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Edition 42 No.2

Summer 2019

Intervention



Stanley (Stan) Andrews Munroe
1944-2019

Inside:

- Remembering Stanley Munroe
- Stories of Interest from the Deafblind Community
- Lessons from Charlotte's Web
- 2019 "Lend-a-Hand" Charity Golf Classic
- CDBA National Student Awards
- News from CDBA Chapters
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The Canadian Deafblind Association (CDBA) was formerly known as the Canadian Deafblind and Rubella Association (CDBRA). "Intervention" magazine is published twice yearly in the Spring/Summer and Fall/Winter.

The Managing Editor would be pleased at any time to receive photos, articles, news items, letters, notices of future conferences, meetings and events, as well as stories about deafblind children, their families and adults - young and old.

All written material should be in the English language and may be edited for length. Opinions expressed in articles or letters are those of the author and not necessarily representative of the views of CDBA. "Intervention" magazine is available electronically and in print form to CDBA members, their families, and others upon request without subscription. Please contact:

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A Message From the President

Carolyn Monaco



As most of you will know by now, we lost our dear friend and colleague Stan Munroe earlier this year. It's hard to imagine CDBA without Stan. He was one of our biggest supporters and cheerleaders for over 40 years. I am pleased to dedicate this issue of our Intervention magazine to Stan Munroe, a dear friend and colleague whose hard work, inspiring words and fun-loving times will always be with me.

Deafblind International (DbI) Conference

I have just returned from the 17th Deafblind International World Conference hosted by Able Australia. CDBA was well

represented by members from British Columbia, Ontario and New Brunswick. The DbI international conference is held once every four years and provides a wonderful opportunity to network with people from around the world as well as access the latest research and best practises. The conference was well supported by over 40 Canadians, second only to Australia in the number of attendees from a single country. It was announced during the closing ceremony that the 18th DbI International Conference will be held in Ontario Canada in 2023. The consortium organization, Deafblind Network of Ontario, made up of service provider organizations in Ontario will be the host organization. This will be the second time this conference will have been held in Canada. The first time was in 2003 in Mississauga Ontario hosted by CDBA. I would encourage everyone across the country who has an interest in deafblindness to think about attending this conference while it is here on "home soil".

2019 Annual General Meeting

The CDBA National Board of Directors and Chapter executive directors will be meeting in Fredericton, New Brunswick

September 19-22 and this year's Annual General Meeting will take place on September 21st. It is always a productive and inspiring time to be "face to face" with our colleagues from across the country. For more information about the AGM go to our website www.cdbanational.com



I hope you enjoy this edition of our "Intervention" magazine and thank those who have submitted interesting and insightful articles and photos as well as a special thank you to Tom McFadden, our national executive director, for organizing the content and Sandra Owen-Peters for assistance with proofing.

Renew your membership or become a member of CDBA at

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Editorial From the National Executive Director

Tom McFadden



I am delighted to welcome our members and other interested parties to this Spring/Summer 2019 issue of "Intervention" magazine.

This issue is devoted particularly in memory of Stan Munroe, a pioneer really in the

history of the deafblind community worldwide who is mourned but not forgotten by his many friends and colleagues with the Canadian Deafblind Association and Deafblind International.

We are so pleased to be able to share with our readers the incredible importance of Intervenor in the lives of those who are deafblind; the technology of a small Bluetooth gadget called a Phonak Roger Pen that changed the life of a 72-year old with acquired deafblindness dramatically; a Harvard grad with deafblindness who uses movement to promote access for people with disabilities; how a medical student with deafblindness is following her dream of becoming a doctor but fighting discrimination, and on a young teenager with dyslexia who helps a man who is deafblind on an Alaska Airlines flight heading home alone.

In a very unique but heartwarming story, we profile on page 10 how Keller, an abandoned but very special dog who is deaf and blind, inspired a #1 best-selling book "Keller's Heart" on Amazon for children with special needs.

You will undoubtedly enjoy reading the third installment of "Lessons from Charlotte's Web" by mom Frances Jablonca - "Shoes don't just have soles, they have Soul!"

New Beginning

On June 24, 2019 CDBA National held its 33rd annual charity golf tournament at the Dragon's Fire Golf Club in Carlisle, Ontario (see more on pages 18 & 19). After more than 30 years with insurance giant Marsh Canada I am pleased to say that the extensive search for a new signature sponsor for our 2019 golf tournament has resulted in another insurance and investment company The Cooperators stepping forward to begin what we hope will be a new and exciting partnership for our annual golf fundraising charitable event.

June 2019 was Deafblind Awareness Month

Initially proclaimed in 2015 by the Canadian Senate, Deafblind Awareness Month was once again celebrated during the month of June. Like-minded organizations now work with a single voice via a national coalition on which CDBA serves to educate Canadians about the unique dual disability of deafblindness, affecting an estimated 65,000 consumers.

CDBA National George Brown College Student Awards 2019

CDBA National annually presents distinguished service awards to two graduating students in the George Brown College Intervenor for Deafblind Persons Program. The awards are for a graduating student who showed outstanding ability in working as an Intervenor with a child who is deafblind, and a graduate who demonstrated outstanding achievement in the field placement component of the Program. They are profiled on page 30.

The field of deafblindness will be a better place because of these two outstanding individuals.

I leave you with this positive thinking quote from Benjamin Franklin:

*"The best thing to give an adversary is **forgiveness**; to an opponent, **tolerance**; to a friend, **your heart**; to your child, **a good example**; to a father, **deference**; to your mother, **conduct that will make her proud of you**; to yourself, **respect**; to all men, **charity**"*



Playgrounds Can Alienate Children with Disabilities. Now, They're Being Built with Accessibility in Mind

By Matthew Hague



Until Hannah Houghton started Grade 3 in September, 2017, she had never romped on the playground of her school, McGirr Elementary in Nanaimo, B.C. In fact, she had never been on any of the 20-plus jungle gyms and adventure parks in her hometown.

Houghton had friends to pal around with and, similar to most kids her age, enjoyed being outside. What stopped her, however, was that none of the playgrounds in her vicinity were wheelchair accessible. As a baby, she was diagnosed with spinal muscular atrophy type 2. It left her without the ability to walk across the shifty gravel that separated her from her classmates.

"Starting in kindergarten, I used to see my daughter sitting on top of the hill overlooking the playground at school, with no one around except her adult supervisor," Hannah's mom, Mabel Houghton, says. "She would simply be watching her friends play. So I made a promise to her. I said: 'You are going to get on that playground.'"

There's no reason Hannah shouldn't have been with her friends sooner, especially these days. According to Easter Seals, more than 5.3 million Canadians, almost 16 per cent of the population, have some form of disability. Among that number, almost 200,000 are school-aged children such as Hannah. Many

more are parents. That's a large number of people who either can't take in the simple pleasure of a park, or supervise their own kids at a park, unless the space is properly designed to accommodate them. Which they should be.

These days, novel designs are making it much easier for people of all abilities to enjoy recreational spaces that until recently were restrictive. That often means wheelchair accessibility, but also goes well beyond it. New materials and thoughtful equipment are also removing barriers for those with vision impairments, hearing deficiencies, social anxieties, autism and sensory development delays.

The benefits of such innovations are potentially huge. According to a study by education journal *Physical & Health Canada*, children with disabilities are almost four times less likely to get exercise outside of school than other children. In addition, more than half of young ones with disabilities have few to no close friends. Both issues are in part owing to difficulties accessing the venues – parks, camps, gyms, schools – where socialization and physical activity often take place. Imagine the isolation that's inevitable if all a child can do is watch their peers have fun.

Inclusive play spaces are an invitation to belong. Plus, even for the fully able, they add surprising, often beautiful new components to scamper over. Quite literally, everyone has more fun.

One of the biggest challenges for accessible play is the ground surface. Although some wheelchairs can manoeuvre over a bed of wood chips, which are American Disabilities Act (ADA) compliant, sand, gravel and

other uneven, unstable materials tend to be hazardous. For the design of Mississauga's Jaycee Park, which was named by *Today's Parent* magazine as one of Canada's best accessible playgrounds, Toronto-based Earthscape Playgrounds used a poured-in-place rubber surface. Not only is it more vibrant than little grey stones – at Jaycee, it's done in a swirling composition of green, blue and orange – it creates surreal, Dr. Seuss-like mounds and has a springy, plush quality that's a joy to bounce around on.

Toronto-based designer Adam Bienenstock, founder of Bienenstock Natural Playgrounds, prefers natural materials like sand to synthetics like rubber – something that may seem incongruous with design for all abilities. He often employs large, reclaimed tree stumps – about 400 years old, many that fell over naturally, all still covered in their rough and weathered bark – that are meant to encourage kids to climb all over. "The average child these days spends 48 minutes per day outside versus 7.5 hours on screen," Bienenstock says. "I'm trying to provide playgrounds that give them experiences they aren't otherwise getting."

But subtly layered within most of the structures are elements that broaden inclusiveness. The textures of the designs – the gnarly bark versus smoother wood surfaces – help those with underdeveloped sensory systems better engage their sense of touch, depth perception and hand-eye coordination. One park, called Pasquinel's Landing Park in Denver, offsets a communal play area with a more secluded enclosure for quiet alone time – something that can be necessary for those with autism spectrum disorder.

"These environments not only help

kids engage their environments," Bienenstock says, "they also help some kids relax."

"These environments not only help kids engage their environments," Bienenstock says, "they also help some kids relax."

Importantly, then, such playgrounds also have to be engaging for able-bodied children as well as a variety of ages. To wit, playground critic Dana Wheatley, along with her three young kids, rates adventure parks for her website, the *Calgary Playground Review* (calgaryplaygroundreview.com). Recently, she took her family to Jumpstart's new Calgary outpost. "It's fantastic on every level," she says. "None of my kids, who range in age from four to 10, wanted to leave."

Jumpstart is ultimately what helped Hannah Houghton get onto her

playground at McGirr Elementary in Nanaimo, B.C. The school was one of the charity's first test locations; they got involved after Mabel sent an e-mail to Jumpstart vice-president Marco Di Buono, trying to find a way to pay for a more inclusive play structure and fulfill the promise that she made to her daughter.

McGirr now has a fully accessible playground, one with a colourful rubber surface, a quiet corner for kids who want alone time and accessible swings with heavy-duty harnesses. In addition to Hannah, children come from all over Vancouver Island to enjoy the space. It's also become popular with parents who have accessibility requirements as well, allowing many of them to interact directly with their kids on a playground for the first time.



One of the most popular elements is an accessible merry-go-round, which is wide enough for a wheelchair to roll on. Hannah particularly loves twirling around, and her mom loves watching her have fun. "Seeing Hannah on the merry-go-round, screaming with the other kids – it's amazing," Mabel says. "It's just so great to see her be a part of the group with all the other kids."

Haptic-feedback Clothing Designed to Guide the Deafblind

By Ben Coxworth



Some of the SUITCEYES prototypes, including the most-recently-created checkerboard vest.

Haptic signing is a process in which a hearing, sighted person conveys information to a deaf and blind individual by touching their back or other parts of their body. It's effective, but what happens if the deafblind person wants to be more independent? Well, new haptic-feedback clothing could help.

The technology is being developed via the three-year European Union SUITCEYES project. That acronym stands for Smart, User-friendly, Interactive, Tactual, Cognition-Enhancer that Yields Extended Sensosphere.

It incorporates a computer-connected wearable camera that identifies important items

such as people's faces, obstacles in the room, or objects that the user wishes to locate. This information is translated into vibrations or other haptic signals, which are delivered to the user's body via a network of actuators built into their clothing.

Originally taking the form of a prototype dress, the SUITCEYES tech is now in its fourth generation, and has been built into a one-off vest. The back of that garment has a checkerboard pattern, each square containing a separate actuator that buzzes the wearer in a different place to convey different information.

Plans now call for a number of such vests to be manufactured, so that the technology can be tested on a larger scale.

"Historically, textiles have always been something closely tied to humans," says Assoc. Prof. Nils-Krister Persson of Sweden's University of Borås, which is leading the project. "Now we are taking the next step and making textiles be a tool for communication."

Harvard Alumna Uses Movement to Promote Access For People With Disabilities

By Juan Siliezar



Kerry Thompson, Ed.M. '08, didn't start a dance program to promote human rights. But after seeing how dance brought people together around a common interest — whether they had disabilities or not — her program gracefully pivoted in that direction.

Thompson, a Louisiana native, expanded her nonprofit, Silent Rhythms, from including people with disabilities in dance to using dance to promote inclusion in society. It's a paradigm shift, she feels, that will help change how people perceive those with disabilities, who often face discrimination and barriers restricting them from fully participating in society.

"Inclusion is still not a given in the U.S." said Thompson, "and that's why rather than accept that to be a fact, our society has to address it, challenge it."

So Thompson, who earned her master's degree at the Harvard Graduate School of Education and is deaf and blind, set out to do her part to move society forward.

"I love that [in dance] you can communicate with your partner without having to say a word," Thompson

said. "To me, that's why dancing is the perfect way to bring the [deaf-blind, deaf, hearing-impaired, and hearing communities] together."

Step by step, tango by tango, Thompson has taught dance to more than 5,000 individuals with disabilities, alongside those without them. Her effort has helped educate, raise awareness, and promote inclusion among people without disabilities while inspiring and bringing confidence to marginalized communities such as the deaf, who are often overlooked in dance because they can't hear the music.

"As a teacher, I love when my students start with all these fears and self-doubts, but the more they do it, the more fun they have," she said. "They are freed of their inhibitions and think, 'I can do this.' One student who has been with me for four years told me that he can now walk better. Before he struggled with walking due to balance challenges."

Thompson understands many of the difficulties her students with disabilities face. Born with Usher syndrome, a rare genetic disorder that causes deafness and gradual vision loss, Thompson was born deaf and at age 10 began contending with progressive blindness. While most people can see 180 degrees, she can now see only 10. "It's like seeing the world through a tiny hole on a piece of paper over your face," she said.

According to the U.S. National Library of Medicine, approximately 100,000 people in the U.S. — not even 1 percent of the population — live with Usher syndrome, which accounts for most deaf-blindness. "Most people will never meet a person who is deaf-blind and most can only think of one person in history with deaf-blindness: Helen Keller," Thompson said.

Despite hardships and even outright discrimination because of her disabilities, Thompson has overcome many of the barriers she has encountered. She can sign and read lips, and at a young age she learned to speak verbally with the help of a speech pathologist. As her eyesight has declined she has learned to read braille and use a white cane and tactile sign language (signing into the hands). She graduated from Louisiana State University, and at Harvard earned her master's in human development and psychology. She moved to Boston for better career opportunities after being rejected in Louisiana because she was deaf.

"The response was, 'We need someone who can hear,'" she said.

This type of discrimination has fueled Thompson's advocacy work outside of Silent Rhythms. At the Disability Rights Fund (DRF), a grant-making collaborative that supports people with disabilities around the world, she serves as the inclusion and analytics officer. She is also on the Massachusetts Statewide Advisory Council and the board of directors for DEAF, Inc., and serves as a liaison representative for the DeafBlind Community Access Network Advisory Council.

"[I realized] that it is up to me to fight for my rights, not just assume that they will be given to me because a law says so," she said, referring to the Americans with Disabilities Act and the Individuals with Disabilities Education Act. "The work at DRF is really about empowering people with disabilities to take the lead. Change for people with disabilities cannot happen without people with disabilities themselves taking the lead."

At Silent Rhythms, Thompson does just that by connecting people who

otherwise might not be able to communicate with one another. At one workshop, she teaches basic salsa and phrases in American Sign Language. It's followed by a dance social where people communicate with the phrases and steps they just learned. The workshop gives disabled and nondisabled dancers a reason and opportunity to connect and understand one another.

Other workshops Thompson teaches at Silent Rhythms are specifically for the deaf-blind and for anyone who knows sign language. In the summer, she also teaches Salsa in the Park, which attracts around 500 people every Monday evening.

Thompson started dancing 15 years ago when a friend invited her out. "I jumped at the chance to go," she said. "No one had ever asked me before. Most people without disabilities overthink when it comes to inviting someone with a disability to come along — then just simply don't ask."

Thompson quickly fell in love with salsa. She followed it up with bachata, cha-cha, merengue, swing, and a little tango. It was difficult, but once she understood the count and steps, she was able to put it together and get in rhythm, she said.

"My blindness usually restricts my movement out in the real world," she said. "I have to go slow and take careful steps. Dancing makes me feel like the real me can come through."



Kerry Thompson has taught dance to more than 5,000 individuals with disabilities, alongside those without them. A Salsa in the Park event can attract as many as 500 people.

And while she cannot hear the music, Thompson can certainly feel it.

"I find that people who can hear and can see focus so much on those senses that they do not realize the other senses they have," she said. "I'm extremely sensitive to touch and the world around me. As much as a person who can hear listens to the music with their ears, I listen to it with my feet. I can feel the vibration pulsating from the floor."

Recently, however, Thompson almost stepped back from dance and from society in general. Her vision continued to deteriorate and things she had once

found easy were becoming increasingly difficult.

"A lot of people with deaf-blindness feel this way — that we have to hide from society," she said. "Or rather that society is too difficult to navigate, so why try?"

Thompson persisted, though, realizing that if she and others like her do fall back, the inclusive society she hopes for will never become a reality. She's willing to keep doing her part no matter the difficulty, one salsa and one tango at a time.



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Deaf, Blind Dog's Incredible Spirit Inspires Children Who Are "Different"

By Adriana Sandoval



John Gray is well known for his work in broadcasting. As a news anchor he's covered some of the biggest stories of our time and won several awards for his work in television. Now he and his special pal, Keller, are winning hearts together.

While volunteering at his local shelter when he met Keller, a 4-month-old double merle Australian Shepherd. Like other double merle dogs Keller is completely blind and deaf. He was abandoned near a railroad track and left to fend for himself.

When he arrived at the shelter staff weren't sure what to do with him. According to John, on top of his disabilities, Keller was "just an absolute mess." Some suggested putting him down as an act of mercy, but a veterinarian there asked for the chance to fix him up with the hopes that someone would want to take him home. That person was closer than they may have expected. John tells iHeartDogs,

"I met him and he touched my heart instantly. I told my wife about him and she wanted to meet him. As weeks went on we kept checking with the shelter to see how he was doing and if they found a home yet. After he had surgery and was ready to be adopted I told them not

to bother looking for a family, we wanted him."

They Grays knew that Keller was not like other dogs, and that a disabled dog could be a challenge. Still, they wanted to give him a place in their home.

"I was terrified bringing home a dog with disabilities; would he be OK? Would my other dogs pick on him?"

With caution, they introduced Keller to their German Shepherds, Sebastian and Winston, and their worries quickly melted away.

"My fears were all wrong, he was fantastic and the other dogs LOVED him and took care of him. The other dogs love Keller and play with him all the time. He doesn't like being alone (because he's in darkness and silence) so they let him sleep on them or touching them all the time."

Sebastian and Winston accepted Keller as one of their own, like a brother. Aside from being a bit protective, like big brothers would be, they don't treat Keller as though he's disabled – and Keller doesn't seem to notice anyway!

Still, because of his disabilities, Keller does navigate the world differently than he would if he had all his senses, but he has never allowed it to get him down. John was inspired by Keller's spirit and zest for life, and thought that his story could help others who are living with challenges of their own – specifically, children.

"After living with Keller for a year I was so inspired by how he handles his special needs, I thought children who are facing challenges need to see this puppy and how he took the lemons life gave him and made lemonade. He navigates the house and yard with ease and is loving with everyone he meets.

"I want to help children who feel isolated, different, maybe they are struggling with a disability, or low self-esteem, to show them none of us is perfect and when life deals you some tough cards, like Keller, you should hold your head up and don't give up."

John had previously written a book for children feeling the loss of a pet called "God Needed A Puppy." It was well-received and has earned over \$20,000 for charities. Children's books were familiar waters for John, and his subject was one close to his heart. "Keller's Heart" is the story of a lonely little deaf girl named Raven whose disability causes others who don't understand her to treat her differently. Things change when she finds a friend in Keller, a dog who may be different, but not broken.



In its first two weeks of sales, "Keller's Heart" has been the #1 best selling book on Amazon for children with special needs. Not only does it mend hearts and give hope to children who may see themselves in the book as they read it, the Grays are also donating a portion of the proceeds to shelters that specialize



in caring for special needs dogs like Keller. So far, over \$3,000 has been donated.

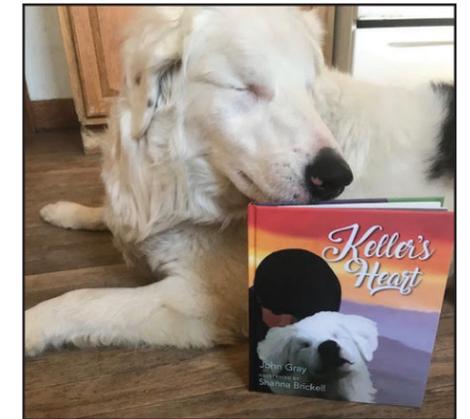
John says it warms his heart that his book is touching so many young lives, but he also hopes it will inspire others to give the special-needs dog at the shelter a chance. In fact, John's family has been so happy to have Keller in their home that they've since adopted Eli, another deaf double merle dog!

"I also thought his story could show people that they shouldn't be afraid to adopt animals with special needs, they are awesome. That's one of the coolest things, because of my Facebook posts about Keller in our lives and now the book I get messages from people who are now seeking out double merles and other animals that aren't 'perfect' by our normal standards but perfect the way are.

"I also want more people to look at Keller and think, 'Next dog I adopt will be a rescue who isn't the first dog or cat

someone would normally pick. I'll take the special animal."

Follow John and Keller on Facebook! John Gray's books, "God Needed A Puppy" and "Keller's Heart" are both available on Amazon, and a portion of the proceeds from either will be donated to charity!



Heartwarming Moment Dyslexic Teen Helps Deaf, Blind Man on Flight

By Samantha Beniac-Brooks

A US teen has touched hearts around the world after helping a blind and deaf man who was alone on a flight.

Tim Cook was heading home on an Alaska Airlines flight after visiting his sister, but couldn't communicate with attendants.

When an air steward asked over the intercom if anyone knew sign language, 15-year-old Clara Daly stepped in.

The flight attendants explained Mr Cook was only able to understand "finger-spelling", a method of spelling words using hand movements.

Clara is dyslexic and had started learning sign language about a year ago as a better way to communicate without having to read or write.

Her proud mother, Jane, was one of many passengers on board who watched on as she knelt down alongside Mr Cook and started to gesture into the palm of his hand.

She shared her daughter's act of

kindness on Facebook.

"They explained that the passenger was not only deaf but also blind. The only way you can communicate with him was by signing into his hand," Ms Daly wrote on Facebook.

Mrs Cook said she helped him ask for water and how much longer was left on the flight.

"Several times he requested her assistance throughout the flight. Toward the end of the flight he asked for her again, and this time he just wanted to talk. She spent the remainder of the flight until landing with him. He asked her lots of questions, and she signed-spelt the answers into his hand."

Over 1,600 people have liked a series of images shared by Mrs Daly, showing Clara gesturing into Mr Cook's hand with a big smile on her face.

The story was also shared by Lynette Scribner who sat in the same row as Mr Cook. Her version of the story has



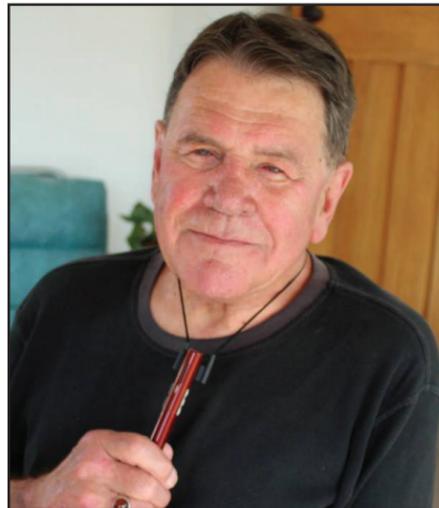
already received over 1.1 million likes on Facebook.

Mrs Daly said she was proud of her daughter.

"The flight attendants and the passengers around him were all taken by Clara. They took these photos which they shared with me this morning," she wrote.

Generous Donor Opens Up New World for Deaf, Blind Man

By Christine Walsh



that deteriorated due to cataracts and glaucoma and also experienced hearing loss later in life.

"They've done everything they can for me medically, but my age is defeating me," he said.

"The thing is with sensory losses your brain fills in the gaps. That can be problematic for people like me who live alone especially because you think you can do things that you can't."

"I use a cane to get around because even though I can see the edge of the gutter I have no idea how deep it is."

His age may be defeating him, but technology isn't and a small bluetooth gadget called a Phonak Roger Pen has changed his life dramatically.

Roger Pen looks just like a pen but it's a wireless microphone that streams clear quality audio to the user via audio shoes that are attached to their hearing aids. The pen decreases sound distortion and reduces background noise.

"It's put my world into cinemascope - already it is making a huge difference to my life.

"I'm terrified I'm going to break it, but they're fairly sturdy. I use it every day."

Roger Pen has helped him be more efficient in his community work, hear better in large groups, enjoy audio books and more.

"I haven't tried music yet, it's so good I don't want to do it all at once. I'm dying to hear music on it. That will be really cool."

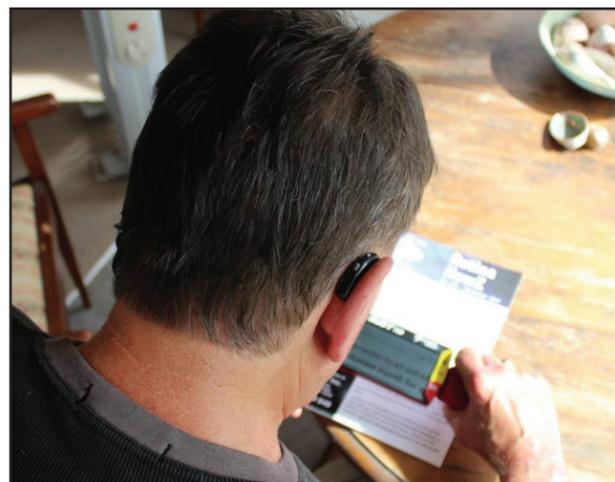
Tanswell had trialed the gadget free for



a month through his audiologist, but unfortunately didn't qualify for funding to buy it.

When Te Karaka Foundation stepped in with their grant from a fund for people with hearing and visual impairments he was thrilled.

The fund was established through the generosity of one of its donors and Te Karaka chairman Ken Horner said it gave them "great pleasure to hear of the delight the grants have brought the recipients."



CDBA National Support Fund

Purpose:

The purpose of this National Support Fund is to provide CDBA members living in Canada who are deafblind with another option for acquiring funds to assist them with the purchase of:

1. Intervention services during or as the result of an emergency
2. Intervention services for individuals confined to a hospital
3. Specialized education or recreation programs
4. Specialized equipment
5. Other services or equipment resulting from specialized or unique circumstances

The funds provided are short term and are to supplement other sources of funds and not intended to replace funding which may be otherwise available.

Emergency:

Defined as an unplanned event for which the individual or their advocate has had less than 14 days to prepare.

Supplemental:

To add to other funding sources which may be insufficient to cover short-term hospital stays, short-term special education programs or specialized equipment etc.

Criteria:

Persons Qualifying:

1. Those individuals who have been identified as deafblind and/or in a deafblind service program.
2. The individual or their family must be a member of CDBA.

Request for Funding:

Application:

Requests for funding may be received from any source on behalf of any qualifying individual or family from across Canada. The application form is available for download on the CDBA National website or by contacting the CDBA National office. Requests must be submitted in writing (preferably using

the application form) and include the following information.

- Name of person who is deafblind;
- Name and address of person making request;
- Description of the circumstance for the request;
- Indication of any requests to other organizations for support and their response;
- Any other pertinent information concerning the request.

How to Apply:

Contact the CDBA National Office info@cdbanational.com for an Application Form or go to the CDBA website at www.cdbanational.com



I am a member of the Canadian Deafblind Association. I am also a senior citizen who is deafblind who lives in North Bay, Ontario. I am totally blind, prosthesis in both eyes. I have no natural hearing. I use Cochlear implants in both ears. I am an active advocate and like to be involved in my community. I can't participate at meetings without help. Intervention in North Bay has improved but still is not the same level provided than in areas such as greater Toronto, Ottawa and London. I needed to have a FM system that I could use to participate at meetings and be active since intervention services supply is lacking.

I have been using the Rogers pen system for over a month now and it has made a tremendous difference in my ability to interact with others, when I can't get intervention support. I use two-hand manual communication and speech.

With the help of CDBA's National Support Fund, I now have equipment that works directly with my cochlear implants and provides clear voices and is easy to use. The power required to operate this system lasts all day. Technology makes a huge difference in my life, but it costs a lot and without support from CDBA I would not be able to obtain this special equipment.

Thanks for making a huge difference in my life and allowing me to give back to my community in the ways I can.

Penny Leclair

Dear New Parents of a Deaf and Blind Child, From a DeafBlind Adult

By Amita Srinivasan



As a society, we label people. Rich, poor and smart are but a few of the labels we unconsciously use every single day. Labels give us a sense of control and enable us to gather information, but they also box people into neat little categories. In that sense they also limit us. Let me explain. I am DeafBlind. I have CHARGE syndrome. These labels can seem overwhelming to observers. They can make me seem unapproachable. "How do you even talk to a Blind and Deaf person?"

Labels can obscure the person behind the label. Since I am writing this article to address the parents of children who have received a similar diagnosis, I would like to tell you my story. When I was born, the NICU doctor who diagnosed me told my parents "your child is severe-profound deaf, is blind with bilateral colobomas, and has paralyzed vocal cords." They were part of my diagnosis, but these labels took on a life of their own.

Deaf, Blind, Mute. They just seemed insurmountable, a veritable Mt. Everest in front of my two hapless parents and associated members of my family. Many in my family were scared and shocked. Many just shut down and wrote my life

off. Many looked at me with pity. "How do you even begin?" My parents heard the labels, took their time to digest them and but then saw right through them to the real me. They saw the mighty fighter in the tiny fragile infant hooked up to multiple machines and

tubes. They heard the challenge in the hoarse cries, saw the determination in the dark eyes and felt the power in the tiny hands trying to pull out the irritating breathing tubes. They chose. They chose to focus on the person rather than the labels. My parents harnessed the information contained in the labels to provide therapy and medical care for me, but they never lost sight of the actual baby before them. They were scared, but then tried to reach out to all the resources they could: the internet, nurses, doctors, other parents and teachers, in order to help me.

I got fitted with BTE hearing aids at 2 months old when doctors ruled out cochlear implants. Believing communication was critical, my parents went to local classes to learn sign language (SEE 2). My mom took intervener training online to help me with tactile learning since my ophthalmologist was not sure about how my vision would develop. My dad glued pictures around the house to help me learn to use my residual vision. But in between all these doctor and therapy appointments, my parents found the time to take me out on walks in the stroller, hang out at the park and to simply have fun with me. In

fact, now I really do not remember much about the surgeries, the scopes and the intense medical intervention, but I can still remember going out and catching ladybugs in spring, signing Brown Bear Brown Bear a hundred times a day, and visiting the public library to pick out my favorite books.

My parents made mistakes too. They were scared I would be isolated and would not let me discuss my disabilities with anyone. They thought they would wait and see how my vision would develop instead of teaching me cane skills right from the start. I use a cane now, but I am always uncertain in new places. But even if they did make some mistakes, they never lost sight of giving me a happy and fun childhood with great memories in spite of anxious moments of medical tests, ER visits and painful surgeries. They used all those scary labels as a starting point for information and worked with them.

As years pass, 19 of them to be precise, some labels have faded while new labels have emerged. My parents now have collected a few labels of their own: middle aged, grey haired, Ph.D. and manager. I have also earned a few more labels to add to DeafBlind: student, honor graduate, college freshman (hook 'em horns!) and photographer. And I am proud of all of them because I am confident in who I am. Disability is just a part of me but not all of who I am.

Labels can be overwhelming. To a new parent they can be scary and paralyzing. Never let labels obscure the person or baby before you. Those neat little categories, those labels: they do not define the person before you. So to answer the question I posed: How do you even talk to a Blind and Deaf person?"

The answer: Just like with everyone else, you will find a way to communicate!

Deafblind Medical Student Pursuing Her Dream Despite Discrimination

By ITV Report, www.itv.com



Alexandra is a third-year medical student at Cardiff University.

A deafblind medical student is following her dream of becoming a doctor.

25-year-old Alexandra Adams, is a third-year medical student at Cardiff University. Born deafblind, she has experienced bullying as a child and also while training as she works towards her dream as a doctor.

Alexandra says she was sent home after

facing discrimination from a doctor while training.

"Bullying now as an adult is much worse than when I was in school. On my first day of placement, a doctor came up to me and said, "Imagine if you were a patient, would you want a disabled doctor treating you? Absolutely not." And I was sent home.

I went home and that was the first time I sat there and thought is medicine really for me?

Another doctor looked at me with disgust and said "I don't want you touching any of the patients."

We need a culture change in workplaces, not just in the NHS, but in all kinds of work." – Alexandra Adams



Alexandra was born deafblind.

A Welsh Government spokesperson responded saying: "Bullying and discrimination are totally unacceptable in NHS Wales. We expect the NHS to be a place where all staff feel valued and supported."

The medical student from Cardiff is completely deaf without hearing aids and her sight is gradually deteriorating.

Despite disliking sciences in school, she was inspired to become a doctor after spending a 18 months in hospital for a number of operations on her stomach.

Although she is stronger and more independent, she is calling for a change of culture within workplaces.

"It's not because people are trying to be mean, it's because they have a lack of understanding, a lack of acceptance and accommodation for people who might be a little bit different to them."

"Don't let it stop you from doing something. It's better to try and fail than to fail to try."



Alexandra decided to become a doctor after she spent 18 months in hospital

Memoriam – Stanley (Stan) Andrews Munroe



Stan Munroe, 74, of Port Morien, Nova Scotia, and a former resident of Owen Sound, passed suddenly the evening of February 11th 2019. Survived by the sunshine of his life, Carol, and his children, Andrew, Jonathan (Sarah), Sarah and grandchildren, Madden and Maia.

Born December 4th, 1944 to Madden and Margaret Munroe, brother to his beloved Irma (the late Ralph) and father and friend to all who knew him. Stan obtained his Masters in Biology from the University of New Brunswick and was a wildlife biologist with the Ministry of Natural Resources in Owen Sound, Ontario until his retirement in 1997. He was also one of the founding members of the Canadian Deafblind Association and later a member of its board of directors, including serving as president. He also worked for CDBA as its executive director and information officer. Most recently, he was information officer for Deafblind International (Dbi), and editor of the bi-annual magazine, the "Dbi Review."

In 2007, Stan and Carol left for Port Morien and opened the Port Morien Rectory Bed and Breakfast. Always the entertainer, he and Carol made friends with the guests who came to stay. Stan dedicated his life to advocating for persons who are Deafblind and empowering

their families, caregivers and professionals across Canada and around the world. He had a passion for cooking, gardening, the arts and always made sure to tune in to his beloved CBC.

A celebration of life was held in Port Morien, Nova Scotia on Saturday, March 2nd 2019 at 2pm at St. John's United Church, to be followed by a reception at the Port Morien Legion. In lieu of flowers, the family asks that donations be made to Andrew's group home, Lions McInness House, in Brantford, Ontario or a charity of your choice.



CDBA Remembers Stan Munroe

As we all know by now, our friend and colleague Stan Munroe, a retired civil servant and long-time advocate for the deafblind community, passed away suddenly in February of this year. Stan suffered a massive stroke in Toronto while en-route to his home in Port Morien, Cape Breton after an extended visit with family on the west coast.

Stan held a MSc and worked for many years as a Biologist for the Natural Resources Administration with the Ontario government.

Carolyn Monaco, President of CDBA National, wrote "Stan wore many "hats" in our field following the birth of his eldest son Andrew, who was deafblind as a result of congenital rubella syndrome. Stan's work with and dedication to the Canadian Deafblind Association (CDBA) spanned a lifetime – first, as a Founding Member, then subsequently as a volunteer member of our Board of Directors; as CDBA National President, as Special Projects Coordinator and ultimately as National Executive Director. Upon retiring from his ED role in 2010, Stan served as Information Officer for Deafblind International (Dbi) on behalf of CDBA National."

Tom McFadden recalled how helpful and kind Stan had been to him as a mentor. Following his hiring as CDBA National Executive Director in January 2011, Tom benefited immensely from Stan's knowledge and experience as a passionate advocate for those who are deafblind. "Stan proudly fought for accessibility of care for those living and coping with the unique disability of deafblindness."

Carolyn remembers how Stan took a lead role in two separate studies on the impact of congenital rubella syndrome in Canada. The information gleaned in these two studies provided valuable information to individuals, families, medical personnel and educational personnel across the country and around the world.

Stan also led a group of volunteers from across the country through a process to put together the first registry of individuals with deafblindness. The collection of this data provided organizations and governments with numbers, locations and etiologies of Canadians who were deafblind, upon which services could be established and first-hand input acquired.

"Stan embraced each of his roles with commitment and unwavering determination to advocate for persons who were deafblind. He was especially proud of his work to inform and empower families of persons who were deafblind, not just across Canada but around the world. He often referred to his role as editor of the Deafblind International Review magazine as a 'labour of love', as it afforded him the opportunity to interact with so many wonderful people worldwide.

Stan was respected by all who knew him for being positive, kind, hard working and fun loving. We will be forever grateful for his contribution to our field, both professionally and personally."





Annual "Lend-a-Hand" Charity Golf Classic Raises Much Needed Funds for Canadian Deafblind Association

On Monday, June 24th a turnout of 76 golfers enjoyed a terrific day on the course for the 33rd annual "Lend-a-Hand" Charity Golf Classic, generously sponsored for the first time by Cooperators Insurance Justin M. James & Associates Ltd. This year's event was held at the beautiful Dragon's Fire Golf Club in Carlisle, Ontario.

The fun-filled day saw golfers and volunteers enjoy a BBQ lunch, buffet dinner, prizes and some healthy competition and camaraderie, all while helping out a worthy cause. CDBA as always was grateful for the hard work of a dedicated core of volunteers - Carolyn Monaco, Sandra Owen-Peters, Nancy Mactavish, and Kim McFadden.

Thanks to the generosity of our title sponsor as well as those companies and participants who kindly donated prizes for our raffle table, this event raised nearly \$10,000. These funds go towards a wide range of activities for persons who are deafblind and their families, carried out by CDBA National through its National Support Fund.



Volunteers: Carolyn Monaco, Nancy Mactavish, Sandra-Owen Peters, Kim McFadden



Justin James, Title Sponsor with The Cooperators and Tom McFadden, Executive Director, CDBA National



Men's Low Team Score: Joe Bardaro, Matthew Donohoe, Rob Hampson, Ed McCormick

Ladies Low Team Score: Lorraine Smardon, Lynn Huges, Vicki Dawson, Christine Schelcht

Mixed Low Team Score: Beryl Moore, Michael Jenkins, Maddie Jenkins, Ryan Ward

Ladies' Closest to the Pin: Christine Schelcht

Men's Closest to the Pin: Ross Taylor

Closest to the Line: Patrick Cassidy

Longest Putt Made: Joe Bardaro

Putting Contest: Mike Crawford & Dave Homulos

Golfers Green Hole-in-One Challenge-Closest to the Pin:
Ryan Moloney/Vicki Dawson



Government Plans Next Steps in Disability Program Review

By Emma Graney



Alberta's long-awaited review into a billion-dollar disability program will be released in the next few weeks, along with the government's next steps to improve the system.

The Persons with Developmental Disabilities (PDD) review began in 2018 under the NDP. The government-appointed panel wrapped up consultations with the public, advocates and interest groups late last year.

Alberta's new Community and Social Services Minister Rajan Sawhney was handed a copy of the panel's draft report when she was sworn into office in April.

Sawhney's press secretary Natasha Kornak told Postmedia in an email the minister has gone over the report and discussed the government's planned direction with co-chairs of the review panel, stakeholders and the disability community.

"She looks forward to releasing the report to the community at large in the coming weeks as well as outlining next steps," Kornak said.

The review is of particular importance to the disability community after reports PDD claims across the province have been being delayed since the UCP took power in April. There are about 12,000 Albertans who receive support through the PDD program, with amounts varying depending on each person's needs. The province spent \$853 million on PDD in 2017-18.

Continuing conversations

While there's no word yet on what the PDD review might contain, one researcher is crossing her fingers it's just the beginning of conversations about the program.

Nilima Sonpal-Valias has researched disability policy for more than 20 years and is currently the director of strategic initiatives and stakeholder engagement

with the Alberta Council of Disability Services.

Her paper, released Thursday by the University of Calgary School of Public Policy, examines the history of the program.

Sonpal-Valias found despite numerous funding increases over the years, PDD program beneficiaries, their families, advocates and service providers feel the system still has many challenges.

"The review and its aftermath offer a timely occasion for all these groups to offer their input and make recommendations to help influence policy reform," she wrote.

Sonpal-Valias told Postmedia she's hoping for two major recommendations from the PDD review.

First, she'd like to see responses to problems that recognize people with disabilities and the programs that serve them don't exist in isolation. That means examining how health care, education and other sectors intersect with PDD.

Secondly, she'd like governments to apply a disability lens to all new policies so they understand how people with disabilities are affected.

"It would be fabulous if the government remains committed to that collaborative, community, co-operative approach that has been the spirit with which this review has moved forward so far," Sonpal-Valias said.

"If the current government continues forward with that, I think it would help them achieve their (election) platform goals and help us achieve a better community."

Why the First Deafblind Person to Graduate from Harvard Law Doesn't Want to Be Called 'Inspiring'

By Aili Nahas

"My years of isolation taught me to create the future that I want," says Haben Girma, 31

Haben Girma doesn't believe in setting limits.

Deafblind since birth, the disability rights attorney has nonetheless spent her life breaking the boundaries of what some would assume a person unable to see or hear can do, including scaling ice glaciers, surfing, and in 2013, becoming the first Deafblind person to graduate from Harvard Law School. She also penned a self-titled memoir, *Haben: The Deafblind Woman Who Conquered Harvard Law*, which released on Tuesday.

"I hope people can move away from seeing people with disabilities as

incompetent," says Haben, 31, who now works as an advocate fighting for protections and inclusion for people of all abilities. "If we remove barriers, we can have great inclusion."

But Haben balks at the notion that she's an "inspiration." Says the advocate: "Some people use it as a disguise for pity. They'll say, 'You're so inspiring,' but in their mind they're thinking, 'Thank God I don't have your problems.'"

An Oakland, California native, Haben, whose father is Ethiopian and mother Eritrean, was born with some sight and hearing, though both decreased over time. She is still able to hear some high-pitched sounds, and speaks in a high vocal register.

Haben struggled in school, both socially and in her attempts to keep up with classwork when she didn't hear the assignments, but by the time she graduated from Lewis & Clark College and then Harvard, "I realized I needed to take responsibility for my education." Says Haben: "My years of isolation taught me to create the future that I want."

Today, Haben travels the world for speaking engagements — and to shed light on all-too-common struggles that the disabled (her word: "it's more direct") encounter every day.

"Society is constantly silencing people with disabilities," says Haben, who has a guide dog and communicates via a dual keyboard system she devised to



"My years of isolation taught me to create the future that I want," says Haben Girma, 31

convert type to Braille text.

In particular, Haben is passionate about internet accessibility, helping to win a landmark case in 2014 against a site that failed to provide access to blind readers.

"People with disabilities already face so many barriers in the physical world," she says. "There's no reason to have barriers in the digital world when we have the power to convert those 1s and 0s into engaging applications that everyone can use."

In the end, "my dream world is a place where people with all types of disabilities are included," says Haben. "There is so much work to be done."



Lessons From Charlotte's Web

By Frances Jablonca

Lesson #3

#5 Shoes don't just have soles, they have Soul.



Frances Jablonca, of the CDBA AB writes about her experience as a mother of a child with deafblindness. Charlotte MacKinnon passed away in 2015 at the age of 22 but her spirit remains strongly in memory.

Charlotte our daughter who is deafblind, had a "thing" about shoes. Not in the typical Imelda Marcos sense of collecting way too many shoes. Nor did she particularly delight in accumulating shoes that were especially glitzy and feminine. On the contrary, her taste in shoes was staid; she was content with plain brown Birkenstocks, sensible black sandals and sturdy slip-ons, everyday shoes. Her fascination with footwear was that it became a way to identify people and a way to identify with important people in her life. It also enabled her to be able to predict events and helped her to make sense of her world. Who knew shoes could have such a profound impact?

From a young age Charlotte was extremely cognizant of people's footwear. I was told by her Intervenor in elementary school that even as early as kindergarten, she'd learned how to ID the teachers by

their footwear. She'd memorize the shoe color and to some degree the style of the shoes of the various school staff that met her during the morning routines before school. Then, as they walked down the hallway, or stopped at the door of her classroom throughout the day, she'd tell her intervener who she had just noticed walking by. It was fascinating how a child with 20/200 vision could pinpoint shoes from a such significant distance.

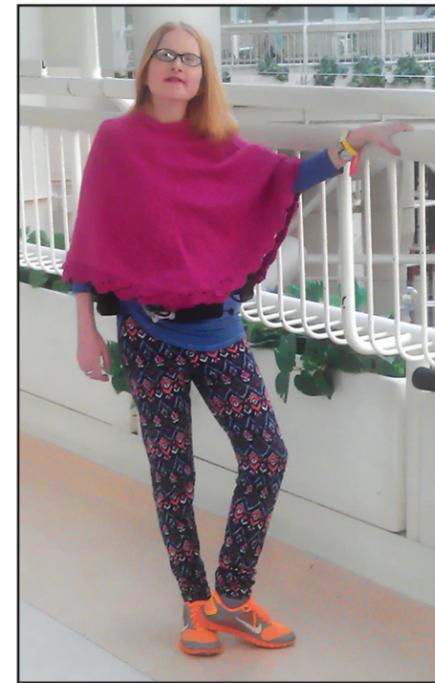
My footwear was of particular importance to Charlotte. When we would go somewhere together, Charlotte made sure that our footwear 'matched'. She had pre-determined from her stash of shoes, for each pair of mine, as the established match that she wanted us to wear. The coordinating pair was then the permanent 'match' for as long as I owned that particular pair of shoes. She would routinely wait for me by the shoe closet to pick out my shoes for our outing in the entrance hall, and after checking to see which ones I'd selected, she would dig around in the shoe closet for her corresponding pair. I was flattered that she had wanted to be like me, but tried to encourage her to consider choosing more age-appropriate styles; brighter, more youthful style footwear, perhaps with a bit feminine bling. I'd hoped she'd at least want to copy the more trendy shoes of her young intervenors, as she typically was good at copying behaviors, but she wasn't terribly interested. The upside to Charlotte not feeling compelled to follow high fashion trends was that she wasn't an aficionado of stiletto heels. With CHARGE Syndrome, the circular canals of the ears are typically underdeveloped, affecting balance, so I made sure that most of her footwear reflected that; low heels and lots of adjustable straps or laces, and decent arch support for her flat little feet. The down-side, however, was that when I chose to wear high-ish heeled shoes with less support, we would end up in long discussions between

us about how her needs on particular walking surfaces required a particular footwear different than what I needed. Charlotte wasn't convinced by my arguments, so more often than not, for the sake of expediency, I'd sacrifice my preferred choice so we could get out of the house on time.

Furthermore, I had to think carefully about changing my shoe choice at the last minute. If I happened to make a quick shoe change, Charlotte would follow suit and frantically kick off hers in order to locate her 'match' to my new choice. She'd be especially annoyed with me if I had changed out of a pair that happened to be one her favorite 'matches'. Though not pleased, she would finally acquiesce in order to be 'the same' as me.

When it was time for me to 'retire' a pair of shoes for various obvious reasons, more long, painful discussions between Charlotte and myself ensued. We all understand the typical attachment to a comfortable, old pair of shoes that has molded perfectly to our feet, but when the bond is with someone else's shoes things get complicated. Somehow, it was beginning to look like Charlotte's bond to me, her mother, was inextricably tied to our shoes.

The shoe-match system was intricately applied to each type of foot wear: fashion boots, winter boots, walking sandals with closed heels, Birkenstock sandals, dress-up sandals, rubber crocs, and runners. The slipper, however, trumped all other footwear in status. With even more exuberance than her rules for matching her outside footwear with mine, was her insistence for me to follow the stringent indoor 'slipper rules'. As long as I was in the house, I was to have slippers on my feet, so that she too, could have hers on. If I hadn't immediately slipped them on when I got out of bed, or upon arriving home, (because I'd forgotten or they weren't handy just then), Charlotte would



find them and mercilessly hunt me down and throw them down at my feet for me to slip on. After all her effort - and the convenience - how could I not go along with her ritual? If I happened on a rare occasion, not to succumb to her wishes, she'd kick her slippers off and stomp around the house in a huff, so we could be 'the same'. In the back of my mind, I knew I should probably pursue more diligently how to minimize this behavior, or explore this with a psychologist, as it was somewhat extreme conduct. Looking back now, perhaps it was a behaviour typical of a specific diagnosis. At the same time, I could see that dual sensory-loss could result in very unique world perceptions and coping skills of these individuals, and I saw Charlotte's connection to my footwear as something linked to this. Charlotte had CHARGE Syndrome and so her vision defect, the colobomas of the irises, resulted in Charlotte seeing best in the lower fields of vision.

Therefore, she naturally would be noticing feet and footwear. Because of her poor balance and proprioception, she didn't walk independently until she was three years old. In the meantime, she rolled everywhere in the house. (She particularly

loved rolling into our bedroom to be in front of our mirrored-sliding closet doors that provided her with hours of stimulation. She'd become quite skilled at opening and closing the doors with her feet). From this vantage point on the floor, she gathered important information about the comings and goings of people around her. As she was profoundly deaf, she couldn't hear to make predictions of what events were ensuing.

Charlotte observed that I wore slippers in the house, so that meant I was staying home. Then, she observed that when I took them off and put shoes on, I would be leaving the house. Her observations provided her with the ability to predict events in the absence of the normal incidental information we get from our vision and hearing. She then came up with a set of rules that made sense to her that gave her a sense a security. Even if her logic was backwards; I take off my slippers because I am leaving home, instead of, I am leaving home because my slippers are off, her set of rules provided her with a sense of security.

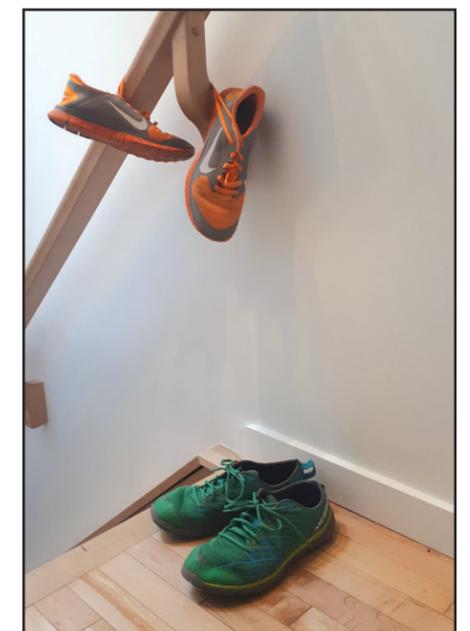
While it was only with myself that she so passionately copied footwear, she had developed quite a sense of humor involving her near, philosophical relationship to footwear. One of my favorite stories was when we'd had one of Charlotte's favorite families over for a visit. She must have been about six or seven years old. When it was time to leave we moved towards the entrance hallway and saw that each pair of our visitors' shoes had been taped to the floor with masking tape! "Don't leave!" couldn't have been communicated much clearer!

At night, if I was already in bed, or in the morning before I got up out of bed, she might walk into my bedroom just to check in on my slippers, lifting one up and giving it a little kiss, maybe cradling it in a hug. She had a mischievous smile on her face, so I knew she was fully aware that she was being silly. At the dinner table, she'd often reach for my feet under the table with hers, resting her slipped

feet on top of mine in a cozy moment of tactile communion. The silly Slipper Antics continued in other ways. When her dad came home from work, one of his slippers was often in a precarious pose, balanced on the stairwell rail, or even on her head! Sometimes it was hidden somewhere; perhaps slipped into a boot in the closet. She'd make sure she was watching when he discovered it, and she never made it so difficult to find that it became a nuisance. It was their moment to have a laugh together.

However entertaining her antics were, her insistence at following the 'shoe rules' could at times be tiresome. But, during her lengthy stressful stay in hospital at the end of her life, I cherished participating in her footwear rituals. It was a fitting farewell to be in 'matching shoes'; a tribute to a unique bond which started at the opposing end of the human heart. Our soul connection had strong roots in soles of our feet.

Afterward: To this day, Charlotte's bright orange NIKE runners are draped over the stairwell banister in our home. She picked out this pair as her match to my brilliant green runners, rated very highly among her favorite pair of footwear. This was also the last pair of matching shoes we wore together.



The favorite 'match' hanging from the bannister.

CDBA Chapter News

CDBA Alberta Frances Jablonca, *President*



CDBA Alberta Chapter has been continuing to provide clients with funding for intervention and assistive technology. We had our 3rd Charlotte MacKinnon Memorial Wagon Ride this June in honor of Deafblind Awareness Month. Again, we were blessed with perfect weather; blue skies with just the right amount of cloud and a breeze to keep us and our trusty horses cool. The staff at Rafter Six Ranch supported us as usual, and kept the fires going for the tasty weiner roast. Our members came down from Calgary and Edmonton for this enjoyable event.



CDBA Chapter News

CDBA British Columbia Theresa Tancock, *Family Services Coordinator*



With June being National Deafblind Awareness Month, we anticipated a fun-filled month! We had been busy all year collaborating with the National Deafblind Awareness Month Committee (NDBAMC) and specifically with the Deafblind Planning Committee (DBPC), here in British Columbia.

Canada to light up in blue, however, due to demand some landmarks in BC required us to choose a different date. As a result, the blue lighting schedule was as follows:

- June 2: BC Place Stadium, Vancouver, BC
- June 3: City Hall, North Vancouver, BC
South Okanagan Convention Centre, Penticton, BC
- June 7: Anvil Centre, New Westminster, BC
- June 9: City Hall, Vancouver, BC
- June 23: Canada Place Sails, Vancouver, BC

Staff and individuals from CDBA-BC and DBPC met for dinner on June 7th and 23rd prior to witnessing the lighting of the Anvil Centre (New Westminster) and the Canada Sails (Vancouver). Fun was had by all!

On June 8th, a Family Bowling Event took place, followed by the Annual General Meeting for CDBA-BC. Participants explored the CDBA-BC Sensory Tent, bowled with their family and friends and ate pizza and cake! There were many smiles and much laughter at Revs Bowling in Burnaby!

The photos below are a true testament to the fun that was had celebrating this nationally recognized month. We are already looking forward to next year's celebrations - planning will be underway very soon!

The National Deafblind Awareness Month is a collaboration of agencies and Non-profit organizations across Canada that support individuals with deafblindness. Together, we have created a Nation-wide calendar of events that occur during the month of June, which can be found at www.deafblindnetworkontario.com. A toolkit is also created that includes items such as media announcements, articles related to deafblindness and Intervention and the NDBAM logo.

This year, CDBA-BC collaborated with the Deafblind Planning Committee to organize activities. Several landmarks were lit up in blue in recognition of this momentous month. June 3rd was chosen by the NDBAMC to request landmarks across



CDBA Chapter News

CDBA New Brunswick Kevin Symes, *Executive Director*



The Canadian Deafblind Association-NB Chapter has been enjoying the welcoming of the warmer weather these last few weeks. Although the winter and cooler spring didn't stop our clients and intervenors from enjoying many activities, inside and outside the office. Several of our clients have been participating in swimming, volunteering in their community, playing games and enjoying social time in the Snozelen room during clubhouse, along with making yummy treats in our teaching kitchen.

June started out with a bang, with celebrating Deafblind Awareness Month with two celebrations. Fredericton area enjoyed their event at a park with lots of food, cake and outdoor activities. Moncton and Bathurst area celebrated with pizza, treats and bowling. Both events were a success and everyone enjoyed getting together to celebrate.

We furthermore have a busy summer ahead of us with a day trip to St. Andrews to go Whale Watching and getting geared up for our annual Sensory Camp in September, with Disney being our theme. Everyone will get to dress up as their favorite Disney Character.

CDBA-NB would like to wish everyone a fun and safe summer.



David Brown, Mike Stewart, Kevin Symes
Mike Stewart honorary member of CDBA-New Brunswick



Kevin Symes, Tim Fox, David Brown
Tim Fox volunteer of the year



L to R – Ghita Gaudet, Julie Sproul, Sheila Rogers, David Brown, Renee Landry, Charles Landry
Absent with regrets – Rob Johnson, Beth Major
CDBA-NB Board of Directors 2019-20



After 14 years our very own Sheena, retires from work at TD bank.



Fredericton celebrated Deafblind Awareness at O'Dell Park in Fredericton with lunch, cake, and outdoor activities.



Our Moncton and Bathurst clients celebrated Deafblind Awareness enjoying pizza, treats and bowling.

CDBA Chapter News

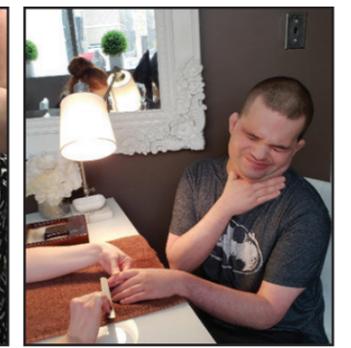
CDBA Saskatchewan Dana Heinrichs, *Executive Director*



Norrie Camping



Alex's new hairdo



Tony getting a manicure

At CDBA Sk we love to be out in the community, our programs for the Individuals are designed specifically for each person, focusing on their interests and supported by our team of Intervenors.

We are always so pleased to see the smiling faces, growth of communication and new levels of independence from day to day. We hosted our 15th Annual Lend A Hand Charity Golf tournament with the help of our corporate sponsor MacDermid Lamarsh law firm and the Cosmopolitan Club of Saskatoon with a few extra golf teams entered. We had a few showers in the morning but it turned out to be a beautiful day of golf, networking and raising funds – this year brought in just over \$20,600!

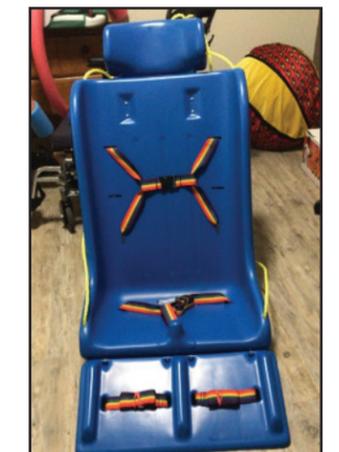


CDBA Sask hosted our 34th Annual General Meeting on June 20th, 2019. A time to gather and reflect on the past years achievements and challenges and look forward to the future. One board member stepped down from the board so we now have 2 openings for new members.

CDBA Sask is proud of our Intervenors and their hard work day in/out. We would like to highlight Nadine F from the Anderson house; she was presented with the 2019 Sask IV of the Year Award. Congrats for your dedication and excellence at what you do.

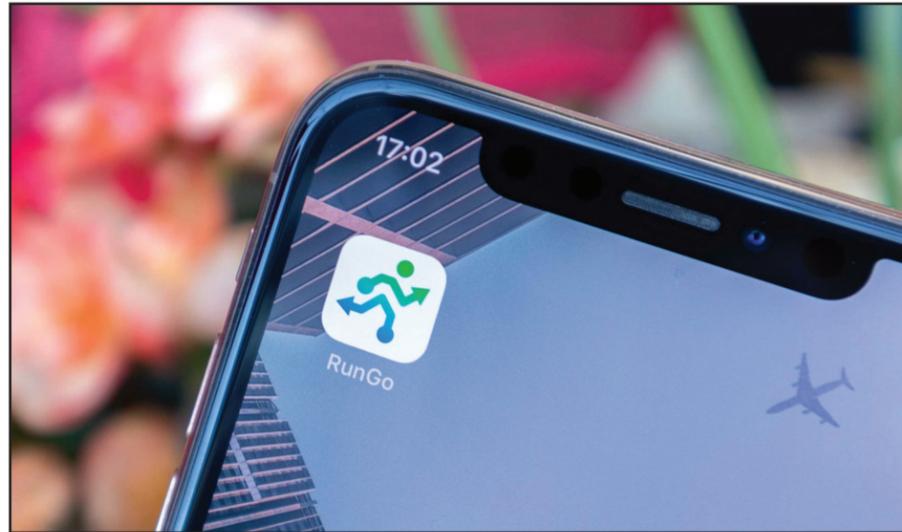
We have received some grants through our community partners allowing us to purchase some new equipment and dive into some summer projects. Thanks to the Affinity Credit Union, Saskatoon for the funds to purchase a therapy swing, pool flotation unit and wheelchair scale (to be purchased), and the Cosmopolitan club for the raised sensory garden and \$ for the scale. Thank you!

One of our most recent highlights was receiving word that we were approved funding for a new position from the Government of Saskatchewan! We are currently searching for the right candidate to fill the position of Programs Administrative Assistant. This role will be a huge asset to our management team balancing out the demands and work levels for both myself and the residential program coordinators.



Apple's Accessibility Efforts Land Canadian Helen Keller Award in Deaf-blind Achievement

By Shruti Shekar



Apple has been presented the Canadian Helen Keller award for the company's contributions to the disability of deaf-blindness.

Sarah Herrlinger, Apple's director of global accessibility policy and initiatives, said in a recent interview with MobileSyrup that the Cupertino, California-based tech giant was honoured to receive the award and recognition.

"I think it shows some of the leadership we've done through the years. Apple has led the field in trying to include accessibility in our products and in particular for a case like this, to work with some of the groups that might otherwise be marginalized..." said Herrlinger.

Herrlinger has been with Apple for 16 years, and during the past four, she's held her current role as director of global accessibility policy and initiatives. Throughout her career at Apple she says one of the company's core tenets has been to create products that work for "as many people as possible."

"As we looked at the creation of the iPhone, knowing it was a touch screen device, one of the things that was important to use from the start is asking 'are there people who would be left

behind and how do we make sure that doesn't happen?'" she said.

Herrlinger said Apple was one of the first companies to make touch screen interaction accessible to the blind community.

"When you think about the touch screen, it's a piece of glass and has little tactile feedback, so making something like that work as well for members of the blind community as anyone else, was very important to us," she said.

She noted that when a product is designed at Apple, from the very beginning of conceptualizing the accessibility team is brought in to talk about how the product will be utilized by individuals in all communities.

"Disabilities or limitations do not come from the individual with the disability. It tends to come from the society around that person," she said, referring to a thought process she was told very early on in her career by a close friend who is deaf and blind.

"At Apple, we consider accessibility to be a basic human right and a value. We have tried to lead by example in the best ways we can and if that makes other people think about it more, then great," she said. "It's not just one company that

should do this, because we all need to be thinking about it. It is something that affects everyone in the world."

Apple being presented the award coincides with Global Accessibility Awareness Day, which falls on the third Thursday of every May.

Running made easy with accessibility features in RunGo

In Canada alone, at least one in five Canadians have some sort of disability and an estimated 500,000 Canadians are blind or partially sighted, according to Stats Canada. Over 65,000 Canadians live with deafblindness and an estimated 5.59 million suffer from some form of eye disease.

It's also worth noting that when someone says they're blind, it doesn't necessarily mean they can't see anything. It just indicates the degree an individual can see is limited to a certain percent.

This is what Rose Sarkany, an avid runner, explained. Sarkany is both hearing and sight impaired.

"Most people have 175 degrees of vision. I now have approximately five degrees. So it's like a very small tunnel vision," the 55-year-old explained in a phone call.

Sarkany explained that her vision started to degrade as she got older and her doctors have told her that it will progressively get worse.

"It was disheartening to think that I would have to quit running because I really have come to love running, especially trail running. I just don't want to be that person that gives up," she said.

Sarkany now uses a running app called RunGo, a "virtual running partner"

that offers users turn-by-turn voice directions for different paths, routes, and races.

She said before she started using the app, which launched in 2014, she would often get lost on runs.

"It was very easy for me to miss streets because I can't really see signs and turns," she said.

The app's founder, Craig Slagel, said in a phone interview that the inspiration for the app was to create something that regular runners could use, but also happened to include capabilities for those who have disabilities.

He met Sarkany at a runner's expo in Vancouver and from that moment felt she would be able to help in developing accessibility features for the app.

"We got a lot of feedback and from the very beginning we had good use of voice from her in trying to make the app as accessible as possible," he said. "I wanted to make a hands free eyes-free experience."

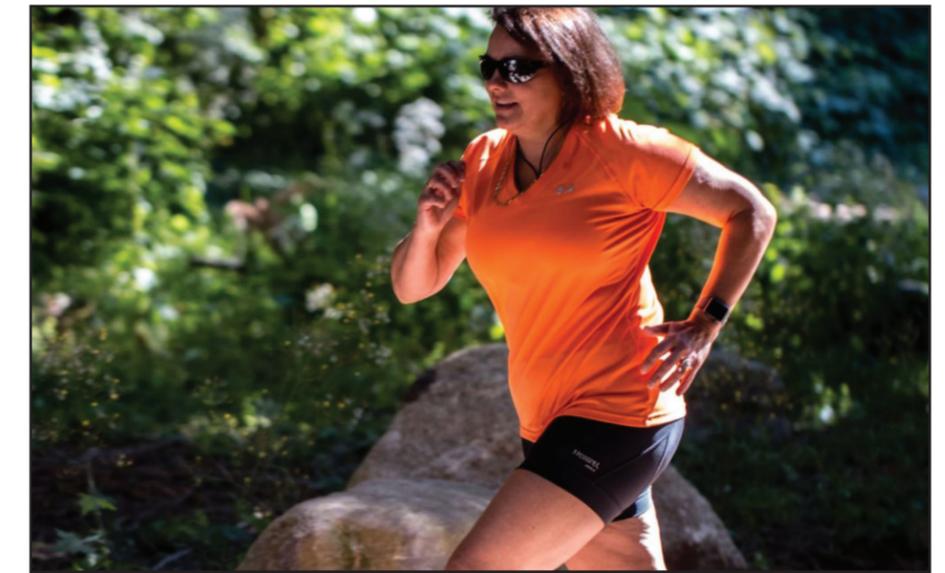
Apple's accessibility has helped RunGo use AR to aid runners with sight, hearing impairment

Slagel said after a few iterations of the app, they included haptic feedback and augmented reality.

With haptics, the user will get a small

vibration shortly after a direction is announced.

Slagel said many times runners might miss their cue to turn, so the short vibration helps. Slagel said he also attended Apple's Worldwide Developers Conference (WWDC) a couple of years ago. He explained that this is when the



team decided to include AR in the app. Apple's WWDC 2019 this year is coming up in June and MobileSyrup will be on the ground covering the event.

"People assume that when you're blind it's black, but legally blind people have a certain amount of vision...and for

Rose, it's like looking through a straw," he said. "With the AR feature, people who get confused when they get to intersections and they're trying to figure out where to go, the AR feature will overlay a nice big 'right' arrow over the street you turn on..."

Sarkany said the app made her feel

"like a regular runner."

"Accessibility should be a necessity and not an option and I think that's what Craig and RunGo app are doing. It's making a necessary thing for everyone and it's nice to see technology be so inclusive," said Sarkany.

2019 Donor List

A sincere thank you to the following donors whose generosity during 2019 helped CDBA continue to offer quality services and support to consumers who are deafblind and their families

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Joan Mactavish
Linda Mamer
Allana Pierce
Wanda Schellenberg
Barbara Severs
United Way of Lower BC



Jemma Waito-Taylor – The Andrew Love Memorial Award presented by CDBA National President Carolyn Monaco

The Andrew Love Memorial Award of Excellence

This award is presented to a graduating student of the George Brown College Intervenor for Deafblind Persons Program who has shown outstanding ability in working as an Intervenor with a child with deafblindness.

The award winner receives \$150 from the Andrew Love Trust Fund and a certificate provided by George Brown College.

The award was first issued in 1993.



Aislynn Curran - CDBA National Award for Excellence in Field Placement presented by CDBA National Executive Director Tom McFadden

The Canadian Deafblind Association - George Brown College Award for Excellence in Field Placement

This award is presented to a graduating student who demonstrated outstanding achievement in the Field Placement component of the George Brown College Intervenor for Deafblind Persons Program.

The award winner receives \$100 from CDBA National and a certificate provided by George Brown College.

The award was first issued in 1998.



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All people who are deafblind will live rich meaningful lives.



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