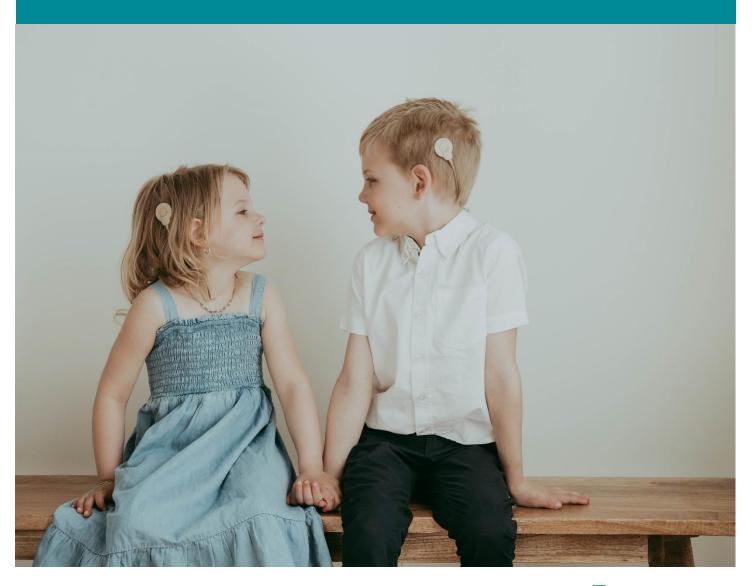
Provincial Population & Public Health Newborn Screening Programs

Early Hearing Detection & Intervention Program

Family Stories





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Learn more about the EHDI Program at ahs.ca/EHDI



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Land Acknowledgement

Our work takes place on historical and contemporary Indigenous lands, including the territories of Treaty 6, Treaty 7 & Treaty 8 and the homeland of the Métis Nation of Alberta and 8 Metis Settlements. We also acknowledge the many Indigenous communities that have been forged in urban centres across Alberta.

Acknowledgements

The Early Hearing Detection & Intervention (EHDI) Program would like to thank the families who have shared their stories in hopes of supporting other families who have participated in the EHDI pathway.

Letty's Story (2020)

When she was two months old, baby Letty was diagnosed with permanent hearing loss, through Alberta's Early Hearing Detection & Intervention (EHDI) Program.

Only a couple of weeks later, she received hearing aids. Her parents could see her respond to their voices right away. "I was holding her, and I was super-excited. I remember her first reaction. It was just awesome. There's nothing quite like it," recalls Darcie Plouffe, Letty's mom.

Now Letty is 13 months old. She wears her hearing aids all day, every day.

She's learning to talk, and she loves to sing and make noises and copy everyone around her. "She has a handful of words, too: Mama, Dada, Up," Plouffe says.

"The first time she said Mama, I cried."

Plouffe has some advice for parents of newborns: have your baby's hearing tested as early as you can. "Just do it," she says. From Plouffe's perspective, "it's that quality of life. Hearing is part of that. It's so important."

Support is available for babies diagnosed with permanent hearing loss and, she adds, "the reward after has been so great."







Kayleb's Story (2021)

Chelsea Stewart will never forget how she felt when her baby son Kayleb heard her voice for the first time.

"It's the most magical moment you'll experience in your life," she says. "You can't even put into words how amazing it is."

Little Kayleb could hear the family's dogs bark. He could hear his older brother talking to him. He could hear his mom and dad's voices, and soon, he started talking: dada first, and then mama.



It wasn't always that way, however. Shortly after he was born, Kayleb was screened and diagnosed with permanent hearing loss through Alberta's Early Hearing Detection & Intervention (EHDI) Program.

"I was so overwhelmed and anxious about the initial diagnosis," Stewart recalls.

But she quickly realized she had a full team of healthcare professionals to support her family's journey.

"There's a huge network of people who are going to guide and support you," she says, a group that includes AHS audiologists, speech language pathologists and more.

"You're never alone."

By the time Kayleb was three months old, he already had his first set of hearing aids.

"He's now 20 months old and he's the most special, incredible little boy," Stewart says.

"He can hear and understand and be with his brother and play and watch cartoons, and all those other fun things, just like every other kid.

Lilah's Story (2022)

Lilah Carter was just a week old when she did not pass her newborn hearing screening and was later diagnosed with permanent hearing loss. It came as a surprise to her mother, Bailey Carter, who was hardly expecting the news.

"We have no hearing loss in our family," says Carter. "It was heartbreaking to hear, but at the same time, I was happy we were catching it early."

Alberta's Early Hearing Detection & Intervention (EHDI) Program screens newborns for permanent hearing loss as early as possible to ensure supports are in place for babies and their families. Hearing screening is quick, safe and will not hurt your baby.



Bailey Carter and her husband Tyson pose with their daughter Lilah and baby Gavin. The Carters were not expecting Lilah to be diagnosed with permanent hearing loss so early in life. Since the diagnosis, they have worked with a speech language pathologist and audiologist to ensure Lilah has the support she needs. Now fitted with bilateral hearing aids, which she proudly called her "ears," Lilah has started kindergarten with her peers.

"Newborn hearing screening is the best way to find out if your baby has permanent hearing loss," says Tanis Howarth, director of Provincial Audiology. "Your baby's hearing is important for their healthy development. Finding hearing loss early helps prevent delays in speech, language and learning development."

The family, who lives in Wembley, 20 minutes from Grande Prairie, immediately started working with a supportive team of audiologists and speech language pathologists, who have helped Lilah and her family along their journey.

"We want to give babies the best start to life possible," says Dr. Huiming Yang, medical director of AHS Screening Programs. "Providers work together and with the family to ensure children with hearing loss have the care and support needed to help them reach their full potential."

Carter admires the close relationships her family has formed with Lilah's team and the comfort they provided.

"We were always informed of what was going on at every step of the way," says Carter. "They might not have kids who have hearing loss, but they understand the situation and they are always there to make you feel comfortable."

Carter remembers Lilah's reaction when she was first fitted with her bilateral hearing aids—which she now proudly calls her "ears."

"They warned us it wouldn't be like the videos on the internet, but it was cool. You could tell everything sounded a little different and you could see it on her face."

While Lilah's hearing has deteriorated a little, the four-year-old is excelling at school with her peers and loves being in kindergarten.

Carter hopes to increase awareness around the EHDI Program and wants other parents to know they're not alone.

"Don't be scared there's something different with your child. There are supports in place to help. You're not alone."



Levi's Story (2022)

Kaylin Scriba thought her son Levi was going in for routine screening with Alberta's Early Hearing Detection & Intervention (EHDI) Program shortly after he was born, but she wasn't expecting him to be diagnosed with permanent hearing loss at just one month of age.

"After the diagnosis, there were lots of emotions and it didn't feel real," she says.

The next step was getting Levi set up with the supports he needed for his development.



At three months, he was fitted with bilateral hearing aids, which took some time for him to get used to.

"It was overwhelming for him," says Kaylin, "but they were adjusted, and he calmed down and got used to them."

As part of Levi's ongoing care, he has been working with an audiologist and speech language pathologist.

"They had really good knowledge of kids going through this and what to expect, especially at the age where Levi is grabbing everything and wanting to pull out his hearing aids," she explains. "They were very accommodating and reassuring."

Currently, Levi, two and a half, is on track with his development and loves his hearing aids.

Kaylin wants other parents to know how important it is to get their newborns screened for hearing loss as early as possible.

"Screening is very important because kids develop differently. Don't skip out on it."

Caleb and Annalia's Story (2023)

Kristen Bohl and her family have a unique experience with Alberta's Early Hearing Detection & Intervention (EHDI) Program — their daughter Annalia's hearing loss was caught early thanks to the program, while her older brother Caleb had a delayed diagnosis prior to the program's existence.

Caleb was born in August 2016 and spent 12 days in the NICU.

"We were going to all of his appointments, but at a year and a half, my husband mentioned Caleb wasn't hearing us," says Kristen. "We brought up the concern with a nurse, but it was difficult to get accurate testing at the time, due to his age. He'd already started to learn body language, lip

Annalia and Caleb Bohl both live with permanent hearing loss. While Annalia's loss was caught early through Alberta's Early Hearing Detection & Intervention Program, her brother Caleb's was caught much later. "The timing of when Caleb and Annalia received their diagnosis has had a profound impact on their development," says their mother, Kristen. "Annalia's speech is much further along than Caleb's, but they're both learning and adjusting to the world around them."

reading and how to respond to people, which confused everyone."

Eventually, Caleb was referred to the Alberta Children's Hospital, where he was diagnosed with permanent hearing loss — and the Bohl family began their journey to help Caleb through his new diagnosis.

Six months after Caleb's diagnosis, his little sister Annalia was born in August 2018. Unlike Caleb, she was screened at two days old and diagnosed with permanent hearing loss soon after.

"When we got the diagnosis for Annalia, it was hard for our family." Adds Kristen. "It's a very isolating diagnosis, but as Annalia and Caleb grow, they'll have each other to lean on for support."

Hearing is important for many areas of child and brain development. Finding hearing loss early can help prevent delays in a child's speech, learning and social skills. All babies born or living in Alberta are offered screening for permanent hearing loss.

"The timing which Caleb and Annalia received their diagnosis has had a profound impact on their development," says Kristen.

Today, both children, now ages 7 and 5, have been fitted with cochlear implants.

They both attend speech-language services. The siblings attend Deaf and Hard of Hearing school programs, with a goal to get them into their community schools. As they grow, they'll be taking more responsibility for their devices, such as learning how to put them on themselves and take care of batteries.

While their experiences with hearing loss are unique, their days with the family are pretty normal.

"Annalia loves to dance and sing and she's such a chatterbox making up musing and songs," says Kristen. "Caleb is supercurious and always has an interest in how the world works. He loves to build things with Lego."

Kristen would like other parents to know how important screening is for hearing loss.

It's overwhelming how many appointments you go to as a new mom, but they're all so important. If your child has a rare diagnosis, it becomes your whole world — but you get to give them the head start they need to reach the important milestones."



Maddison's Story (2024)

Many children with hearing loss are born to hearing parents and, in most cases, there's no history of hearing loss in the family.

Life brought a new challenge for Lindsay Craig and her family when their daughter, Maddison, was diagnosed with sensorineural hearing loss a month after birth. Alberta's Early Hearing Detection & Intervention (EHDI) Program delivered the news after performing an Auditory Brainstem Response (ABR) assessment.

"It was a shock. We had to learn so many things in order to understand her hearing loss, such as new terminology and technology," says Craig, who advocated to ensure Maddison got interventions early to address her hearing loss.

"Hearing is important for many areas of child and brain development. Hearing loss can delay your child's speech, learning and social



Maddison, 5, has big dreams of becoming a 'kid doctor' and isn't about to let her hearing loss get in her way. Thanks to Alberta's Early Hearing Detection & Intervention (EHDI) Program, she was diagnosed with sensorineural hearing loss only a month after birth and fitted with hearing aids at five months, giving her the ongoing support she needs for her development.

skills," says Dr. Patti-Jo Sullivan, provincial director of Audiology. "Early screening means we can provide timely intervention to optimize language, development and overall health outcomes for infants."

In a few short months, Maddison's family spent time with a speech pathologist, audiologist, social worker, infectious disease doctor, pediatrician and an ophthalmologist to get the care needed for her development.

"At five months, she was fitted with a trial pair of hearing aids. Along with that came a new learning curve — finding the best way to keep them on her head," says Craig. "We even had the opportunity to get together with other parents who were going through similar hearing-loss journeys as we learned how our child will experience the world."

Fast forward to the present, and the five-year-old Maddison has just completed her first year of kindergarten. She loves school and tells the world she wants to be a 'kid doctor' and work at the 'rainbow hospital' when she grows up.

"She's on track with her speech," adds Craig. "She's so enthusiastic and bubbly. She loves to sing and talk."

Craig urges new families to take advantage of early screening. "With screening, parents can be aware of the things their children need, so they can get the support they need to intervene early. The earlier you get that support, the better the outcomes can be," she says.

"Had we not been able to detect Maddison's hearing loss, we might have had to play catch-up later—and required far more extensive support from the system."

Craig would also like to offer some reassurance for families who may be dealing with a new diagnosis: "Life is still just as beautiful."

