

Easter Seals Manitoba

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The SMD Audiology Program

It's about programming for people

When a child is born with a hearing loss, it can leave families struggling to come to terms both with the diagnosis and what to do next.

That's where Jerri Lee MacKay enters the picture. As a professional who holds a Master of Science Degree in Audiology, Jerri is trained in the diagnosis and management of hearing loss. As the only audiologist on staff at SMD, she's kept busy testing hearing, diagnosing hearing issues and their origins, and fitting hearing aids for the approximately 65 Deaf and hard of hearing children who are part of the SMD Audiology Program at the Communication Centre for Children in Winnipeg. If that's not enough, she also sees an additional ten to twenty children through other affiliated programs for follow up on an ongoing basis and provides consultative services for other SMD departments as needed (i.e. workshops on educational equipment or trouble-shooting hearing aids).

But of all the work Jerri does with children, she feels that it's her work with the entire family that matters most.

"The birth of a child is often an extremely emotional time and when you add the diagnosis of a significant hearing loss, new parents are often overwhelmed," says Jerri. "Knowing that there is someone who can help them, someone who has experience with infants and young children, can help to allay some of the fears that the parents experience."

Jerri certainly has more than enough experience to put parents' minds at ease. She's worked with young Deaf and hard of hearing children for over 20 years and has worked with a wide array of professionals who come together to provide the best possible services for children who are Deaf or hard of hearing.

"I maintain a strong working relationship with ENT's – Ear, Nose and Throat specialists – in the community, especially in the early stages of diagnosis when parents are still looking for the cause of the child's hearing loss or an infection is making the hearing loss worse," says Jerri. "I connect with other Audiologists on a regular basis to ensure that they are apprised of any changes within our program and keep them informed regarding the referrals they make. I work closely with other Audiologists and hearing aid dispensers because regulations in Manitoba require that all hearing instruments be dispensed by a practitioner licensed by the Hearing Aid Board. When I fit a child with a hearing aid, the device actually comes from a hearing aid dispenser in the community, so the dispenser and I work together to choose the right instrument for the child and then he/she orders the device from the manufacturer."

"I also work closely with any other programs or professionals involved with the child. For instance, if the child is enrolled in a community day care or kindergarten program, I will work with the staff to ensure that they understand the hearing loss, can manage the hearing aids and can attend to any acoustic changes that might be required. If the child uses a cochlear implant – or if the family is exploring the option of a cochlear implant for their child – the cochlear implant Audiologist and I will work together to ensure that the family's needs are met."

Over the course of her career, Jerri has seen a lot of changes with respect to services for children with a hearing loss. But one change stands out among the others – one that has made a large difference in the lives of many families.

"One of the biggest changes is the fact that children with hearing loss are being identified at a much younger age than they were when I first started here 21 years ago," says Jerri. "This is due largely to the fact that there is a real emphasis on universal screening of newborns for hearing loss. Although Manitoba



Jerri Lee MacKay waits for her next client

doesn't have a province-wide newborn screening program yet, there are many locations in which screening occurs."

"Before wider screening programs began, many of these children were not diagnosed until age three or older. With the advent of earlier screening, I am often getting referrals on babies as young as four weeks of age. From an early intervention perspective, this is great news. However, it does present a huge challenge to the families as they try to understand the diagnosis at such an early stage in the process of bonding with their newborn."

That's why Jerri – and the SMD Audiology program – are such vital parts of Manitoba's wellness landscape. It's about more than just providing a service or information. It's about helping families come together, work together and grow together.

"I can remember the first meeting with almost every family I've worked with and can honestly say that I've learned something from every one," says Jerri. "Those initial meetings are often the most emotional. I've seen families in absolute turmoil as they try to come to terms with the diagnosis and what it means for their child. I have listened to, talked with and struggled alongside many parents as they make decisions for their child."

"In the early stages, they are filled with so much uncertainty about what the future will hold for their child. But with each passing milestone – from the first time the hearing aid is switched on, to the first time their child turns to their name, to the first word spoken – their anxiety and worry decreases. It is such a privilege for me to be a part of that journey."

"It is awfully hard not to become attached to these kids and their parents and I can't help but feel very humbled by how strong these children and their parents become. It is incredibly rewarding when I walk out to greet a family and the child comes running to give me a hug or when they cry because it's time to leave. I can't ask for anything more!"

Thanks Ronald!

The only thing bigger than Ronald McDonald's shoes is his heart. Ronald McDonald House Charities recently donated twenty thousand dollars to the Communication Centre for Children. This generous donation will go towards new equipment that will enable SMD to provide state-of-the-art audiology services to Deaf and hard of hearing children. On behalf of the Communication Centre for Children - and all of SMD - thanks Ronald McDonald House Charities!

The Speed of Services

Early service equals peace of mind for one Winnipeg family

The earlier parents find out about their child's hearing loss, the sooner they can begin putting supports in place to help their child's development. It's not always easy to tell if a newborn has a hearing loss.

When Kaelyn Anderson was born, her parents John and Lori weren't expecting to find out their daughter had a hearing loss. The hearing testing done by the Neonatal Intensive Care Unit at St. Boniface Hospital was just part of the routine for children who had been in the NICU.

"At the first appointment, I was sure there was nothing wrong with her hearing because with the type of loss she has, she hears the low tones almost normally and would startle to loud sounds just like any infant would at that age," recalls Lori. "I was very surprised to hear the results!"

The audiologist at St. Boniface Hospital gave John and Lori the names of two local agencies who provide services to children who are Deaf or hard of hearing and their families. John and Lori visited both agencies and SMD really stood out to them.

"After visiting SMD, I just felt very comfortable," says Lori. "I was very excited to know that I would be bringing Kaelyn right to SMD for audiology appointments. I thought we would have to go to a hospital for ongoing services. No one was pushing me to make a decision about anything and it was really easy asking questions."

The ability to begin working with SMD right away was a large factor in the Anderson's decision-making.

"I am a Child Development Counsellor and I work with Special Needs Preschoolers," says Lori. "As a part of my job, I realize the importance of early intervention and knew that it was important to get all the wheels in motion quickly."

"That first day, Jerri (the SMD Audiologist) did the fittings for Kaelyn's ear moulds and the hearing aids were ordered. I think we got them two or three weeks later!" (Kaelyn was also the youngest child fitted for hearing aids at SMD; she was only three months old at the time!)

"We started having regular audiology appointments at SMD and our first appointment was the next week. Everything just fell into place as soon as I had that first meeting at SMD. I was very pleased that it all went so quickly!"

As Kaelyn gets older (she's now eleven months old), the happier the Andersons are about the fact that they got involved with SMD early.

"She was much more responsive to quieter sounds, we didn't have to raise our voices or even be right in her face to get her attention," says Lori. "I believe that her language skills are a little behind, but she is copying what we are saying and following simple directions already."

As for the future, the Andersons are already working with SMD to give Kaelyn every possible advantage.

"We have been offered several services since getting involved with SMD," notes Lori.

"I am learning and teaching her sign language in case we need it in the future, but we are still focusing on Kaelyn's verbal skills. Jerri has also let us come in anytime I had concerns about Kaelyn's hearing aids, ear infections, or just questions I needed answered. All the staff has been great about answering our concerns for Kaelyn's hearing loss and the potential for her hearing to get worse over time...and that's allowed us to be more prepared for the future."



Kaelyn is a little girl with a big grin!

FAST FACTS:

- Hearing loss is the most frequently occurring birth defect and is the number one disability in the world.
- Approximately 5 to 6 infants per 1000 are born with some degree of permanent hearing loss.
- Approximately 3 out of every 100 school-aged children are affected by some degree of hearing loss.

Statistics courtesy National Centre for Health Statistics (NCHC)



I'll support Manitobans with Disabilities

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From time to time, we share our list with other organizations to find new supporters. This allows us to continue helping people with disabilities in your community. If you prefer not to have your name shared, please tick here.



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Call us at 1-866-282-8041 or donate online at www.smd.mb.ca or eastersealsmanitoba.com

Seeing the Big Picture

How one family found support for their son – and their whole family – through SMD

Life can change so quickly.

Peter and Karen Chow were living in Omaha, Nebraska when, after already having two daughters (Robyn, age 4 and Jessica, age 3), their son, Cameron was born. Two days later, Cameron was diagnosed with a hearing loss.

“Karen and the nurses noticed a few things different about Cameron at birth – hypertelorism (eye spacing) and the looseness of his joints,” recalls Peter. “They started testing EVERYTHING immediately, and by day three, they had done the third test confirming his hearing loss.”

Like many parents in similar situations, Peter wasn't sure how to respond to the unexpected news.

“I was stunned and terrified,” he says. “I had never had everyday exposure to someone with special needs, though I was aware of friends of the family that had cousins or other relations that needed more help. Your brain is forced to make a huge shift in terms of expectations.”

Making things a little more intimidating was the fact that the Chows had been planning to move back to Winnipeg. Naturally, they wanted to arrange support services for Cameron before the move. A group in Omaha put them in touch with SMD.

“We were in contact with SMD months before we came home so that we would be able to step into Winnipeg and have a team in place ready to support Cameron,” says Peter.

Having that team working with them has made a big difference to the entire Chow family, from making the regular monthly visits and hearing tests work with their schedule to helping make sure Cameron's hearing aids are molded and fitted correctly. The family also has nothing but praise for the staff.

“Cameron's life is full of support systems,” says Peter. “Family is first, but the SMD group is part of that very necessary second group. They spend time evaluating and suggesting things to aid in Cameron's gradual development.”

“Another big part of SMD's involvement is support for the family. They let us know how we are doing in terms of supporting Cam's growth and basically act as cheerleaders for us. Having a child with special needs is a terrifying rollercoaster of emotion that SMD helps to slow down and smooth the bumps. The SMD group helps us to look at the BIG picture.”

That big picture is nothing but bright for Cameron. His tests show that his hearing aids are working well for him and, by working with other members of his SMD team, Cameron's speech continues to develop wonderfully.

When asked what he would tell a family in a similar situation, Peter doesn't hesitate: “I would advise them to get in contact with SMD as soon as possible. SMD has a professionally run audiological facility that will give information about their child's hearing faculties as well as give support with hearing aids and molds.”

“Cam will be going to preschool in a couple of years,” says Peter. “I truly appreciate the fact that SMD is now able to provide the audiological help that we need. I believe it is a HUGE benefit to have the audiological group integrated with the rest of our SMD team, including both a teacher for the Deaf and a speech therapist.”



Peter and Cameron Chow pay a visit to their favourite Audiologist, Jerri Lee MacKay

What is Easter Seals?



If someone were to ask... “What is Easter Seals Manitoba?” would you know the answer?

Easter Seals has been active in Manitoba for over 50 years, helping raise millions of dollars to aid programs and services for children and adults with disabilities. These programs and services are carried out by SMD – the Society for Manitobans with Disabilities. Each year, through a variety of Easter Seals initiatives, funds are

raised to support services, programs, public and consumer education, self-help resources, advocacy and research.

The two – Easter Seals and SMD – are intrinsically intertwined. When you hear one, you can't help but think of the other.

The Wait of the World

How the Fiskes went from waiting for services to a wonderful experience

Waiting can be difficult under the best of circumstances...so imagine how much more difficult it would be if you were waiting on a service that could have a tremendous impact on the rest of your child's life?

Bruce and Terri Fiske faced just such a wait when they found out their son Wyatt had a problem with his hearing (The couple also has two hearing children, Dylan and Shaey).

"At our insistence, we got our pediatrician to give us a referral for an audiologist in our area of North Eastern Manitoba," recalls Bruce. "We were told it would be a minimum of sixteen month wait in the region."

"When Terri called again later, she was told we would likely have to wait until Wyatt started kindergarten."

It was discouraging news, especially knowing that the longer services for Wyatt were delayed, the more impact it would have on his learning and communications development. So the couple decided to take action on their own.

"Terri sought a private audiologist out when services were stalled and our concerns were finally addressed," says Bruce. "This audiologist independently referred Wyatt to the Children's Hospital and the ENT – Ear, Nose and Throat Specialist – we currently work with."

"Wyatt was diagnosed in December of 2004, so he was two years old, turning three. He has enlarged vestibular aqueducts, which is a malformation of the inner ear and is subject to minor apparent trauma."

"That means that, as well as being a progressive condition occurring in a stepwise fashion, his hearing may also drop if he is playing rough or even if he goes on an airplane ride. I think some days it appears to be better than others but I'm not sure why that is. We try to take as many precautions as we can but maintain life as usual for the most part."



Wyatt is ready for whatever fun spring might bring!

Following the diagnosis, the Fiskes gathered information on available communication programs for children in Winnipeg, including the one at SMD. The Fiske family felt that the SMD program would be more adaptable to their needs and offer a broader range of experiences for Wyatt.

But there was a problem; funding issues had put the SMD program on hold. Because there were no funds available for an SMD audiologist at the level required for Audiology Program Participants, the Fiskes had to look elsewhere.

In May, 2006 however, the Fiskes received some good news: the SMD Audiology Program was back and in full swing.

"We thought it was great," says Bruce. "The ongoing assessment means we can now go in and any problems with Wyatt's hearing aids can be dealt with and adjustments can be made as his hearing changes. It has really helped." Team work with the ENT at children's hospital and the audiologist at SMD is excellent

"We noticed an obvious change in his overall attitude and outlook being in the program at SMD. You can see it even looking back at pictures."

Through the SMD Program, Wyatt is involved in everything from outreach program (visitation by educators at his day care), occupational therapy, sign language, socialization, speech and language development, early learning and school preparedness. And the family can't wait to keep going.

"I would like to continue with all his development even as he enters kindergarten," says Bruce. "He has developed relationships that I believe would be healthy to continue."

"He really looks forward to going to school... even though, like most kids his age, he also likes being at home!"

Art for Angels

Wednesday, April 18th, 2007
ALIVE in the District
(140 Bannatyne, Winnipeg, MB)
Doors open at 6:30pm

Tickets are \$125 each and companion tickets are \$20.

A ticket entitles you to receive a wonderful piece of artwork (\$125 or greater value), appetizers & champagne. The companion ticket allows you to attend and enjoy the evening, as well as the appetizers and the champagne.

For tickets call Dana Todd at 975-3089

The Drop Zone:
Be a hero for
Easter Seals
Kids!



Thursday, August 16th, 2007

The Drop Zone offers daredevils who raise \$1,500 or more the opportunity to rappel from the 17th floor of the RBC building right at the corner of Portage & Main, Winnipeg (with professional assistance, of course!).

Visit www.thedropzone.ca to register or call Dana Todd at 975-3089

The Second Annual Easter Seals Dancing with Celebrities

Friday, September 14, 2007
Delta Winnipeg Ballroom

An evening of dining, music by the Ron Paley Orchestra and a dance competition featuring some familiar faces, including:

John Sauder, CTV News

Jay Oliver, 102 CLEAR FM

Craig Larkins, Global TV

Kathy Kennedy, 92 CITI FM

Laurie Mustard, Winnipeg Sun

Kate Stutsman, Global TV

Ashley Prest, Winnipeg Free Press

Tickets are \$150 or a table of 8 for \$1100.
Call 975-3111 to pre-order your tickets.