



**Canadian  
Deafblind  
Association**

Supporting Access  
and Opportunity  
for All

[www.cdbanational.com](http://www.cdbanational.com)

*Imagine...*

*...Life without sight, Life without hearing, Life without BOTH*

Vol. 42 No.2

Winter 2018

# Intervention



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- Book Review – “An Exceptional Fellow”
- Lessons from Charlotte’s Web #2
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- Inspirational Articles About Communication and New Technologies
- 2018 Recipients of National Awards for Volunteer & Intervenor of the Year

SHARING THE KNOWLEDGE TO  
**ACT**  
 ACCESSIBILITY. COMMUNICATION. TECHNOLOGY  
 "Now is Your Time to ACT"

**17th Deafblind International World Conference 2019**  
 AUGUST 12-16, 2019 | GOLD COAST, AUSTRALIA





The **17th Deafblind International World Conference**, hosted by Able Australia, will take place August 12 -16, 2019 at the Surfers Paradise Marriott Resort & Spa on the Gold Coast, Queensland, Australia.

The conference theme is:

**Sharing the knowledge to ACT: Accessibility. Communication. Technology. "Now is your time to ACT!"**

In keeping with this theme, we aim to showcase research, experiences and best practices that are shaping the world for those who are deafblind. This conference is not only for academics and professionals working in the field of deafblindness, but also professional interpreters and communication guides, people who are deafblind, together with families of people with both acquired and congenital deafblindness.

EVENT HASHTAGS

#dbi2019australia  
 #deafblindworldconference

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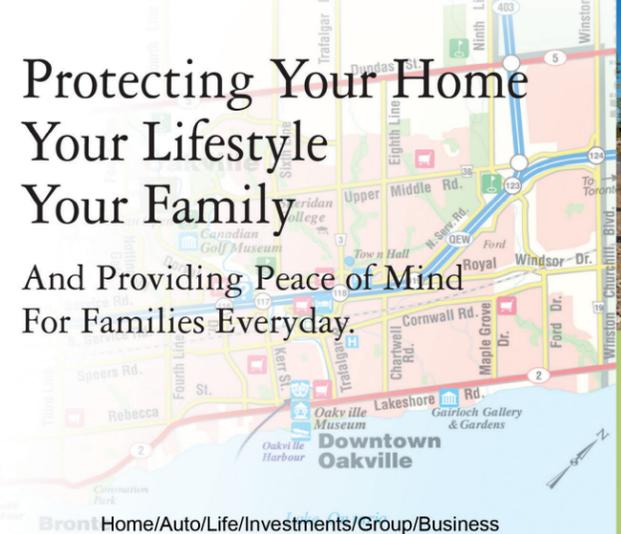
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The Canadian Deafblind Association (CDBA) was formerly known as the Canadian Deafblind and Rubella Association (CDBRA). "Intervention" magazine is published twice yearly in the Spring and Fall.

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



### CDBA National 2018 AGM

CDBA National held our Annual General Meeting along with one and half days of Board meetings in September in Toronto. This is the yearly opportunity for the Board of Directors and the National & Chapter Executive Directors to meet face-to-face. The energy and enthusiasm created by bringing this group together is something I think we all look forward to. While we have monthly conference calls, there continues to be no better way to really share, plan and create than face-to-face around a unified table of respected colleagues with a common goal to better the lives of individuals who are

deafblind across this country. Our Board of Directors and staff contacts are all profiled on page 31 of this issue.

For me personally, one of the highlights of our AGM is when a representative from each chapter highlights their chapter's activities from the past year. It's always exciting and educational to hear what each chapter has been doing. Often representatives will share photos or videos of events. Our 2019 AGM will take place in September in either Fredericton or Moncton New Brunswick, with further details to follow.

### A New CDBA Chapter is Emerging in Ontario

As most of you are well aware, the Board of Directors and Executive Director of our former Ontario Chapter have been working for a number of years now to leave the fold of our national organization and rebrand under their own name. That process is now complete. We remain unsure as to the rationale for this decision but accept that a group of individuals have the right to make changes that they determine meet their needs. The name of the new organization is "Sensity".

We are however very excited that an ever-growing number of people living

in Ontario, both family members and professionals working in the field have indicated a real interest in creating a new CDBA Ontario Chapter. We are exploring ways in which we can assist our Ontario members to make this happen. Stay tuned!

### Deafblind International Conference

During the week of August 12-16, 2019 Able Australia will host the 17th Dbl World Conference and a number of CDBA members from across the country will be in attendance. The Dbl World Conference is held once every four years and provides a wonderful way to network with people from around the world as well as accessing the latest research and best practises.

I hope you enjoy this edition of our Intervention magazine and thank those who have submitted interesting and insightful articles.



**Renew your membership or become a member of CDBA at**  
<http://cdbanational.com/en/membership.html>

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## Editorial From the National Executive Director

Tom McFadden



Welcome to this Fall/Winter issue of "Intervention" magazine, in which we focus on "touching" and new signing training; innovative technologies for "watching" TV; and apps that will help persons who are deafblind to communicate. We have profiled on page 10 a film - in which a deafblind actor has been cast in a lead role for the first time - about an unlikely connection between a teen without a home and a man who is deafblind.

You will undoubtedly enjoy reading on page 20 the second of several "Lessons from Charlotte's Web" by Frances Jablonca - "You cannot smile until you are ready".

On the international front, on page 26 you will meet a woman from Belfast, Northern Ireland who is deafblind but with an unbelievable drive and persistence to do what nobody thought she could.

On page 8, Wanda Schellenberg reviews in interesting detail an inspirational book by Svein Olav Kolset entitled "An

Exceptional Fellow". This is a must read for father's everywhere with a child who is deafblind!

Finally, read about the tabling of Canada's First National Accessibility Law!

### The Power of Volunteers

This past October, Charity Village partnered with Volunteer Canada to offer a free webinar on "the value of volunteering". In her subsequent article, Paula Speevak wrote "Volunteering reflects our values - what we care about, our vision for our community, our notion of justice, and our sense of responsibility for the planet and all those with whom we share it". In addition, volunteers "provide value through their leadership and governance, by setting strategic direction, forging alliances, and executing fiscal oversight". It has been my own experience that, as Ms. Speevak states, "Board volunteers can raise the profile of an organization, open doors, and bring important perspectives from members and stakeholders". At CDBA, we are blessed to have such people - you know who you are - helping to provide direct services that increase the impact of Chapter programs for persons who are deafblind.

### Farewell to a Friend

On July 9, 2018 CDBA National held its 32nd annual golf tournament at the Nottawasaga Golf Resort near Alliston, Ontario. For more than 30 years, insurance giant Marsh Canada has sponsored this charity event and, during that time, has raised over \$675,000 for CDBA National. I am saddened to say that 2018 will represent the final year

of our involvement with Marsh. It has been a very special relationship with the event management team at Marsh for which we will be forever grateful. The search for a new signature sponsor for our 2019 golf tournament, to be held July 8th at the Dragon's Fire Golf Club in Carlisle, Ontario south of Milton has begun in earnest.

### June is Deafblind Awareness Month

Initially proclaimed in 2015 by the Canadian Senate, Deafblind Awareness Month will once again be celebrated during the month of June 2019. 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 Awards 2018

CDBA National annually presents distinguished service awards to the Intervenor and Volunteer of the year during its AGM in September. Featured on page 12 of this issue, Jacky Mackenzie of Saskatoon, Saskatchewan was presented with the Andrew Love Memorial Award of Excellence for demonstrating outstanding ability to intervene with a consumer who is deafblind. Dwain McLean of New Maryland, New Brunswick was recognized for his passion, enthusiasm and voluntary commitment to CDBA for nearly a quarter century! The field of deafblindness is a better place because of these two outstanding individuals.

**"Optimism is the faith that leads to achievement; nothing can be done without hope or confidence"**

— Helen Keller



# Utah Center for Deaf and Blind Takes Part in New Signing Training

By Spencer Burt



Jelica Nuccio, center, trains interpreters in an organic form of American Sign Language called Protactile ASL.

TAYLORSVILLE — People who are deaf-blind have to communicate and experience the world around them using mostly just one sense: touch.

Recently, a group of deaf-blind Utahns learned an emerging method of sign language that could change their lives.

Jelica Nuccio and John Lee Clark, both nationally recognized trainers, came to the Sanderson Center for the Deaf and Hard of Hearing Nov. 8-10 to teach deaf-blind individuals and interpreters Protactile American Sign Language.

While tactile sign language helps the deaf-blind to understand by feeling someone's hands while they sign, protactile signing provides a way for the deaf-blind to better communicate and understand conversations, and more fully experience the world around them. It utilizes the whole body, such as the legs, arms, chest, back and head.

For example, lightly tapping on a deaf-blind person's arm or knee signifies that the listener is nodding in agreement. Quickly rubbing back and forth on the same areas would signify "no," a disagreement or another negative

reaction. Drawing a question mark on the deaf-blind person's chest means the listener is confused or doesn't understand.

Protactile ASL is new to Utah's deaf-blind community, Stephen Ehrlich said. It was developed "organically" by

people in the deaf and blind community starting in 2007, and he thinks Utah was just out of the loop for a while.

Ehrlich, who was born deaf and visually impaired before eventually losing sight completely, participated in the training. He said although having three full days of training was great, he wishes they had more.

"It was very rich experience for everyone involved," he said in sign language via interpreter Clay Anderson.

Ehrlich teaches sign language at the Sanderson Center, particularly to adults who are developing deaf-blindness. He is also part of a committee that will discuss what the next step will be in continuing protactile education.

"We will keep practicing it," he said. "This is just the beginning of a new journey for us."

Dan Mathis, assistant director of the Sanderson

Center, said the purpose of the protactile training was to make communication more inclusive and accessible. He said that among the deaf and hearing communities, people who are deaf-blind are sometimes left out and overlooked.

"We don't recognize that community enough," Mathis said. "Protactile signing is a way to bridge those communities better. So it's a learning experience for myself as well."

More specifically, both Mathis and Ehrlich said the goal is to help local deaf-blind individuals become future trainers and teachers of protactile signing. This would provide good job opportunities for deaf-blind people, who have a hard time finding work, Ehrlich said.

Ehrlich also works at Sears, where he repairs broken ratchets. It's difficult, he said, because he feels isolated with such a limited way of communication.

He doesn't like that feeling, so he likes to rake leaves and shovel snow and do other things outside that keep him busy.

Mathis said many deaf-blind people feel isolated from their surroundings, but protactile ASL gives them a way



to feel more connected. An interpreter can use a deaf-blind person's back as a map to describe the room, helping them visualize who is there and what they're doing.

Tony Bonny, an ASL interpreter for staff members at Utah Schools for the Deaf and Blind, was excited about what he learned at the trainings.

Like Ehrlich, Bonny wishes he had more time to learn protactile signing.

"I really enjoyed myself. I'm actually exploring other options to get more training, because I felt like I just really wanted to jump and immerse myself in this language," he said.

Traditional ASL a visual language,

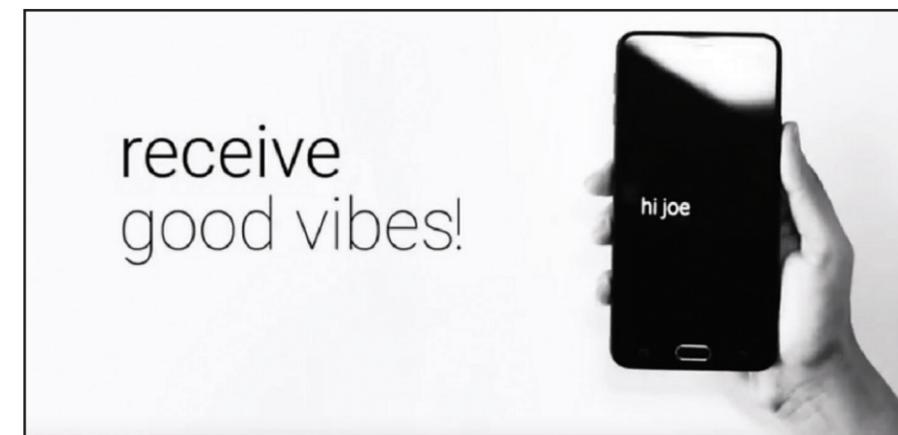
creating a "picture in the air," Bonny said. He was glad to learn a way to do the same in a purely tactile way, "creating messages that you could not necessarily see and conceptualize, but feel and conceptualize."

For more information on PTASL, check out this article: <https://www.perkins.org/stories/how-pro-tactile-american-sign-language-ptasl-is-changing-the-conversation>



Jelica Nuccio, center, trains interpreters in an organic form of American Sign Language called Protactile ASL.

## New App Helps Deafblind People Communicate



### Good Vibes uses Morse code and vibration, and is now available on Google Play.

A marketing company has launched a mobile app which enables two-way communication between deafblind people.

Cheil India created the Good Vibes app, which works by using the vibration capability of a smartphone combined with Morse Code to "represent the alphabet in a binary fashion".

The developers say the app goes one step further than other methods of

deafblind communication such as Braille and pro-tactile sign language, which depends on physical contact.

Users can tap a smartphone screen in varying ways to activate different Morse code symbols. For example, a "short tap" translates as the Morse code "dot" while a "long tap" on the app is translated as a "dash".

The app uses haptic feedback and does not have a visible user interface. Developers say this is the "first time in history" that an effective tool has been created for two-way communication

between those who are visually and hearing impaired.

The gestures and taps create letters and words which are transmitted as vibrations to be deciphered by any trained deafblind person.

Good Vibes was developed with charity Sense International and aims to "spread positivity in the lives of the deafblind".

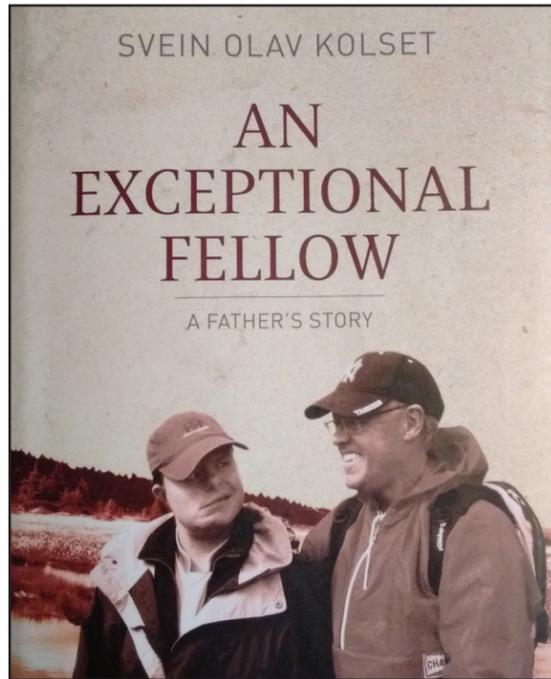
Vijay Simha, executive creative director of the app, said: "After interacting with the deafblind and their caregivers, we knew we had our task cut out. We had to design a user experience that replicates 'touch & feel' – the only form of two-way communication used by the deafblind.

"With the Good Vibes app, we dug deep and explored a whole new dimension of app design: one that works for those who can't see or hear. The result is 'the invisible UI' – probably the first of its kind. And it works like magic."

It can be downloaded for free on Google Play.

# An Exceptional Fellow – Book Review

By Wanda Schellenberg



On a spring day in 1975 a boy was born, an exceptional boy. In the book entitled "An Exceptional Fellow" a father recounts the story of his son. With clarity and compassion in a style that is somewhere between prose and poetry Norwegian author Svein Olav Kolset highlights the joys and the significant challenges of his son's life. He writes with broad strokes that cause us to think philosophically about priorities held by our civil societies as well as with attention to the most minute details of daily life that make us wonder at the human ability to survive.

"Why does a father write?", Mr. Kolset asks. Thus begins this probing and intelligent book, questioning everything from the author's own motivation to tell of this personal and dramatic journey, to the meaning of suffering.

At the time of their son Torgeir's birth, Svein Kolset and his wife, Tove, were two young students living in a small ground floor flat with a communal bathroom that was down the hall. With hopes and dreams not unlike all first-time parents, the shock that all was

not as it should have been with their newborn seemed to slow time itself. "It is actually impossible to put the experience into words", Mr. Kolset writes. Confusion ensued. "None of the doctors had ever seen such a case. It was not possible to make a diagnosis there and then." Their baby was transferred to a different hospital capable of dealing with complex pediatric cases while his mother had to remain at the birthing hospital. "The people around us – family, friends and personnel – were essential in the crisis, but the uncertainty was still terrible." They were not able to absorb the situation fully, but gathered enough to know that

"a new kind of life was knocking on the door. A life where we would be obliged to trust our own resources wholly and fully. We had no idea of what we were getting into. But we had one another."

The acknowledgement that this was going to be a different kind of journey allowed Svein and Tove to gradually make adjustments, practically and emotionally. As academics, Torgeir's parents sought to comprehend the "framework conditions" affecting their son. There was a long list including facial paralysis, poor hearing, poor eyesight, poor swallowing ability. "There was more to come. We were faced with a human being who was trapped in a biological prison. He was fighting for his life. He did not give up. Not even when a nurse put the feeding tube down his windpipe. And subsequently injected the food directly into his lungs. We will never forget it."

The compelling thing about reading someone else's story, though it may be utterly different than our own experience, is that it draws us to a deeper understanding of our fellow

travellers in life, it creates connections where formerly there were none, it elicits empathy. It was at this point in the book that I wanted to bow my head, to grieve deeply – for Torgeir, for his parents, for my own child, for all children who are born with compromised bodies, who are so dependent on others for their well-being, who have to struggle all their lives.

Through strenuous days and sleep-deprived nights, mutual love and concern for Torgeir brought the couple together in a new way. "The demanding tasks that we have faced have strengthened the unity that we share," Mr. Kolset writes. Buoyed by a valuable gift of a washing machine, they coped by dividing up the work, creating a daily routine, having naps in the library, and occasionally enjoying important times of socialization when friends would stop by for late-night visits over tea and bread. Somehow, studies were completed and Torgeir was cared for.

From the beginning, feeding Torgeir was an extreme trial. Any attempts to feed him orally were disastrous and ended in coughing fits and vomiting. Due to paralysis of muscles used for swallowing, Torgeir was fed through a nasal-gastric tube for the first 20 months. His parents learned how to insert the feeding tube themselves – unheard of at the time. Wanting so much to include him in their lives they one day tried again to put a little food on his tongue. This time he swallowed the food, there was no coughing, and he finished the whole jar. A miracle! Family and friends had to be told this life-altering news..."Torgeir has a new taste for life."

Eating orally strengthened Torgeir and soon after, he began to walk. He was interested in just about everything around him, except people. His father expresses how frightening it was to realize that Torgeir had no desire for

social contact. He had a stiff body that was always on the move, and getting him to relax enough to sleep was particularly exhausting as it could take hours. "The doctors explained that Torgeir had clear signs of autism. The challenge was: How to channel this energy in a positive way."

Over the years many new activities were tried. They often did not work out, at least not right away. Torgeir developed incredible stamina, so physical activities like swimming and skiing were introduced. Neither came easily, but with time and great patience he learned to master both and take great pleasure in them. Cooking, too, became very enjoyable and it was heartening to see how easily he learned when doing something he really liked.

For a few years Torgeir and his family lived in California so that his father could take up a position at a cancer research institute in San Diego. Torgeir was then in his mid-teens. While there, he was taken to the Medical Center at the University of California to meet with a specialist in Goldenhaar's syndrome, as it was long thought that this was the syndrome he had. It turned out not to be the case at all. Torgeir was diagnosed with CHARGE syndrome – a diagnosis that did not exist in 1975. Slowly things began to fall into place. A few years after returning to Oslo, connections were made with deafblind specialists. The recognition of the effect of these major sensory impairments then led to a new focus on communication, and learning tactile sign language now began in earnest.

The significant communication issues that had presented themselves over the years, unfortunately, often resulted in agitation and self-abuse. Torgeir gradually gained some independence from his family, however when trouble arose he remained incapable of explaining what was going on. One such incident occurred when, for a period of time, Torgeir was repeatedly pinched by a fellow student on the school bus. Many queries were conducted. The reason

for his frequently arriving at school very upset was eventually discovered by the bus driver, who was then able to move him to a safe spot. This incident brought home a sobering reality to Torgeir's parents – that they would not always be there to solve his problems. "We must live with that. Not always being able to help. That is brutal."

Torgeir gained further independence when, at age 20, he transitioned into his own home. He took part in day-programs where staff tried to find different activities for him. During an unsuccessful day outdoors helping to clear a forested area, where poor eyesight and poor balance were clear disadvantages, one staff noticed that Torgeir was extremely sensitive about one of his legs. A follow up x-ray revealed a broken leg that was already in the process of healing! Again, his father writes of the heavy burden of not always being able to understand when problems arise. "We slept poorly for many nights."

Though there were definite positives of independent living, there were challenges as well. Inexperienced helpers, indifferent helpers, not enough helpers, or too many helpers coming and going – these are some of the issues that had to be contended with. "The rest of us cannot imagine the effect that this ongoing stream of new and different individuals has on Torgeir and his peers. And this happens every day. Every week. All year round." Again and again, Mr. Kolset asks, "Are the users to adapt to the system, or is the system to be adapted to the users?"

The quest for how best to ensure a good life for his son steers Mr. Kolset to ask pointed questions that recur throughout the book. Like any parent of a child with special needs, he understands the need for a qualified team to further his child's development. The roles to be filled on the team are numerous, and he asks, frequently, "Where are the methods and the professionals, so that we can move forward?" Undoubtedly, the need for good support and understanding

of the specific needs of deafblind individuals is universal. A correct diagnosis should connect a family to new professional contacts like special education teachers, therapists, and behavior psychologists, etc., and should then lead to sufficient funding, training, appropriate schooling, programs, housing, and Intervenor services. Yet, for many reasons to do with poor public funding, sticky bureaucrats, lack of long-term vision and, sometimes, misinformation, advocating for those with many needs who cannot speak for themselves is an uphill battle and not for the faint of heart.

Speaking plainly, and without a trace of self-pity, Mr. Kolset suggests that there is a justice issue at play here. "Working for groups that do not make a difference in the polls...or in the world of top-ten requires courage and energy...the ability to think long term." While progress has certainly been made towards a more open and inclusive society, there is still a long way to go. Society must assume responsibility for the weakest, he asserts. They should not be funded out of the pockets of private individuals. He writes, "Some of us must find the strength to make a fuss..."

Make demands,  
send applications,  
negotiate,  
stipulate requirements,  
refer to acts and legislation.  
Diplomacy can also help.  
One can never give up.  
It never ends.

Regardless of how resourceful parents of children with disabilities may be:

We are vulnerable.  
We need help and support.  
Not just with the big stuff.  
Just as often with the small."

I was both saddened and relieved to see this list - glad for his boldness to say these things out loud. This is surely a collective cry for help, a chance to put aside our brave faces for a moment and speak the truth.

From burnout to bitterness, Mr. Kolset acknowledges the myriad ways in which

## An Exceptional Fellow – Book Review *continued*

By Wanda Schellenberg

the strain of constantly caring for a child with disabilities is hard on families. Despite this, he and his wife chose a perspective that determined that “this was going to be something good.” It required shifting focus, now and then, away from Torgeir towards other people and other activities. It required enjoying simple pleasures (“Swedish coffee with breakfast rolls”), not isolating themselves, and having a circle of support. It required employing an underused but valuable resource: other families and siblings. “The experiences of others are important when our own problems are to be solved.” We can ask - how do other families manage, how do they organize things, how do they keep their family together, how do they care for other children in the family, how do they juggle paid work, bits of free time, and caregiving, how do they stay positive?

And another burning question – how does one go further? Torgeir’s parents are truly thankful for many caring, thoughtful people who have shown genuine interest in him and have taken responsibility upon themselves to make adaptations, and to think creatively about the conditions needed to help him grow. But in light of Torgeir’s deafblindness and other hurdles,

how does one continue to increase knowledge – in medicine, in education, in psychological areas – in order to further understand his world? “I know more than when he was born. But not enough”, Torgeir’s father says. The drive to know more is key, I think, to maintaining a vital, interesting life for our loved ones with disabilities. Inevitably, this will come with a restlessness or dissatisfaction with how things presently function, but perhaps that is appropriate. Parents, educators, politicians, therapists, can never afford to become fully satisfied with the current state of affairs for those who cannot speak for themselves.

So...why does a father write? After fully engaging our social consciences throughout this book, Mr. Kolset goes on to captivate our hearts and souls as well, essentially asking the ultimate existential question – what does it mean to be human? Seemingly leaving no stone unturned, he wades into the tricky area of medical genetics – the assessments, the screenings, the merits allotted, the labels given, the decisions made. “In the world of theories, a day could arrive when only healthy children are born. But that will never happen. Luckily. Is Torgeir damaged goods? He is a fabulous human being. Born with

many biological limitations. That does not diminish his value.” We need our special people, he asserts, to give us perspective, to show us what is meaningful, to teach us benevolence, and to offer us a deeper appreciation for life itself. This father writes to lift Torgeir and his peers out of oblivion, to give them a voice, to plead for a warmer society, to say “There is very much that is good, but there is a long way to go.”

And why is it imperative that we care? To quote former Norwegian prime Kåre Willoch in the introduction to this book...“for purely humanitarian reasons, but not just that: the whole of society wins, culturally speaking and in terms of compassion, if it fulfills ideal requirements for care of the weakest among us.”



**Wanda Schellenberg lives in Vancouver and is a board member of CDBA-BC. She and her husband have**

**3 children and their youngest is a daughter with deafblindness.’**

## Filmmaker Teams Up With HKNC In Sands Point

By Christina Claus

Inspired by his first encounter with a deaf-blind man seven years ago, filmmaker Doug Roland created *Feeling Through*, a film about an unlikely connection between a teen without a home and a deaf-blind man, which was made in association with the Helen Keller National Center to cast the first deaf-blind actor in a lead role.

Seven years ago Roland was leaving a friend’s home in the East Village at 4 a.m. and saw a man on a deserted street corner holding a sign stating that he was deaf and blind and needed help crossing the street. Roland mistakenly tried to speak to him, but realized it wouldn’t work, so the two communicated through pen and paper. Roland helped

the man get to his bus stop, but they missed the bus, so the two sat and had a conversation through pen, paper, and later the palm of the man’s hand until the next bus came an hour later.

“He was a very genuine and charismatic person,” said Roland. “We made a connection and that experience has resonated with me since then. First and

foremost, when I work on a project, it has to really resonate in a core place and that experience stuck with me for seven years, so I wanted to turn it into something.”

And seven years later, Roland created a film inspired by that one night. After writing the film, Roland knew he needed to connect with the deaf-blind community, so he googled organizations and soon found himself on a call with Helen Keller National Center (HKNC) executive director Sue Ruzenski.

“I was very excited, but I’m always a bit skeptical,” said Ruzenski. “But, once I met Doug, I recognized his insight and passion for the project.”

Filmmaker Roland and the HKNC entered into a partnership on the project, giving Roland a core understanding of the deaf-blind community and assisting him on casting a deaf-blind actor.

“It’s been very exciting because it’s something so new and so out of the



HKNC Executive Director Sue Ruzenski was recently joined at HKNC by filmmaker Doug Roland (left) and Producer Luis Augusto Figueroa (right) to discuss *Feeling Through* and casting a deaf-blind actor in the lead.

everyday of what we do here,” said Ruzenski. “And we see this as an opportunity to reach people and raise awareness for the deaf-blind community. This film is a way to educate people that’s more about connecting with who they are as people.”

With the help of those at HKNC, Roland began holding auditions to cast the

first deaf-blind actor in a lead role. The process required multiple auditions and interviews with the help of interpreters. While conducting the initial round of auditions, Roland became aware of Robert Tarango, who wasn’t scheduled to audition, but was soon brought in anyway.

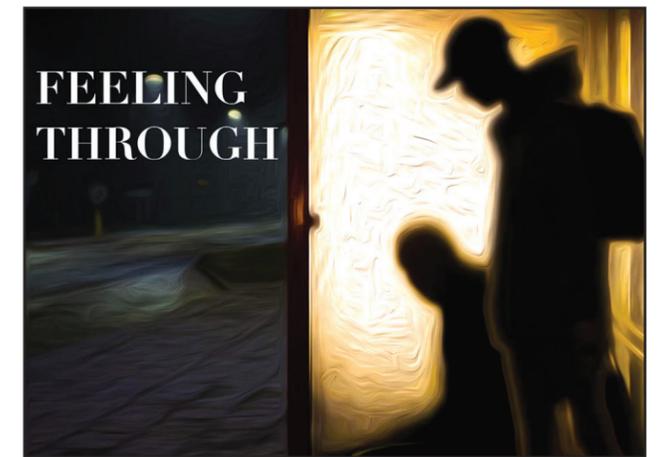
“It was one of those cheesy things where we just knew,” said Roland. “Before he even started doing anything, I knew. He’s a really warm and genuine guy. His personality was apparent when he walked in the room.”

While the film will include a deaf-blind actor in its cast, it is not a story of deaf-blindness. The story follows the protagonist, a teen in a challenging situation, which puts him out on the streets at night where the teen meets a deaf-blind man and the two form a connection.

“It’s a story about human connection,” said Roland. “It’s about the transformative power of human connection and how it empowers the teen to deal with other challenges in his life.”

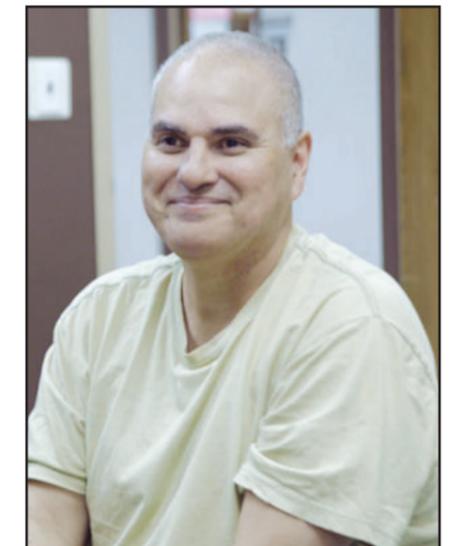
To go along with the movie, Roland and HKNC decided that a documentary of the making of the film would be beneficial to the deaf-blind community and would generate more awareness and understanding of what the deaf-blind community is like.

“Most people, when thinking of someone who is deaf-blind, the only person they know is Helen Keller,” said



Ruzenski. “We want to expand people’s understanding. More and more people who are deaf-blind are achieving such incredible success in life and are not as well known. The film and documentary are ways to bring attention to the fact that anything is possible for people who are deaf-blind.”

The film was funded through a crowdfunding website called Seed and Spark. Through the website, the film hit 80 percent of its goal, which was enough to get the project started. *Feeling Through* is still accepting donations through the HKNC website, [www.HKNC.org](http://www.HKNC.org) by clicking the donate button and indicating that the donation is for the film or through mail to 141 Middle Neck Rd., Port Washington.



Robert Tarango

## 2018 Andrew Love Memorial Award for Intervenor of the Year

By Megan Gillis

**Editor's Note: This award is presented to a special Intervenor who displays outstanding skills; is a dedicated and compassionate individual who has devoted time and effort to enhance the quality of life of a person who is deafblind.**



Jacky Mackenzie has been employed with CDBA-SK Chapter since 1990 and is coming on to her 28th work anniversary and throughout these years Jacky has been a valued employee and Intervenor.

Jacky has a quite calm about her that makes the Individuals she serves comfortable and supported in their day to day lives.

Jacky is also:

- Resourceful and finds ways to communicate with Individuals and facilitates ways for them to express themselves and is willing to embrace new ideas.
- Patient and genuine; taking interest in the Individuals lives, allowing them to achieve their best every day.
- Dedicated and goes above and beyond the job description to ensure every day is a good day and also invites the Individuals join her family on special activities.
- Positive in all situations that allows her and others the ability to meet the needs of the Individuals.
- Compassionate, caring and thoughtful; it's contagious to all those around her.

The list could go on but Jacky has consistently provided a high standard of interactions with the deafblind individuals she serves and is extremely deserving of this award.

## 2018 CDBA National Cherry Bulmer Award for Volunteer of the Year

By David Brown

**Editor's Note: This national award is named after Cherry Bulmer in recognition of the passion, enthusiasm and commitment to which she dedicated her time and effort to CDBA**



Dwain McLean served on the Board of Directors of the Canadian Deafblind Association of New Brunswick since 1993 and also on the Board of CDBA National since 2009. After 24 years of service with the CDBA organization, Dwain reluctantly decided to retire from both Boards of CDBA in September of 2017.

Dwain was an educator in New Brunswick for many years. Also, within the education sector, he went on to take a position with the New Brunswick Teachers Association from which he subsequently retired. He has been active in several volunteer activities including the Kindness Club Foundation, the Canadian Cancer Society, the Canadian Red Cross, and the New Brunswick Association for Community Living. As a hobby, he also dabbled in the dog breeding business for a number of years.

During his time with CDBA, Dwain had an adept ability to express his ideas and thoughts during discussions around important matters. His input was greatly appreciated by his colleagues on the Board of Directors. Because of brilliant rationalization, when he spoke, he drew the attention of everyone in the room.

Because of his years of service with CDBA, both provincially and nationally, Dwain is extremely deserving of this honour.

## Text of the Award Presentation at the CDBA National AGM in Toronto ON September 22, 2018

By Cherry Bulmer

"It is lovely to be here today to see old friends. And, good to get acquainted with those new faces who are working hard to benefit persons who are deafblind. Thank you all.

It has been several years since we made it to a CDBA AGM but it is my pleasure to be here to present Dwain McLean with the CDBA National Cherry Bulmer Award. This is presented to an individual who has made an outstanding volunteer contribution to the Canadian Deafblind Association at the national and chapter level. Many of us came to this organization out of necessity. We had to speak for our deafblind children so their needs could be met and they would be able to live fulfilled lives. But Dwain didn't come from that – he came from his spirit to do good in the world. And, CDBA was the beneficiary of that giving spirit for 24 years!

It is a double honour for our family to give this award to a "New Brunswicker". Cara was born in Fredericton 48 years ago. Because of the efforts of CDBA – National and Provincial – she is living a full independent life with Intervention.

It is my pleasure to give you – Dwain McLean – this award and with it the deepest gratitude of the Canadian Deafblind Association for your community spirit, your time, and your gifts as a volunteer.

## 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 [www.cdbanational.com](http://www.cdbanational.com) or by contacting the CDBA National office [info@cdbanational.com](mailto:info@cdbanational.com). 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.



# He is Deaf and Blind. For Him, Talking Means Touching.

By Theresa Vargas



Tony Daverso, a support service provider, uses sign language and a "Pro Tactile" method to communicate with Jason Corning, who is deaf and blind.

As Jason Corning and his husband, Jason Lin, prepared to climb the Sydney Harbour Bridge, Lin hesitated. His fear of heights tugged at him.

"Are you sure?" Lin asked again.

"Why not?" Corning told him. "You will never know what it's like unless you try it."

One spouse encouraging the other might not seem extraordinary. But that day, as Lin and Corning stood in blue and gray jumpsuits about to ascend the world's tallest steel arch bridge, only one of those men could hear and see.

Corning has been deaf and blind since birth.

"People just focus on his disability, but for me, I don't think there's anything that could stop him," Lin, 28, told me when we spoke recently.

I had called him to speak about a different type of bridge his husband was now climbing. Several months ago, Corning left his job with the federal government and decided to start his own company, one that aims at creating more accommodating spaces for people who are deaf, blind or both.

If you want to see an example of what that looks like, just walk into the

Starbucks that opened in recent days in Washington. It is the first in the country designed for the deaf and hard-of-hearing. There, customers can write or use American Sign Language to place their orders and their names will appear on a screen when their lattes and mochas are ready.

Since its opening Tuesday, the place

has drawn excitement and praise - and probably a lot of profits because it is just blocks from Gallaudet University, the world's oldest university for the deaf and hard-of-hearing. It deserves all of that. A Signing Starbucks is a significant step toward inclusiveness.

But here's the thing: The deaf community doesn't only drink coffee. And within the deaf community, there are people who are partially or fully blind. That's where Corning hopes his company, Three Monkeys Communications, will come in.

Corning, 32 and president of the Metro Washington Association of the Deaf-Blind, started the company in July and said he plans to fly across the country to places that want to learn how to better accommodate the deaf-blind community.

Many times, when we think about losing critical senses - and it is a risk we all face as we age - we envision the ways our world might collapse inward. How instead of seeing 20 feet in front of us, we might be able to see only two inches in front of us, or less. How instead of hearing someone shout our name from across the street, we might hear words spoken in our faces as whispers, or not at all. How it would feel safer to stay

within the same familiar space. What struck me about Corning's company was its aim to expand the world for people who have limited or no use of two senses that many of us couldn't imagine functioning without.

I visited Corning at his Maryland townhouse recently to find out more about him and the company he runs from his second-floor office.

I was nervous. I had spoken to him through an interpreter over the phone, but I had no idea how we were going to talk in person. I don't know ASL, and even if I did, I wasn't sure if he would be able to see me signing. Deaf-blind, contrary to how it sounds, does not always mean a total loss of both senses; it is defined as a significant impairment of both.

When I arrived, Corning shook my hand, introduced me to his service dog, Niko, a 5-year-old yellow lab, and it became immediately clear how we were going to get through the interview. Corning was going to have to teach me what he hopes his company can teach others: how to adjust.

Corning, who has a master's from Johns Hopkins University, communicates mostly through sign language and a "Pro Tactile" method that involves touching. He also types on a computer. Although he is legally blind and needs Niko to guide him when he walks, he can read letters on a screen if they are magnified in front of him. Using a cochlear implant and a hearing aid, he can also hear slightly if a person speaks loudly and clearly in front of him in a quiet environment.

For my visit, Corning asked Tony Daverso, a support service provider, to join us. Daverso, who is also deaf, is trained to use Pro Tactile, which can convey to a deaf-blind person what ASL can't: facial expressions and body movements.



Jason Corning works in his home office as his service dog, Niko, waits nearby.

When I smiled, Daverso used a finger to trace a smiley face on Corning's arm.

When I nodded, Daverso moved his fist up and down quickly on that same arm.

When I had questions, I wrote them in my notepad and Daverso conveyed them to Corning, who then replied verbally.

"Why do you believe this company is needed?" I asked him at one point

"We have a lot of deaf-blind people who have a hard time finding a job," he said.

"And a lot of people don't know how to work with deaf-blind people."

Lin didn't speak any sign language when he met Corning six years ago. They met online and grew to know each other first through email because Lin lived in Taiwan. Lin said Corning eventually taught him to sign, and he surprised Lin with his independence.

A moment in their relationship that stands out to Lin came a few months before they decided to get married in 2014. Corning flew by himself to Taiwan to meet Lin's parents.

"That really impressed me, for a deaf-blind person to do that," Lin said. "It really opened my horizons."

In their home, Lin said, Corning does most of the cooking, and if there is a problem with their computer, he is usually the one to fix it. He also handles their travel arrangements and has made plans to go to the Philippines and France by himself next year.

Lin said that because of his job managing software for a nonprofit organization in Annapolis, Maryland, he doesn't often have time to travel with Corning. But recently, he joined him on a trip to Wisconsin, where a camp was held for the deaf-blind community. One



Jason Corning uses his service dog, Niko, to guide him as he walks through his Maryland neighborhood.

night featured a talent show for children. Some sang; others told jokes.

As he watched the performances, Lin said, it occurred to him why Corning's company is needed.

"They just want to be like everyone else," Lin said. "They just need some recognition from other people - people telling them, 'You can do it.' "

Maybe, he said, given the chance, they can even show that there are some things they can do better.

## 2018 Donor List

A sincere thank you to the following donors whose generosity during 2018 helped CDBA continue to offer quality services and support to consumers who are deafblind and their families

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Ruthann Turnbull  
United Way of Lower BC  
John & Cynthia Westerterp  
Qi Ling Wu



# 32nd Annual "Lend-a-Hand" Golf Tournament in Support of Individuals with Deafblindness

A typically large turnout of 148 golfers, volunteers and guests had a terrific day on July 9, 2018 to enjoy the Marsh Canada "Lend-a-Hand" Golf Tournament in support of the Canadian Deafblind Association. This annual charity event has raised nearly \$675,000 for CDBA National over the past 32 years – 30 of which have been hosted by the Nottawasaga Convention Centre & Golf Resort just outside of Alliston, Ontario. The beautiful golf course and our gracious hosts have made the decision to return each year an easy one. Their outstanding support in so many ways is greatly appreciated.

CDBA National Executive Director Tom McFadden, as he has for the past several years, challenged each golfer on his designated front-nine par 3 hole during the "Beat the ED" friendly "closest-to-the-pin" competition. Golfers Green once again sponsored a hole-in-one fundraising event on a long back-nine par 3 hole. The Zimmer family – Ralf and Michelle with son Steffen - enthralled the dinner crowd with their warm and candid accounting of life with a child who is deafblind.

Thanks goes to our generous lunch and dinner sponsors; to major prize sponsor WestJet; to Elisa DiFranco and her event management group at Marsh Canada; to Jamie Sheppard and Sylvia Biffis of the Nottawasaga Inn Resort; and to our dedicated core of volunteers - Carolyn Monaco, Sandra Owen-Peters, Nancy Mactavish, Jim & Dianne MacDonald, Erin Rows, and Kim McFadden.

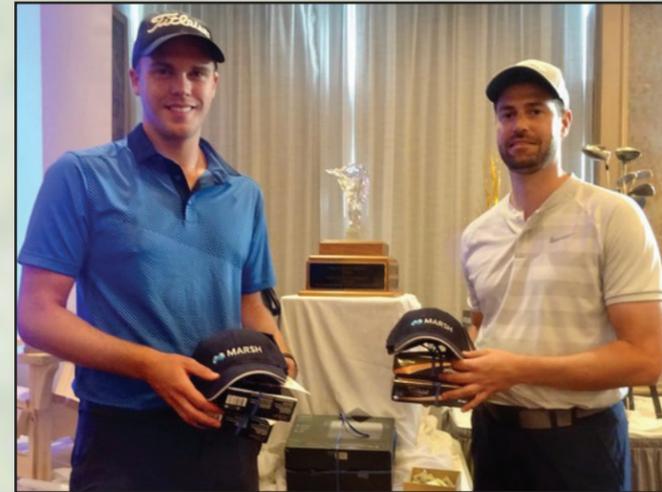
Thanks to all the support from generous sponsors as well as companies and members who donated prizes, nearly \$20,000 was raised. These funds go towards a wide range of activities carried out by our National organization, particularly the CDBA National Support Fund.



Volunteers Kim McFadden & Erin Rows



Golf prize table



Two of the 4 happy golfers from the winning Berkshire team.



Celebrity Guests Ralf, Steffen and Michelle Zimmer

**WestJet Grand Prize Winner:** Barb Kulikowski

**Lowest Score Golf Team:** Berkshire  
Andrew Knight, Gregory Eskins, Andrew Ross, Matt Mann

**Ladies' Closest to the Pin:** Susan Finbow

**Men's Closest to the Pin:** Brady DeSantis

**Ladies' Longest Drive:** Lisa White

**Men's Longest Drive:** Matt Provost

**Putting Contest:** Ryan Jones

**Beat the ED:** Scott Taylor

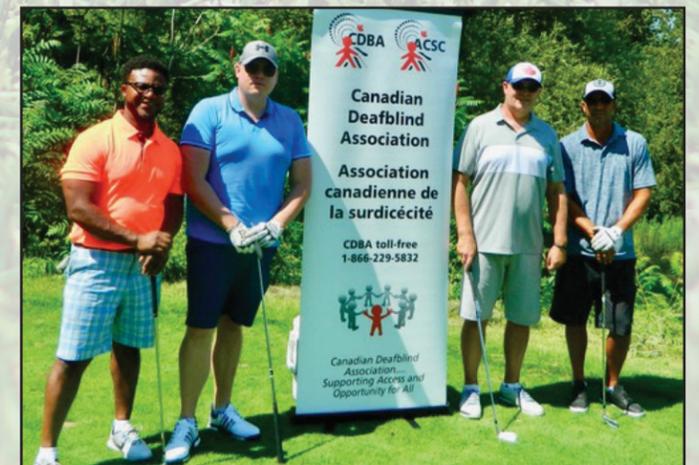
**Golfers Green Hole-in-One Challenge-Closest to the Pin:**  
Andrew Ross/Lorraine Ashworth-Brown



L to R: Michelle Zimmer (Steffen's mom), Steffen Zimmer (Celebrity guest), Barb Kulikowski (WestJet Grand Prize winner), Tom McFadden (Banquet MC), Ralf Zimmer (Steffen's dad)



CDBA National Team



The Cooperators Team

# Canada's First National Accessibility Law Tabled in Ottawa

By Michelle McQuigge



Barrier, as defined by the Act, includes anything "architectural, physical, technological or attitudinal" that "hinders the full participation in society of a physical, mental, intellectual, learning, communication or sensory impairment."

## Act will try to 'identify, remove and prevent' accessibility barriers under federal jurisdiction.

Canadians with disabilities felt a surge of tempered optimism on Wednesday as they watched Canada table its first piece of federal legislation aimed at improving accessibility for people with disabilities.

Disabled residents and advocacy organizations said the introduction of the Accessible Canada Act marked a key step towards greater inclusion and contained several critical points community members had named as priorities during a lengthy cross-country consultation process that helped shape the new bill.

But they also raised concerns about provisions the draft bill appears to lack, such as measures to ensure new accessibility barriers do not work their

way into future government laws.

Minister for Sport and Persons with Disabilities Kirsty Duncan, the third person to oversee the legislation in as many years, celebrated the "historic" act as a victory for disabled Canadians.

"We are here because of the disability community and their advocacy for decades," Duncan told The Canadian Press. "This is the community's legislation."

The Accessible Canada Act, presented hours before the house rose for the summer, fulfills a promise to have disability-related legislation on the table by spring 2018.

The Act's stated purpose is to "identify, remove and prevent" accessibility barriers in areas that fall under federal jurisdiction. This includes built environments, federally run

programs and services, banking, telecommunications and transportation that crosses provincial lines.

Barrier, as defined by the Act, includes anything "architectural, physical, technological or attitudinal" that "hinders the full participation in society of a physical, mental, intellectual, learning, communication or sensory impairment."

The government pledged \$290 million over six years towards supporting its implementation.

## Fines for violating the law could be as high as \$250K

The six primary areas of focus laid out in the draft legislation echo the priorities that emerged during an eight-month consultation with advocacy groups and disabled individuals across the country.

Those who took part in the 2016 consultations wanted to see laws that would help lower unemployment rates that hover around 50 per cent for those with disabilities, reduce the number of buildings inaccessible to those with physical and intellectual disabilities, and remove accessibility barriers for the country's inter-provincial air, rail, ferry and bus transportation systems.

Those consulted also named government program and service delivery as another key area of focus, in addition to government procurement and information-technology.

Another key demand involved enforcement, as those consulted emphasized the legislation needed to have teeth in order to be effective.

To that end, the Act will see the creation of three new bodies to bolster the new law.

A Chief Accessibility Officer will oversee the implementation of the

legislation across all sectors, while a new Accessibility Commissioner will be responsible for compliance. Fines for violating the law could be as high as \$250,000.

A new Canadian Accessibility Standards Development Organization would also be put in place. The board of this organization should be comprised primarily of people with disabilities who reflect the diversity of the population, the government said.

Those that fall under the purview of the new law will be responsible for outlining detailed accessibility plans that must be drafted in consultation with disabled people and revisited every three years.

They will also be required to set up tools to gather feedback on their efforts and produce regular progress reports and the degree to which disabled people were consulted.

The persons with disabilities minister would continue to be responsible for most aspects of the legislation, though Transport Canada would have enhanced powers to handle transportation matters and telecommunications issues would remain before the Canadian Radio-Television Telecommunications Commission.

## Mixed reaction

Bill C-81 is not yet final. It will be debated in both the House and Senate and undergo additional readings before receiving royal assent and officially becoming law, a process that will not even begin until Parliament resumes in the fall.

The people who stand to gain the most from the bill greeted its introduction with a mixture of anxiety and relief.

Gabrielle Peters, a wheelchair user from Vancouver, said the introduction of national accessibility legislation represents significant progress for a country that's long lagged behind Western nations that have had such laws on the books for decades.

Even flawed legislation, she contended, changes the conversation by forcing government to tackle systemic issues rather than focusing on individual stories of hardship.

"We are now engaging on a policy level," she said. "We are being treated as citizens. Accessibility and disability rights are being regarded as part of the responsibility of our elected officials. It is a human rights understanding as opposed to a human interest story in the newspaper."

James Hicks, national co-ordinator of the Council of Canadians with Disabilities, also hailed the bill as a step in the right direction. But he also said a critical community demand had been ignored.

The council and other advocates had insisted the new law make it mandatory for the government to put its own policies, legislation and program decisions through a disability analysis, just as it currently does for gender-related issues.

They said such an approach would help identify instances of discriminatory laws on the books and signal that the feds are willing to get their own house in order before compelling others to do the same.

Duncan said the act does not currently include such language, but said the law will change the culture of how things are done in government.

For Hicks, this represents a missed opportunity that will limit the law's effectiveness.

"There absolutely has to be a disability lens that's applied to every budget and

every new initiative that the government brings out so that we know how to ensure that people with disabilities are not going to be left behind."

Blind Ontario resident Marcia Yale



Minister for Sport and Persons with Disabilities Kirsty Duncan, the third person to oversee the legislation in as many years, celebrated the "historic" act as a victory for disabled Canadians.

voiced concerns about the standards development process, saying the law won't initially have much to enforce when it hits the books.

"The Criminal Code did not come in as a list of standards to be created later," she said. "I would rather have seen them miss the spring deadline and have the law completely written."

Currently only Ontario, Nova Scotia and Manitoba have provincial legislation on the books. Duncan said she hopes the incoming federal legislation will help others follow suit.

"Many provinces are waiting to see what this legislation looks like," she said. "We hope the government will be a leader in this area."

Plain Language Summary of the Accessible Canada Act: <http://www.cdacanada.com/wp-content/uploads/2016/10/Bill-C81-Plain-Language-Summary.pdf>

# Lessons From Charlotte's Web

By Frances Jablonca

## Lesson #2 You Can't Smile Until You Are Ready



Every developmental milestone that a baby accomplishes, such as the first smile between one and two months, or the roll from front to back at three or four months, brings immeasurable delight to parents. There is something profoundly bonding about the first smiles that happen

as baby looks in your face, recognizing that you are mom and dad. As we would discover with Charlotte, however, the typical baby milestone schedule would by no means ever be normal or predictable. Her first smile at 3 and a half months was long over-due, according to the child development charts. But it would hardly have been fair to expect Charlotte to flash a smile when she was continuously being subjected to invasive procedures such as blood tests, IV and feeding tube insertions, and suctioning during the first three months of her life. Hospitals typically aren't environments that are conducive to producing giggles. Even so, having experienced that first smile with our first daughter, I had cautiously hoped that despite the medical interventions necessary for her survival, Charlotte would sense somehow that it was I, her mother, at her bedside and light up in a smile of recognition.

The process leading to the production of the first smiles does have some complexity worth noting. A baby with normal vision and hearing "At around one or two months, ... gradually starts to respond to environmental stimulation. Your baby's first smile when she's fully awake will likely appear between six and 10 weeks. At this age, your baby's brain is developing, her vision is improving and she can recognize your face. Your baby will likely respond to auditory stimuli first, such as music or mom or dad's voice. Next comes a response to visual and auditory stimulation combined. The last thing to make baby smile is visual stimulation



alone."\* Charlotte was severely to profoundly deaf, with vision of 20/200 and no visible macula ( the area responsible for fine focussing ). She could neither hear a soothing voice, nor clearly see the details of faces with her dual sensory defects. In fact, during the first week after her birth, Charlotte kept her eyes tightly shut, like a newborn kitten or puppy. This caused some puzzlement among the staff and concern for us until she was diagnosed and we learned that her pupils couldn't properly contract , thusly unable to block out the bright lights of the NICU, and later the brilliance of sunlight. Charlotte kept her little peepers tightly shut until she was transferred to a ward in the Calgary Children's Hospital where dimmed lights made it comfortable for her to open them. And here too, my job description as mother, underwent some changes as I learned to observe what the characteristics of Charlotte's vision and hearing entailed. I set about doing what I could to stimulate her vision by hanging slow moving mobiles over her crib and placing simple visuals with large, simple black and white graphic designs on the side bars. Eventually, she began to track the movement of the hanging mobiles by moving her head to keep it in her field of vision. Over time, years, her movements would be refined so she could track only with her eye movements.

Charlotte was now over 3 months old, and, although no progress had been made

in the smile department, more importantly, her overall health looked to be stable enough to soon go home with us. First, she would come home on a weekend pass so we could practise preparing her formula, feeding her through her GI (gastrointestinal site, as she was unable to drink orally), and administering her heart medications. The weekend proved to be a blur of exhaustion, as we forged ahead with routines normally supported by our family of hospital staff. We wondered at the time how we would ever manage to take care of this high needs little soul on our own. But we would try. She seemed content in her hand-me down crib with the beautiful, large wooden tropical bird mobile



hung over it. If you pulled its attached cord, the wings would slowly undulate up and down. Especially for Charlotte, I had tied a large, shiny, golden cellophane ribbon to the bottom of the cord for added visual stimulation. And what was not a blur about that weekend, was that she appeared to be fascinated by that golden ribbon, working hard to keep it in her field of vision.

We had all survived the weekend and five days later we triumphantly brought Charlotte home for good. Her three-year-old sister Madeline and I laid her down in her crib, pulled the cord with the gold metallic ribbon attached to her Red



Macaw, and that is when she smiled! My mother ego already taken down a notch or two, I am able to acknowledge that all the necessary developmental steps to producing a smile had aligned. But still, I like to think it was Charlotte's first visual emotional connection with her home that caused her this unprecedented moment of joy!

The end.

(Charlotte didn't smile again for 2 months, but this time it was for a person. She smiled at her Opa while laying in his lap at Christmas).

\*<http://www.justthefactsbaby.com/baby/article/why-babies-smile-92/page=2e>



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## CDBA Chapter News

**CDBA Alberta** Frances Jablonca, *President*



This past June our chapter commemorated Deafblind Awareness Month with our second annual Charlotte MacKinnon Memorial Wagon Ride in the shadow of the beautiful Rocky Mountains. Our event was held again at Rafter Six Ranch. After the Wagon Ride, we roasted hotdogs around the fire pit and socialized. A few brave souls hopped on horses for short jaunts around the ranch. Parents of Charlotte, Rob and Frances expressed their gratitude to members in joining them in remembering Charlotte's cheerful, sociable and adventurous nature.



**CDBA British Columbia** Theresa Tancock, *Family Services Coordinator*



The Early Intervention Program provides support to families of children from birth to five years of age who have been identified as being deafblind. Our consultants meet with families throughout BC to introduce them to this new world of deafblindness. The Early Intervention Program helps the children to develop their true potential during the crucial time of learning in their early developmental stages. Early Intervention can also eliminate the family's feelings of social isolation, stress, frustration and helplessness; as well as enhance their knowledge and skills for teaching their child with deafblindness.

Families learn how to communicate with their child and to support their child with deafblindness in experiencing their world to the best of their ability. They receive consultation throughout the year, as do their child's professional teams. This includes support at home, in the community and while attending preschool or day programs. They also receive support when transitioning into preschool, daycare and kindergarten.

This program allows children with deafblindness and their families to enter preschool and kindergarten with a developed communication system and a true understanding of deafblindness and Intervention. The children are eligible to participate in our other program, the Intervention Program from the age of two years, which allows them to explore their



## CDBA Chapter News

communities and learn life skills with the support of an Intervenor. The Intervention Program then continues during all school breaks until they graduate from high school.

Recently, we hosted an Early Intervention Family Network Workshop. This was offered to our Early Intervention families to allow them to meet with other families and share their stories. Workshops were offered for the parents on the Ear and the Eye, as well as a Transition Panel discussion. The children enjoyed a day of Sensory Exploration with Intervention Support and they made Experience Books to take home and share. A fun time was had by all and we plan to do this again for our families on Vancouver Island.



**CDBA New Brunswick** Kevin Symes, *Executive Director*



We were lucky enough to have another George Brown Intervenor Student with us for awhile this year. Clarissa was a pleasure and we learned so much from having her here. She was a great help and was able to visit a lot of our clients in different regions and gave us advice on what more we might be able to try.

Clarissa is a second-year student in the Intervenor for Deafblind Persons Program at George Brown College who will be graduating in June. She first gained interest in ASL from her uncle who was deaf, but passed away when she was 15 years old. This eventually led her to the American Sign Language and Deaf Studies Program at GBC where she learned about the Intervenor Program. Clarissa loves

learning about anything and everything, and takes great interest in trying new things in her free time. She is an avid reader who highly enjoys murder mystery novels. She loves hockey, basketball, knitting, watching movies, taking her two dogs on long walks and basking in the summer sun. Clarissa currently works for the Canadian Helen Keller Centre as a Deafblind Intervenor.



### Teaching Kitchen

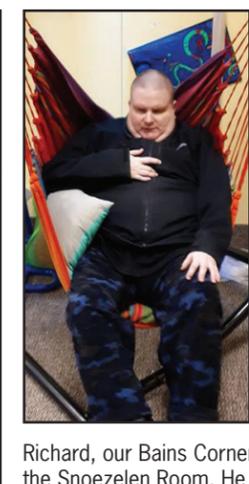
Each month, for 2018, we will be having a recipe contest with a different category. The winning recipe will be tested by our clients in our teaching kitchen. The person with the winning recipe will receive a \$10 gift card from the Superstore. All the recipes will be put into a cookbook for December 2018.



**Peanut Butter Fudge is the winner!**

- 1 cup margarine
- 1.5 cups peanut butter
- 4 cups icing sugar
- 1 tsp vanilla
- 1 tsp salt

Melt margarine and peanut butter on low heat until blended. Add icing sugar, vanilla and salt. Put in 9x9 pan. Refrigerate for 10 minutes. Cut into squares.



Richard, our Bains Corner client, at his first visit to the Snoezelen Room. He seemed to really enjoy it.

# CDBA Chapter News

**CDBA New Brunswick** Kevin Symes, *Executive Director*

## 2018 Deafblind Awareness Month

CDBA-NB hosted two bowling events to celebrate Deafblind Awareness Month in Fredericton and Moncton.



## Touchdowns for Owen

We are the Capital Area Predators and we play girls tackle football in the New Brunswick Varsity Girls Football League.

Owen is our biggest fan! His sister, Corrie, plays on our defensive line, and Owen comes out to most of our practices and all of our games!

Owen gives us so much support during our season that we want to give something big back to Owen.

You see, Owen is 13 years old and has been diagnosed with Cornelia De Lange Syndrome. The syndrome has up to 37 different symptoms that can affect his day-to-day life. Owen is not able to communicate verbally and he has moderate hearing loss in both ears. The syndrome impacts his growth, so he is smaller than other boys his age. He also deals with acid reflux on a daily basis.

Owen depends upon members of his family and others in his circle to tend to his daily needs, such as eating, using the toilet and keeping him safe.

His hearing loss makes it very hard for him to learn how to talk because he can't hear others when they speak to him. Therefore, with the help of the Canadian Deafblind Association (CDBA), Owen has learned some basic sign language, so that he can communicate with his family and friends and let them know important things, like when he is hungry or needs to use the bathroom.

The Canadian Deafblind Association helps Owen and his family very much with the services that they provide. For example, CDBA provides a wonderful "intervenor" who helps him communicate with and receive information from the world around him. His intervener also takes him on outings in the community.

Each year, Owen and his family look forward to their trip to the CDBA's Sensory Camp. What makes camp so very special to Owen and his family is that the CDBA does their very best to accommodate and tailor their experiences to the needs of everyone involved. Without something like this it would make it very difficult for Owen to go to camp, and what kid doesn't like going to camp?



# CDBA Chapter News

**CDBA Saskatchewan** Dana Heinrichs, *Executive Director*



At CDBA Sk our programs for the Individuals, support by our Intervention team – are focused on empowering them to be active and engaged in their homes and communities and we continue to strive for the best to provide person centered support for them now and as life changes things up as we go along.

The Anderson house has been up and running for 1 year now:

- New Individual moved in on Sep 3/17
- Grand Opening On Sept 28/17 with positive attendance and feedback
- Hardscaping completed in Oct/17 to improve water flow in back yard.
- New location of head office for CDBA Saskatchewan

CDBA has purchased 2 new vans for the transportation needs of the Individuals; 1 at the Kerr house and a wheel chair accessible van at the Anderson house.

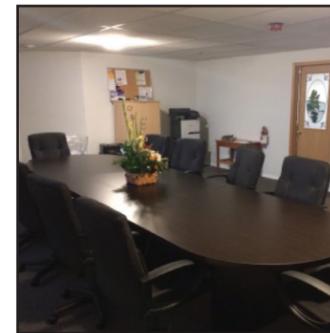
CDBA Sask received a proclamation from the government of Saskatchewan for June 10-16th as Deafblind Awareness week.

We hosted our 14th Annual Lend A Hand Charity Golf tournament with the help of our corporate sponsor MacDermid Lamarsh law firm who supplied golfers/prizes and committee support and the Cosmopolitan Couples Club with a few extra golf teams entered. A beautiful day of golf, networking and raising funds – this year brought in just over r \$21,000!

CDBA Sask is proud of our Intervenor and their hard work day in/out. We would like to highlight Dawn G from Michaels Manor; she was presented with the 2018 Sk IV of the Year Award. As well, at the September CDBA National AGM our very own Jacky Mackenzie was honored with the Andrew Love Memorial Award for Intervenor of the Year! Congrats to both of you for your dedication and excellence at what you do.



Main office



CDBA Board Room



Scott receiving a hot shave



Jacky MacKenzie with the Andrew Love Award

## CDBA Ontario

Several months ago, CDBA National received written notification from the Board of Directors of its Ontario Chapter stating "that the current model and basis for the relationship (was) not sustainable for the Ontario Chapter", and that they would be "work(ing) toward a rebranding". For them, this process will result in a name change and a complete separation from CDBA National and the other provincial CDBA chapters across the country.

While CDBA National does not agree that the decision made by the Ontario Chapter Board is in anyone's best interest, we have no jurisdiction over the decisions that a chapter board makes. CDBA National is an umbrella organization whose mandate is "to promote and enhance the well-being of people who are deafblind through awareness, education and the provision of support to our chapters, members and community partners." We believe that this can only be achieved through a relationship built on trust and mutual respect.

With all due respect to the Ontario Chapter Board, a significant number of members, both family & professionals, have contacted CDBA National to express strong interest in maintaining a CDBA Ontario Chapter, particularly for the purposes of advocacy and information sharing. Therefore, in the coming months, CDBA National will be in discussion with CDBA Ontario members – both past and present - as well as interested parties regarding our belief that a CDBA Ontario Chapter should continue to exist at some level. Stay tuned.

# Meet the Belfast Woman Who Won't Let Being Deafblind Stop Her Doing Anything

By Sarah Scott

When Heather Quayle was 19 she started to lose her sight.

For any young person that would be a devastating thing to come to terms with, but for Heather it was a double blow as she was born deaf.

Now she had to figure out how to navigate life as her sight got progressively worse, one of the hardest things being having to give up driving at the age of 28.

But this inspiring woman vowed not to let being deafblind hold her back and pledged to live every day to its fullest.

Heather, who lives in East Belfast, still goes skiing with friends, travels the world and goes swimming and running.

Speaking to Belfast Live as we mark Deafblind Week, Heather said she wanted to help other deafblind people realise they can be independent and enjoy travelling alone.

"When I was 19 I was in a relationship with a deaf guy, my family are all deaf too, and they found they could not get my attention by waving at me," she said.

"My dad was diagnosed as deafblind when he was 30 and my sister and I were checked as it is genetic but we were told we were OK.

"My boyfriend remembered this and we went to the hospital and that's when I was diagnosed. I had not thought there was anything wrong.

"It was hard because I had just passed my driving test and got a car so when I was diagnosed I was really worried about whether I would still be able to drive."

Heather said it had been a difficult adjustment which took her years to come to terms with, but she was determined

not to let it get in the way of her living the life she always wanted to.

Becoming confident asking people to sign higher up so she could see, as she lost her peripheral vision first, was something she struggled with.



But now she has a newfound confidence and wants to help other deafblind people come to terms with a diagnosis.

"I got nine GCSEs, worked in McDonalds as my first job at 17 and have worked ever since and I love travelling," she said.

"I caught the travelling bug when I went to Australia in 2005 - the Deaf Olympics was on there. Me and a couple of friends travelled in a camper van for three months and finished in Perth. I'll never stop travelling even if my eyes get worse. I've had some close shave moments but I'm a Christian and I really think God catches you when you fall."

Heather also went on her first skiing holiday with friends in March and had her own instructor who made sure she could do everything she wanted.

"I've got tunnel vision so I couldn't see

the ground, the bumps or how steep the slope was," she said.

"I had an instructor who acted as my guide - he skied in front of me and I followed his skis. It cost a lot more but it's not about the money it's about the experience; I got to go with my friends, I felt included, I got to experience what skiing is like and I'll never forget it.

"I could only afford to ski for a few hours a day but when I wasn't skiing I got on the bus and went to the local swimming pool. I asked the bus driver for directions - he could tell I was deaf but I couldn't see where he was pointing to, so he actually got off the bus and walked with me all the way to the swimming pool.

"At the end of the week the ski instructor got a map out and drew the routes that we'd taken. I showed my friends

and they were absolutely gobsmacked. On the last day I went paragliding - when you're skiing people enjoy the views on the way down but I didn't get to see that because I was concentrating on trying to get down the hill safely. It was so worth it, it felt like I was in a documentary - getting really close to the mountains and feeling like I could touch the trees.

"Before I went skiing I had to meet an interpreter every week and ring the resort to try and find a guide - being deafblind often means I have to be more organised. If I'm going to an event they'll probably provide an interpreter but when you're blind you need a specific deafblind interpreter or Deaf Relay interpreter so you have to organise that beforehand. There isn't much awareness about being deafblind compared to being deaf."



Heather when she ran in Uganda. She went on her own and met her group there.

Heather, who grew up in Manchester, moved to Belfast two years ago and admitted she found it difficult to adapt initially. She is a keen runner but due to not knowing the area, found it hard to go out without a guide.

"I do a lot of running," she said.

"When I could drive I used to just get in the car and I really enjoyed being in that bubble and listening to music. When I stopped driving I missed that so I started running to replace it - it gives me that sense of freedom and independence that I don't have normally.



Heather doing the Rampage last year. Her friends all helped guide her

"I prefer to run along the same route where there are no obstacles. I do sometimes fall, but I'm happy to take those risks because I value the independence. I like swimming as well - the lifeguards let me swim along the wall which guides me. They've been brilliant and really understanding - over the years I've learnt how to explain to people if I need access."

She had a difficult experience when she visited the Olympia Leisure Centre for the first

time and tried to swim along the wall for guidance. Another swimmer did not understand what she was doing and she was asked to leave.

But after speaking with the manager, Heather said the staff at the leisure centre are fantastic with her and she goes swimming there at least four times a week.

"They are like a second family," she said.

"If I am in the changing room or pool they will tap me on the shoulder to get my attention and say hello. Some people do still complain because they do not

understand but the manager is on my side which is great."

Heather, who works as a Hearing Aid Liaison Officer for Action on Hearing Loss, gets support from Access to Work and has an interpreter. They use hands on signing so she can feel the signs as she can't see them. They also drive her around as she has to do home visits as part of her job.

Technology also plays a big part in Heather's every day life.

Her Apple watch lets her know in the event of a fire using smart home devices.

She added: "When I'm travelling I use a translation app and the maps on my phone - it vibrates when I need to turn a corner. I also use my phone camera to help me see if it's a bit dark, as the camera is lighter than what I can see."

In a message to other deafblind people, Heather urged them not to give up and said everyone is "perfect the way they are".

"Deafblind people should be confident, people are perfect the way they are, it is society that says there's something wrong. I like to look at the glass half full," she said.

"If I want to do something I will do it, I don't care. Some people will only go if there's an interpreter but if I want to swimming then I will go.

"It is about having the right attitude when you ask for help, people may not understand at first but it is about changing them."

She added: "I have learnt a lot about myself being deafblind, I know it is not easy and there are times I go home and I am upset. Mostly I get upset about missing out on something, if people are telling a joke and I miss it, it's not funny when I get them to explain it to me later, it's not their fault, it is just the way it is.

"You have to learn to love yourself and when you do then you will be more confident going out."

# New Tech Helps Deafblind People ‘Watch’ TV

By Kathiann Kowalski



Ángel García Crespo (right) chats with Javier, who is deaf-blind, through an interpreter (off screen) and a machine that presents words in Braille.

## Innovation lets these individuals know what's happening without asking for help.

You may enjoy TV — as do many people with hearing or visual disabilities. But those who are both deaf and blind need special help to follow along. Now an innovative technology is turning television signals into a form that deaf-blind people can understand.

Deaf people can't hear. But they can use closed captioning to read subtitles of the words spoken on TV. Blind people can't see. But they can make use of visual description in voice-over comments that describe what's happening on the TV screen. Neither method, however, works for people who are both deaf and blind. That makes it harder for them to “watch” television shows or programs.

Roughly 45,000 to 50,000 deaf-blind people live in the United States, according to the National Center on Deaf-Blindness in Monmouth, Ore. By that center's count,

almost 10,000 of them are under age 22. Thousands more deaf-blind people live elsewhere around the world.

Ángel García Crespo is a computer engineer at Carlos III University of Madrid in Spain. His group has invented a new way for deaf-blind people to “watch” TV. He unveiled the technology at a conference, last year, in Aveiro, Portugal. The team went on to describe what they'd done in a paper, earlier this year.

The idea for the system grew out of previous work by García Crespo's group. The team had already worked on making audiovisual materials accessible to people with either vision or hearing disabilities. But the group wanted to help people with both challenges. So they asked some deaf-blind people what would help.

“We heard from them that they would like to know, without intermediaries, what is said in the TV newscasts,” García Crespo says. In other words, the deaf-blind people didn't want to always need someone else to tell them what was going

on. That sent the team brainstorming.

## Getting technologies to work together

Deaf-blind people rely on their sense of touch to communicate. One way to get info is to have someone on hand — literally. A deaf-blind person can get and give information through touch-based hand signals with another person. But it isn't always “handy” to have someone else around.

People who can't see can also get and send information with a braille line, better known as a refreshable braille display. The braille system uses patterns of raised dots to stand for letters and numbers. A refreshable braille display is an electronic machine with a changeable braille display. Dots or pins rise up or drop down based on electronic information sent to the machine. With such a portable device, someone who cannot see a screen can still read email or other information from a computer.

The new system converts TV signals to data that a refreshable braille display can use.

“Key to the system is the possibility of using subtitles to collect TV information,” García Crespo explains. “Subtitles travel with the image and the audio in electromagnetic waves that we do not see. But an electronic system can capture those waves. That is what we do.”

First, a computer program, or app, pulls out the subtitles and visual descriptions from the broadcast signal. The system then combines the information and converts both into data for braille. “No one had done this before,” García Crespo notes.

Now another app gets to work. It sends the data out to people's refreshable braille displays on demand. “This is done in real time, in less than a

second,” García Crespo says. This lets a deaf-blind person “watch” TV as it is broadcast. The system will work with all types of refreshable braille displays, as long as there is a Bluetooth connection available.

Currently, the system is only used in Europe. Teams need to tweak the decoding process to work with the TV signals used by broadcasters in different regions. Indeed, it should soon be available in the United States.

The Dicapta Foundation in Winter Springs, Fla., has been working with García Crespo's team and others to make that happen. They call their project GoCC4All. Apps for Google and Apple phones are just about ready, says Lourdes Fiallos. She's a project manager at Dicapta. Testing with deaf-blind users should start in a few weeks.

García Crespo's team also wants to create a “universal communicator” for deaf-blind people. It would let them communicate with anyone without the need to have a human assistant present.

Anindya “Bapin” Bhattacharyya is a technology-development and training specialist at the Helen Keller National Center for Deaf-Blind Youths and Adults. It's in Sands Point, N.Y. Bapin is deaf-blind himself. And he says the new technology sounds like “a great development.”

Bapin does raise a few questions. “There needs to be a menu to allow me to select a channel or show that is captioned and also has audio/visual descriptions,” he points out.



An innovative system can let deaf-blind people “watch” television in real time on their own. Audio and video information from the TV is sent to a machine called a refreshable braille display so deaf-blind people can read it with their fingers.

Bapin also would like a way to skip an ad. People with sight and hearing can take a break when a commercial comes on. When they hear or see that the show resumed, they can again pay attention. Deaf-blind people would like such a signal to let them know when a show resumes, he says.

Technologies to assist people with disabilities “are fantastic and give deaf-blind people access to digital info and communication,” Bapin says. However, he notes, gaps remain. Examples include self-help machines at some stores and banks. Too often the developers forget to include accessibility features.

Inventing new technologies to boost their accessibility takes work, as

García Crespo's team has learned. For instance, the TV system had to work in real time. Yet no one knew in advance which show someone might want to “watch.” To deal with that, the team has different computer processors handle each TV channel's signal. Then one server centrally manages all of them. It collects the processed subtitles and visual descriptions and then sends them to users on demand.

Getting the whole set-up to work was tricky, but García Crespo liked the challenge.

“I like to solve problems,” he says. “If the solutions are related to technology to improve people's lives, I like those problems better.”



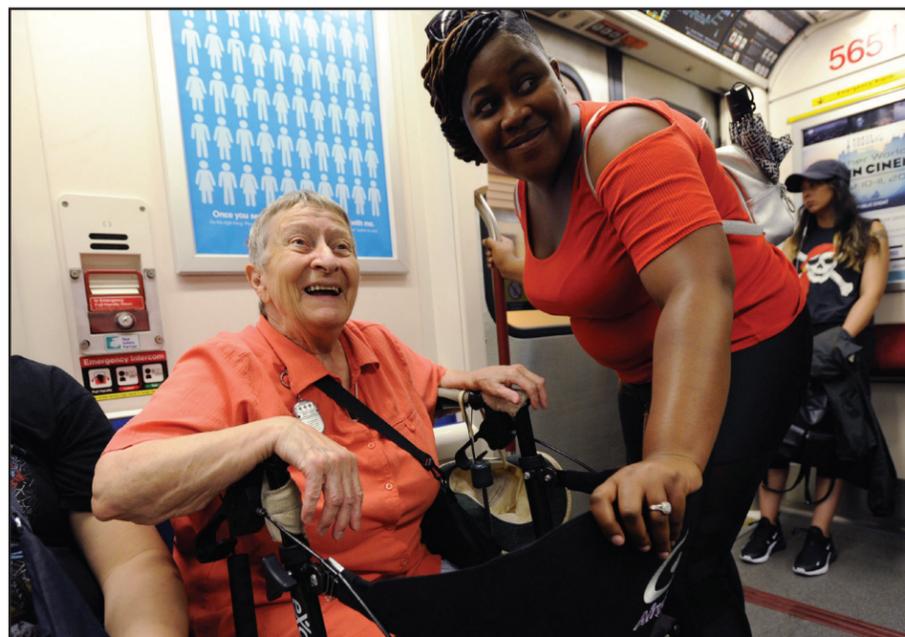
## You can now make donations online!

Through a partnership with CanadaHelps.org, it has never been easier to make a one-time or monthly recurring gift directly through CanadaHelps portal. This service offers an instant electronic receipt, and you can feel good knowing that your transaction is safe using advanced security technology.

To learn more visit the link from our website at [www.cdbanational.com](http://www.cdbanational.com). Thank you for your support in ensuring that, “All people who are deafblind will live rich meaningful lives.”

# Despite Loss of Vision and Hearing, Christine Nichols Hasn't Slowed Down

By Dan Pearce



Fareed Adam has been working as an intervenor after graduating from George Brown College. Without an intervenor Nichols would not be able to go on the monthly excursions.

When Christine Nichols was 26 years old and working as a head nurse at Wellesley Hospital, she was diagnosed with retinitis pigmentosa.

RP is a genetic disorder of the eyes that

causes loss of vision. The disorder is generally inherited from a parent.

Five years ago, Nichols started losing her hearing so her husband Peter called the Canadian Helen Keller Centre for

advice on hearing aids.

For 35 years, Peter was her full-time intervenor until May 18, 2016 when he died.

Nichols found it difficult to manage on her own and called the centre again for advice and within a week she was involved in its outreach program.

Now she lives in the CHKC Rotary Cheshire apartments in North York and is involved in the garden club and participates in Deafblind Association of Toronto events.

For more information on the Helen Keller Centre go to [chkc.org](http://chkc.org)

Core programs at CHKC are skills of daily living (cooking, cleaning, home organization, shopping, personal finance, grooming, etc.), computer essentials/technical devices, adapted communication (sign language, 2-hand manual), Braille and orientation and mobility (safe travel). Intervenor services are offered through a staff intervenor when necessary.



Christine Nichols cheers with Megan McHugh during lunch at the Deafblind Association of Toronto social event. McHugh is the president of the association and organizes the monthly outings.



Intervenor Fareeda Adam helps Christine Nichols off the ferry during an outing to Centre Island with members of the Deaf Blind Association of Toronto.



## Canadian Deafblind Association 2018/19 Board of Directors



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*All people who are deafblind will live rich meaningful lives.*



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