION 

Making the Impossible Possible

Children living with conditions such as a stroke, spinal cord injury or cerebral palsy can suffer from severe limitations in their mobility and capacity to communicate. Fully aware and capable but unable to walk, talk or use their hands, these children are trapped in their bodies.

Thanks to generous community support, world-first research in Brain Computer Interface (BCI) for kids is underway at the Alberta Children's Hospital.

BCI has the potential to engage children — many of whom otherwise cannot communicate — in learning and play. BCI technology recognizes changes in thought patterns via a non-invasive electroencephalogram (EEG) and transmits those signals to control devices such as computers, phones, TV remotes and more.

While wearing a BCI headset, a child can think the word “go,” for example, to move a remote-controlled car forward.

“BCI is an exploding field of study with enormous potential for severely disabled people,” says pediatric neurologist, Dr. Adam Kirton. “However, to date, there has been very little focus on how to adapt it for pediatric users.”

Recognizing the incredible possibilities for children, Dr. Kirton and his team established the BCI4Kids program to try to find new pathways for young children to interact with the world and realize new levels of independence. The Alberta Children's Hospital is one of only a few places in the world giving children the opportunity to access BCI and has garnered a reputation nationally and internationally as a leader in this area of innovative research.

Unlocking Danial's potential

Like many fathers and sons, Ilyas and Danial love to joke around and play video games together. For fun, they sometimes work on colourful works of art and they both have a knack for math. Ilyas is extremely grateful for these small pleasures because there was a time he wasn't sure his boy would ever be able to share these kinds of experiences with him.

Danial was born in Kazakhstan 14 years ago. Soon after, Ilyas and his wife, Madina, received heartbreaking news.

“The doctors there told us that Danial had cerebral palsy and would never be able to do anything,” says Ilyas. “We quickly did our research and knew there had to be better options for our son. We weren't going to give up on him.”

The family moved to China where Danial received better medical support. Six years later, wanting to be closer to Madina's family, they immigrated to Canada.

“Over that time, we saw that Danial could understand what we were saying to him,” explains Ilyas. “We developed a way of communicating with him through his eyes. He would look up or down to answer yes or no. It was pretty basic, but it worked for us.”

In those early years, Ilyas and Madina home-schooled Danial—supporting his hand while holding a pencil, helping him draw big letters and teaching him math. He was an earnest learner. At the same time, the family was supported at the Alberta Children's Hospital by the Augmentative Communications and Educational Technology Service (ACETS) team. Although they tried many communication technologies, Danial's involuntary muscle contractions made it difficult for him to control any of the devices they trialed.

In 2018, Danial and his parents were introduced to the hospital's Brain

Computer Interface research team. Since Danial was so bright and eager, he was a promising candidate to benefit from this leading-edge technology. Should he be able to master it, BCI had the potential to help him bring new levels of ability to control and interact with his environment.

“That first day in the clinic, we were so impressed with how engaged and supportive the team was with Danial,” says Ilyas. “They explained everything so clearly and it took no time at all for him to use his mind to move a remote-controlled car. It was incredible to see!”

It took a few days for Ilyas to fully grasp how profound that moment actually was for his son.

“That was the first time in his life that Danial did something completely by himself. BCI gave him the ability to bypass his broken body and make something happen intentionally all on his own.”

From then on, Danial has continued to hone his BCI skills. Thanks to community support, the family has a BCI system set up at home on which he can play games, practice spelling and do his artwork.

“The technology has so much potential to help Danial in the future,” says Ilyas. In fact, Ilyas was so inspired by the possibilities that he left his career in health care architecture to complete a Masters degree in Computer Science. He has now joined the BCI4Kids research team as a biomedical engineer and is focusing on optimizing the reliability of BCI headsets. He is also exploring the use of artificial intelligence technology as it relates to BCI and its applications for learning and play.

“Recently, Danial set a goal to be able to turn the page on his e-reader using BCI,” says Ilyas. “It might seem like a simple thing, but it would be a game changer and give him more independence.”

Thanks to our generous community, the BCI4Kids team is helping kids like Danial achieve their goals and set even more. With your ongoing support, these experts will gain the knowledge and expertise to help unlock the world for otherwise silent children to engage with their families—and their world—in new and exciting ways. ♥



Program progress through COVID

“Over the past year, despite challenges presented by the global pandemic, the BCI program has grown in a number of exciting ways to help kids and families,” says Dr. Kirton.

Before the pandemic, children in the program had regular sessions at the hospital to practice and participate in activities using BCI technology. With traffic limited at the hospital, the BCI team worked quickly to ensure these vulnerable children continued to benefit from the program in the comfort of their own homes. BCI participants were provided the technology and training they needed to keep up their skills independently with support from the BCI team through online video sessions.

Those video sessions also became an opportunity for socialization during an otherwise extended period of isolation. The BCI4Kids team set up virtual gaming sessions for participants to play against one another or other family members in different households. “Gaming together is a hugely popular activity in school-aged children that brings a lot of joy to the kids,” says Dr. Kirton. “For some of these children, playing with a friend or far away family member hasn't been possible before. BCI has given them an opportunity to connect in new ways.”

Helping kids reach their goals

Beyond games and clinical applications, the ultimate goal of the program and research is to help kids live their fullest life possible. BCI4Kids engages an interdisciplinary team of neuroscience experts, occupational therapists and biomedical engineers to help children set and meet their desired goals — like Danial's desire to turn the page in his e-book and operate his power chair.



Intro to BCI

Attend introductory sessions to try out different BCI systems and activities to see what system is the best fit.



Goal Setting

Work with the team to set a BCI-related goal and develop a plan for how to meet it. The team provides resources to help track, assess and motivate.



Prototyping

The technical team will put together the necessary BCI system and application needed to achieve the goal. Adjustments and improvements to the system will be made as required.



Goal Practice

Participant works towards the goal with support of the entire team. There will be opportunities to reward goal progress and make adjustments to the goal if needed.



Goal Complete

After the initial goal is met, choose whether to continue with a new goal, implement the completed goal in a new setting (school or home) or further refine it.

“For severely disabled young people, BCI aims to make the impossible possible.”

— Dr. Adam Kirton, pediatric neurologist

Next-Gen Solutions from Next-Gen Scientists

Thanks to generous community support, a new generation of scientists is fuelling the research engine at the University of Calgary and the Alberta Children's Hospital. They are tackling a range of child health problems with far-reaching impacts designed to refine treatments, uncover new cures, and ultimately improve the quality of life for kids, here at home and all over the world. Here are five exciting projects happening right now, all of which are made possible by you.



Advancing burn recovery

When a child suffers a burn or ulcer, the result is often pain, immobility, disfigurement and, in some cases, dangerous infections. These injuries often lead to the formation of scar tissue, which can have lifelong impacts on a child's quality of life. **Kiran Todkar** seeks to better understand what is happening at the cellular level that drives either skin regeneration or scar formation. Work conducted in the Biernaskie Lab at UCalgary has shown that by modulating the early immune system response, it's possible to regenerate skin 10 times faster. Todkar is studying the effects different drug compounds have on the process of skin regeneration to provide entirely new drug targets that can be used to mitigate scarring and restore function after severe skin injury. "Considering the lifelong impairment that accompanies severe skin injury in children, effective therapies could have a major impact on quality of life," says Todkar.



New hope in tumour fight

Rhabdomyosarcoma is the most common type of soft tissue cancer in children often forming in their muscles. It frequently recurs after treatment mainly due to stem-like cells that resist therapy and then mutate into faster-growing cells. **Arthur Dantas** is studying the mechanisms that cause these cells to adapt and early work in this field suggests that by blocking the ING5 gene, scientists can boost the benefits of therapies used to treat these tumours. "Our ultimate goal is to understand this stem cell population better and consequently reduce recurrence, greatly improving long-term survival for kids with this cancer," says Dantas.



Predicting and preventing mental health issues

We know most mental health issues first appear in childhood and adolescence. What we're still learning is what causes them in the first place. **Kathryn Manning** is using brain scans and data collected from more than 10,000 ten-year-old kids to identify unique brain patterns that underlie mental health and behaviour. By understanding these linkages, experts would be able to identify specific brain regions and functional patterns that could aid in the delivery of treatments and refined clinical approaches. "This presents a powerful opportunity to both understand and predict children at risk before problems emerge," says Manning.



Improving the diagnosis of heart defects in babies

Congenital heart defects (CHD) occur in about one percent of all babies, yet the cause in most cases remains unknown. CHD diagnosed at birth often results in emergency surgery for newborns and the health problems associated with the condition can last into adulthood. New research suggests the placenta may play a key role in the development of heart defects, so **Bethany Radford** is examining that potential connection. Her focus is identifying structural and molecular changes to the placenta that are commonly linked to CHD with a goal of better prediction options during gestation. "My hope is to better understand, and ultimately prevent, the developmental origins of heart defects," says Radford. "Ideally this will lead to improved early diagnosis and risk assessment."



Back to school after concussion

Concussions in children and youth can cause many symptoms, including headache and sensitivity to sound, that can affect their ability to attend school and effectively learn. Young people recovering from concussions often miss school and may perform below expectations upon return. This can have serious academic, social, psychological, and emotional impacts on a child. **Heather Shepherd** wants to better understand how to facilitate the quickest and most successful return to school for children who have suffered a concussion, and to enable school staff to support them. "Things like rest breaks or extra time to finish assignments may be key in ensuring a child's effective re-entry to the classroom," says Shepherd. "My aim is to reduce the missed school days and struggles a child with concussion may face and develop an enhanced Return to School Strategy for a supportive learning environment." ♥



The University of Calgary is driving science and innovation to transform the health and well-being of children and families. Led by the Alberta Children's Hospital Research Institute, top scientists across the campus are partnering with Alberta Health Services, the Alberta Children's Hospital Foundation, and our community to create a better future for children through research.



Mental Health Lifeline for Families

Aimee Cooper had no idea that extreme stress could cause seizures. She learned this terrible fact last fall after her 11-year-old daughter, Mady, was found unconscious on the school playground and had to be rushed to the Alberta Children's Hospital.

"We were scared and confused," says Aimee. "Nothing like this had ever happened before and then suddenly Mady was seizing four times a day, sometimes for as long as an hour."

After extensive testing, doctors determined that Mady was suffering from psychogenic seizures and needed treatment from mental health specialists in hospital. After two admissions, Aimee and her husband, Trent, were grateful and eager to bring Mady home. Yet they worried about being able to care for their daughter on their own.

Thankfully, that's when they were referred to the Acute at Home program. This innovative community-funded outreach service enables children in mental health crisis to receive care in the comfort of their own homes from specially trained therapists, social workers and nurses. They deliver intensive mental health care for children and teens — in person, by video or phone — using treatments tailored to their needs. It was exactly the bridge they needed.

Aimee says they looked forward to

their weekly Zoom meetings. They also connected with counsellors by phone and text in between. The Acute at Home team helped them better understand Mady's illness, settled their fears, gave them practical tools and advice on how to manage difficult situations, and worked hard to support Mady — both at home and at school.

"During the pandemic, Acute at Home has become one of the most active programs in our service," says Carol Coventry, manager with the Child and Adolescent Addiction, Mental Health and Psychiatry Program.

"It has been absolutely vital to kids and families whose mental health has worsened with school and recreational disruptions, separation from loved ones and concerns about the virus itself."

Today, Aimee is happy to say that Mady has far more good days than bad and she's back to doing things kids her age should be enjoying — like dance, swimming and climbing trees.

"Acute at Home was our lifeline," says Aimee. "We are so grateful to the generous people who've made the program possible. I don't know how we would have survived without it. I feel in my heart, having this support has kept our daughter from having to go back to the hospital many times." ♥



Build them UP

Crews are busy working as construction on the new Centre for Child & Adolescent Mental Health continues. A large portion of the hill on site has been excavated to make room for the Centre, shoring walls have been installed, and crews have finished pouring concrete slabs on the parkade level and main floors. Construction completion is currently expected to occur next summer, with first patients to be seen at the Centre in late fall of 2022.

[BuildThemUp.ca](https://www.buildthemup.ca)

"I feel in my heart, having this support has kept our daughter from having to go back to the hospital many times."

— Aimee, Mady's mom



Getting the Sparkle Back

Megan Hackenschmidt hasn't slept well in months. She lies awake next to her four-year-old daughter Kate listening to her breathe, sensitive to the slightest movement in case it's a seizure. When Megan does eventually drift off, she dreams about Kate seizing. It's understandable. The whole family has been on high alert since last winter when Kate started having convulsions.

Megan and her family will always remember January 10th. That's the day they found Kate completely unresponsive while playing with big sister Sawyer outside their rural Alberta home. Terrified, Megan and her husband Jordy scooped up their little girl from the frozen ground and rushed her to the nearest hospital in Rocky Mountain House.

There, Megan and Jordy were told their daughter had likely suffered a massive seizure. They prayed it was a one-off, but two weeks later, Kate became rigid while eating dinner, as though she were choking. It was another seizure. After a second hospital visit, they left with a prescription, and more concern than ever.

Kate was referred to the epilepsy experts at the Alberta Children's Hospital, where the team used EEG technology to measure the seizure activity in her brain.

Unfortunately, although her results initially came back normal, Kate continued to be plagued by seizures that became a regular and devastating part of her life. She suffered massive

convulsions, or grand mals, weekly and nearly constant smaller episodes — sometimes hundreds a day. Some were absence seizures that made her stare blankly. Others stole her head control so she couldn't eat on her own or play with her toys. Doctors prescribed three medications, and while one effectively managed Kate's grand mals, it came at a cost.

"The drugs stopped the big seizures, but my sweet little girl's essence was gone. She lost her wit and laugh," Megan says. "Her sparkle was gone. And the small seizures were still happening. It felt like who she was, was slipping through our fingers. As a parent, it's absolutely devastating to feel so helpless."

Sadly, one third of all children with epilepsy are unresponsive to current medications. Thankfully, support from people like you has enabled Alberta Children's Hospital specialists to develop tremendous expertise in an innovative therapy called the Ketogenic Diet — a high-fat, low-carb diet specifically designed to alter the brain's chemical balance to stop seizures. Kate's specialists were optimistic it could help her.

"I remember being in the exam room feeling scared, frustrated, but hopeful and Kate just wrapping her tiny arms around me whispering, 'It's gonna be okay, Mama'," says Megan.

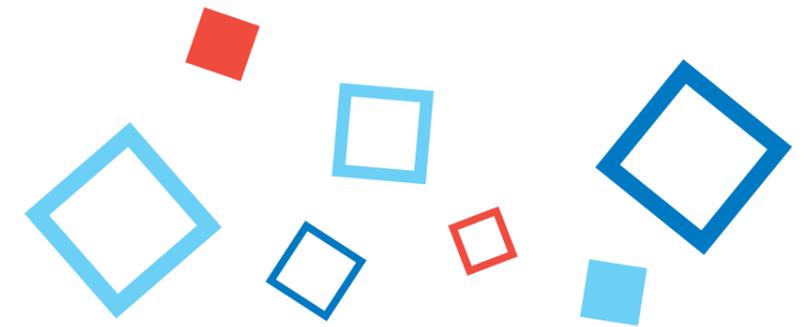
Within weeks of starting the diet, Kate's seizures decreased dramatically. She was even able to stop two of her medications, return to playschool and start T-Ball.

"Her sparkle was back," says Megan.

Then, one morning, just as life was getting a bit easier, Kate awoke to another grand mal seizure.

"While it's clear we are moving in the right direction, this is a long journey," says Megan. "We've learned that treating epilepsy is often a trial-and-error process. Epilepsy takes an emotional toll on the whole family. It can make you experience the highest of highs and the lowest of lows."

Today, Kate's seizures have been greatly reduced with periods of seizure freedom and to her parents'



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— Megan Hackenschmidt, Kate's mom

tremendous relief, she has avoided any developmental delays. While her family still faces uncertainty and adapts to their new normal, they celebrate how far Kate has come.

"Our bad days now are nothing compared to our bad days months ago," Megan says.

Experts at the Alberta Children's Hospital are working to advance epilepsy research and develop leading-edge treatments tailored to each child. With generous community support, families facing the uncertainty, distress and day-to-day disruptions caused by seizure disorders can have more effective treatments, sooner.

With a focus on developing innovative therapies to treat and even prevent seizures from happening in the first place, the Alberta Children's Hospital Epilepsy Program will achieve meaningful advancements in research and care that will immeasurably improve life for thousands of children and families.

As Kate's journey continues, her family is grateful their amazing team at the hospital is with them every step of the way. With their expertise and support from people like you, Kate can look forward to even better days ahead and truly shine her brightest. ♥



Holiday giving

Making a gift at this special time of year means you will help even more children by funding the latest medical advancements that are changing and saving lives every day. If you would like to support the incredible work of the Alberta Children's Hospital Epilepsy Program and kids like Kate, you can do so at childrenshospital.ab.ca/sparkle. Or use the enclosed post-paid return envelope to mail in your support.

KIDS 
helping kids

Top Fund-razor

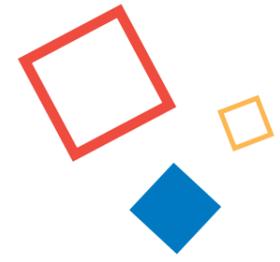
Shane Daalder's haircut in December of 2019 would be his last one for quite some time. Just a few months later, the world essentially closed down due to the COVID-19 pandemic and haircuts were hard to come by. When the barbershops finally reopened, Shane decided to keep his mane growing. At first, it was just a fun experiment — how long would his hair actually get? — however, it then became something much more meaningful.

Two of Shane's friends — Luke and Loic — needed treatment for cancer at the Alberta Children's Hospital. Shane decided he would shave his head for donations to the hospital in order to help kids and families facing similar diagnoses.

"It's pretty sad they are so young and they have cancer," says Shane, 12. "And I knew there would be more kids who have cancer so this was a good place to give the money. I want the research for cancer to be better and better."

In April 2021, Shane had his head shaved — nine inches of hair came off! — in his school gym in front of his classmates. Other classrooms as well as family and friends who had supported his fundraiser were able to tune in via Zoom. He raised more than \$5,300, which he donated to the Kids Helping Kids program at the Alberta Children's Hospital Foundation. His efforts even garnered him a Top Fundraiser award.

Shane was one of hundreds of kids and teens who raised money to support the hospital through the Kids Helping Kids program last year. From his head shave to lemonade stands, online auctions, school fundraisers and more, creative and generous young philanthropists in our community raised \$140,000, bringing the total amount raised since the program began 12 years ago to more than \$4.5 million. ❤️



2020/21 Kids Helping Kids Award Winners

HERO Award
Benjamin Hurkens
Isaac Mork
Lincoln & Theo Nitschke

Top Fundraiser (Age 10 and up)
Shane Daalder

Top Fundraiser (Age 9 and under)
Elysa Ladha

Top Fundraising School
George McDougall High School

Top Fundraising Group
Spartan Titans Hockey Team

CHILDRENSHOSPITAL.AB.CA/KHK



Shane with his friend, Luke



Shane's head shave with volunteer professional hair stylist, Billie Park



We've launched a new website!

Check out our beautiful new site and learn more about how generous support from our community makes a life-saving, life-changing difference for kids and families every day.

CHILDRENSHOSPITAL.AB.CA



Support community fundraising events!

Find out how you can support community initiatives and see what's coming up. Save the date for the Country 105 Caring for Kids Radiothon February 2-4, 2022.

CHILDRENSHOSPITAL.AB.CA/EVENTS



WILL POWER

Did you know that by leaving even a small portion of your estate to the Alberta Children's Hospital Foundation, you can give the gift of future cures, while still supporting those you love? It doesn't have to be one or the other — you can do both.

CHILDRENSHOSPITAL.AB.CA/LEGACY



COMPASSION

The days are long, stress levels are high, and while the pandemic continues to take an unimaginable toll, one thing that doesn't change for the incredible team at the Alberta Children's Hospital is their compassion for the children who need them. We send our deepest gratitude to all the health care workers at the hospital for treating our children with your whole hearts.



Return undeliverable Canadian address to:
28 Oki Drive NW
Calgary, AB T3B 6A8

