



**Canadian
Deafblind
Association**
Supporting Access
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Imagine...

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

Edition 43 No.1

Winter 2019

Intervention



How Burnout Affects a Special Needs Parent

Inside:

- Heartwarming stories about the acquired deafblind community
- Lesson #4 from Charlotte's Web
- 2020 "Lend-a-Hand" Golf Charity Golf Tournament June 27th
- Registered Disability Savings Plan
- Lifeline technology for persons who are deafblind
- Celebrating special needs parents
- Exciting news from CDBA Chapters
- CDBA National Board of Directors 2019-2020
- Latest research into inherited deafblindness
- CDBA National Support Fund Applications



Save the date for the 2020 Lend-A-Hand Golf Tournament!

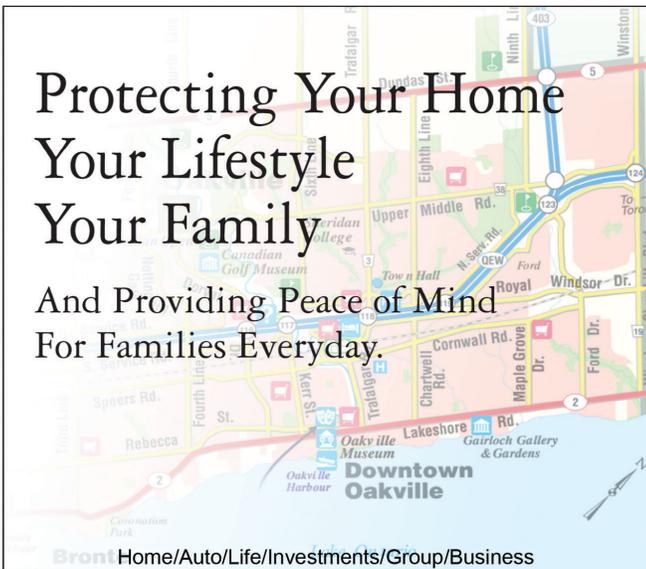
Monday, June 29, 2020
Hidden Lake Golf Club,
Burlington, Ontario
www.hiddenlake.clublink.ca

For more information, contact
tmcfadden@cdbanational.com



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

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

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

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

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A Message From the President

Carolyn Monaco



In late September at our 2019 Annual General Meeting in Fredericton, the following members from across the country were elected to the CDBA National Board of Directors. From British Columbia: Wanda Schellenberg & Leslie Comrie; Alberta: Frances Jablonca; Saskatchewan: Allan

Matheis; Ontario: Sandra Owen-Peters & Carolyn Monaco; New Brunswick: David Brown & Renee Landry

It is my pleasure to commit to another term as president and I welcome the opportunity to work with Sandra as Vice President, David as treasurer and Allan as secretary as well as the remaining board members.

It is always an inspiring and productive time when we meet “face to face” with our CDBA family of colleagues from across the country. The needs of individuals who are deafblind, their families, intervenors and our chapters were at the forefront of our discussions and will be reflected in our 2019/2020 workplan for the coming year.

Many thanks to those of you who contributed to our “Canada Helps” campaign this year. It was a successful campaign and plans are already in the works to expand it for next year’s “Giving Tuesday”. Fundraising at a National level is always challenging for a small organization like ours and so your generosity is very much appreciated.

Our largest fund raiser has always been our annual golf tournament and this year it will take place on June 29th as part of our Deafblind Awareness Month celebrations.

I hope you enjoy this edition of CDBA’s “Intervention” magazine. Many thanks to all those who submitted interesting and insightful articles and photos.

2019/2020 Board of Directors



*Top row L to R Allan Matheis, Sandra Peters, Leslie Comrie, David Brown
Front row L to R Frances Jablonca, Carolyn Monaco, Leslie Comrie
(Absent: Wanda Schellenberg)*

CDBA Senior Staff



L to R: Tom McFadden, Executive Director, CDBA National; Theresa Tancock, Family Services Coordinator, CDBA-BC; Dana Heinrichs, Executive Director, CDBA-SK; Kevin Symes, Executive Director, CDBA-NB



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Editorial From the National Executive Director

Tom McFadden



All members of CDBA, as well as interested family and friends, are invited to enjoy this Fall/Winter 2019 issue of "Intervention" magazine.

This issue contains some incredible stories from the acquired deafblind community including that of Winfield Sainpreux a deafblind

artist and activist, and Emma Blackmore who is deafblind and who believes she is so because her mother didn't get the Rubella shot. In two well-written articles by author Heather McCain, we celebrate parents of special needs children, including those who are deafblind, and the burnout and grief that they oft-times suffer in silence.

We also highlight the incredible impact that Intervenors have on the lives of those who are deafblind; the recent release by Samsung of a Good Vibes App for those who are deafblind that uses very old technology - Morse Code - with today's haptic smartphones; some myths still around about employing people with disabilities; research that exposes genetic mutations that cause Usher Syndrome; and the fight of a Winnipeg man who is deafblind in protesting some accessibility issues caused by diagnostic lab closures.

In a heartwarming story, we profile the story of Piglet, a deafblind dog with life lessons to share...that it's ok to be different! Along this same vein, we thank Charlotte's mom Frances Jablonca for contributing her 4th installment of Lessons from Charlotte's Web - "Not everyone knows dogs can't speak English!"

Enjoy!

Annual "Lend-A-Hand" Golf Tournament off to a good start

On June 24, 2019 CDBA National held its 33rd annual charity golf tournament at the Dragon's Fire Golf Club in Carlisle, Ontario. Supported in many ways with sponsorship dollars and golfer participation, new Signature Sponsor Cooperators (Justin James & Associates), helped make our 2019 golf tournament a resounding success. More than 80 participants and volunteers helped us raise over \$10,000 for the CDBA National Support Fund. Justin and the Cooperators represent

what we hope will be a new and exciting partnership for our annual golf fundraising charitable event.

The 34th annual tournament will be held on Monday afternoon June 29th at Hidden Lake/ClubLink Golf Club in Burlington, Ontario.

June 2020 is Deafblind Awareness Month

This year marks the 5th anniversary since the Senate of Canada recognized June as Deafblind Awareness Month. Like-minded organizations are again working on a collaborative project to "Make a Wave" across Canada and raise awareness about deafblindness. To extend the reach of these efforts, the plan is to compile short video clips from individuals in the field of deafblindness engaging in daily living activities. The objective is to celebrate persons who are deafblind and their contributions by raising awareness nationwide. For more information, contact makeawave.ndbam@gmail.com

Giving Tuesday December 3, 2019 a Resounding Success

Many thanks to all those who each donated online a minimum of \$25 to CDBA National during the one-day Canada Helps fundraiser on December 3, 2019. Your generosity is very much appreciated.

I leave you with this positive thinking quote:

**Yesterday's a memory...
Today's a reality...
Tomorrow's a vision**



Deaf-Blind Conklin Student, Grads to Showcase Art

www.hometownnewsvolusia.com



Winfield Sainpreux poses with his self-portrait. He is creating an original acrylic painting to be featured and auctioned at the Conklin Center for the Blind Shining the Light Gala on Nov. 1.

Three talented artists are preparing to present and auction their works at the Conklin Center for the Blind Shining the Light Gala Friday, Nov. 1.

Aside from their considerable talent, their (un)common denominators are that they are blind or visually impaired with other disabilities, and they are students or graduates of the Conklin Center for the Blind.

Brianna Lawson is an aspiring fashion designer. Winfield Sainpreux is a fine artist and activist in the DeafBlind community. John Dorion is focused on launching his career as a draftsman.

"To see the works of these creative people is truly inspirational, said Kelly Harris, president and CEO of the Conklin Center, in a news release. "We imagine a world in which individuals who are blind or low-vision with additional disabilities are not restricted from the freedoms, possibilities and independence of living a full and healthy life."

This is our vision in action; to help our students identify and achieve their lifelong goals," Ms. Harris said. "The training can be rigorous, but our exceptional staff and our students work closely to transform lives every day."

Ms. Lawson, who is legally blind, aspires to be a fashion designer for plus-sized women. She has an impressive portfolio of designs that includes a wedding dress designed for her sister. She is creating a dress specifically for the Shining the Light Gala. As with all her designs, she sews famous quotations by Helen Keller and others into her garments – in Braille and large print.

Mr. Winfield, who is deaf-blind, is an accomplished fine artist. He has exhibited (and sold) his works in various events and venues. His portrait of Michael Jackson and a self portrait hang in the Conklin Center residential wing. For the Shining the Light Gala auction, he is working on an acrylic piece

featuring a Hollywood celebrity.

He also is working to establish a support organization for the deaf-blind, open to anyone learning or fluent in sign language. He is employed by Alfie's Restaurant on A1A in Ormond-by-the-Sea.

Mr. Dorion returned to South Florida after graduating from the Conklin Center and is pursuing his goal of becoming an architectural draftsman. He is visually impaired and hard-of-hearing. He plans to bring his pencil study of the Daytona Beach Pier to the Shining the Light Gala auction. It's a piece that has generated a great deal of praise and is seen as capturing the iconic pier beautifully.

All three artists are excited about the Shining the Light Gala not only for its fundraising potential for the Conklin Center and the chance to show their works, but in celebration of the organization's 40 years of service to blind and low-vision adults who also have additional disabilities.

"The place is amazing," Mr. Winfield said. "Most of us arrive totally dependent on others and graduate with the skills and experience to live independently. It is a thing of beauty, a great story to tell the community."

The gala will be at The Shores Resort & Spa in Daytona Beach Shores. It will feature a silent and live auction and music.

It will highlight a new partnership between the Helen Keller National Center and the Conklin Center as the leading agency providing services for adults who are deaf-blind in Florida.

Community awards will be presented, as will a special award to volunteer, consultant and advocate Mike Jiloty.

Samsung Introduces Good Vibes App for the Deafblind

By Mark Lyndersay

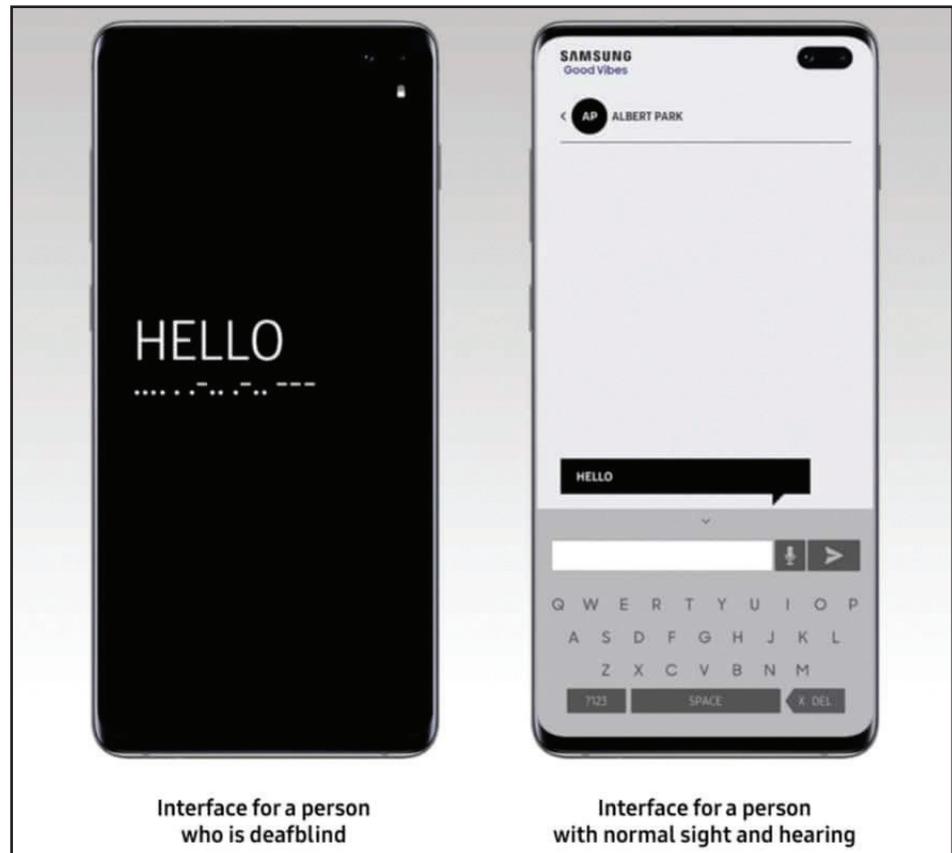
Targeting a very specific sector of the disabled community, Samsung has released a new app that uses very old technology, Morse Code with today's haptic smartphones.

Once a deafblind person has learned the code, the app can translate taps on the screen into words and interpret responses as vibrations on the screen.

It's an interesting development from Samsung and the kind of laser accurate thinking that solves real world problems in a direct way at minimal cost for a dramatically underserved community.

It's unfortunate that Samsung has released the app only on its Galaxy store, limiting its use to the company's smartphone models. This development seems like a great opportunity to change lives with a wider release, perhaps with a caveat that Samsung only guarantees compatibility with its own smartphones.

www.samsung.com/in/microsite/good-vibes/



Canadian Disability Policy Alliance & Canadian Disability Participation Project
November 2019

Myths about employing people with disabilities

A recent study by our colleagues Silvia Bonaccio and associates uses an evidence-based approach to challenge 11 concerns about employing disabled people at 4 stages in the employment cycle : recruitment, hiring, workplace integration, and performance management. They *effectively dispel* such detrimental myths as the following:

- That people with disabilities don't want to work;
- That a disabled employee wouldn't fit in with their workforce;
- That disabled employees would be less productive, more inclined to be absent, or more likely to leave the job.

Their analysis concludes that this underutilized talent pool could represent a significant return on investment for employers who engage in inclusive organizational practices.

[The Participation of People with Disabilities in the Workplace Across the Employment Cycle: Employer Concerns and Research Evidence](#)

A vision of Canada where people with disabilities enjoy full participation and citizenship, supported by a coherent framework of legislation, regulation and programs.



Deafblind Persons Want Tactile Language in Curriculum

By Agnes Nantambi



Stakeholders of NADBU signing on the new strategic plan formulated for the next five years. PHOTO: Agnes Nantambi

Currently, the curriculum recognises sign language but the lack of a deafblind curriculum has brought about a lack of skilled teachers to assist deafblind children to attain some level of education.

People with Deafblindness have asked the government to consider including the tactile language into the education curriculum to enable them to attain some level of education.

Currently, the curriculum recognises sign language but the lack of a deafblind curriculum has brought about a lack of skilled teachers to assist deafblind children to attain some level of education.

“There are no skilled teachers for deafblind children and because of this; these children cannot be absorbed into meaningful employment to provide for their families which has kept them in a vicious cycle of dependency translating

into poverty. The government can train teachers and equip schools which can teach these children so that they can benefit from gainful employment,” said

Yona Waswa the coordinator National Association of the deafblind in Uganda (NADBU).

Waswa said families of children with deafblindness suffer a lot from stigma from communities surrounding them.

“They develop loss of esteem but most importantly, their families spend the most time taking care of these children and spend less time in participating in productive work, ending up leaving in a vicious cycle of poverty. We call upon the government to expand the social protection to cover families of children with deafblindness,” he said.

He said that the world is full of requirements with limitations on resources observing a need to go step by stage in addressing specific issues.

Masiga said his Ministry with other partners is working on a tactile curriculum awaiting recognition by the constitution.



Yona Waswa on the right, communicating with fellow deafblind persons in tactile with their interpreter during the launch of the National Association of the Deafblind Persons strategic plan. PHOTO: Agnes Nantambi

Citizen TV's Yvonne Okwara Impresses With Rare Skill

By Derrick Okubasu

Citizen TV news anchor Yvonne Okwara is respected for her no-nonsense nature when carrying out interviews but very few people know that she is skilled in sign language.

On Thursday, September 26, she uploaded a short clip where she communicated in the rare language and judging by the comments, Kenyas liked it.

She had probably mastered the craft owing to spending time with her, now deceased, deafblind brother Albert Okwara.

In the clip, the presenter looks directly into the camera introducing herself and where she works without saying a word.

"Hi. My name is Yvonne Okwara and I work for Citizen TV. Happy International Deaf Awareness Month. Sign language rights for all. Thank you," she gestured.

Her followers were impressed by her skill and took to Instagram to praise her for it.

"You did well. Plus the smile brightened it up," shared a fan.

In a past sit-down with The Standard, the outspoken presenter opened up about Albert's condition and how it impacted her family.

"In the 60s, while expectant, my mother contracted German Measles. It has no symptoms. By the time she was giving birth to her firstborn son, there were complications. Mental retardation and deafblindness started to set in.

"Friends have fallen along the way, those that could make the choice did so and exited our lives. Called it a curse to the entire community! I won't name names but he knows himself," she recounted.

The family, however, never gave up and stuck with him until he passed away in October 2015.



Citizen TV anchor Yvonne Okwara who has an impressive sign language skill.

Registered Disability Savings Plan

What is it?

The Registered Disability Savings Plan (RDSP) is a Canada-wide registered matched savings plan specific for people with disabilities. It is designed as a long-term savings plan to help the holder be better financially prepared for their future.

Here are some basics:

For every \$1 put in an RDSP account, the federal government can (if your family income is below \$95,259) match with up to \$3! This is the Canada

Disability Savings Grant.

For people living on a low-income (less than \$31,120), the federal government will put in \$1000 each year for 20 years! This is the Canada Disability Savings Bond.

For people living on an income between \$31,120 – \$47,630 they can still receive a partial bond.

Anyone can contribute to an RDSP- family, friends, neighbours... it gives people who want to help a way to do so!

The money can be invested to grow- we have heard that it is the best Return on Investment available. Depending on someone's income, any money saved

immediately triples in value. Once investment decisions are made, it can really start to grow!

The RDSP is exempt from most provincial disability and income assistance benefits. It does not get clawed back and it does not reduce disability benefits payments. Click here to find out how your province treats the RDSP.

People with disabilities can choose what to do with the money when it comes out- there are no restrictions on how the money can be spent!

RDSP Plan Institute, www.rdsp.com

The Story of Piglet, a Deaf and Blind Dog, Comes to Alabama

By Ivana Hrynkiw

Second-graders in Foley spend their days trying to be like Piglet—not the famous Winnie The Pooh character, but a deaf and blind dog with lessons to share.

Joanna Worch is a second-grade teacher at Baldwin County's Foley Elementary School. Every day, she talks about Piglet to her students.

"I think it teaches, yeah (he or she is) different, but that's okay. So is Piglet," Worch said. "It's made such a difference in my class."

How the Piglet Mindset got to Foley

Over the summer, Worch got the idea of Pet Pals. Similar to pen pals, she imagined her students writing letters to animals all over the world and reading the pets responses when the animals 'wrote back.' She put a post on Facebook seeking pet owners who would be interested in letting her students write their pets and writing replies back, and dozens responded—even people across the country she had never met.

Worch decorated her classroom with the photos of dogs, cats, sloths, geckos, fish and other pets that became part of the program. Her students immediately fell in love with the idea.

But, Worch said, she wanted to add a special needs dog to her project. She found Piglet on social media and reached out to Piglet's owner Melissa Shapiro to see if she would be interested in participating in Pet Pals.

Shapiro was interested, and had something to add.

The Connecticut-based veterinarian and dog mom had a curriculum for schools,



with slideshow presentations and online videos, called the Piglet Mindset. The program was aimed at teaching kids how to face challenges with a positive attitude and to be inclusive of others who may be different. The program also teaches optimism, flexibility, resilience, perseverance, and empathy. Other topics in the lesson plan include learning about the five senses, what being 'special needs' means, and methods of communication.

Worch was hooked.

"It's a totally different mindset and approach to reality. It's a different way to view things," Worch said.

Piglet's journey

The double dapple dachshund-chihuahua mix is now two and a half years old. He was rescued from a hoarding situation in Georgia and Shapiro began fostering him at eight weeks old. However, Shapiro and her husband already had six rescue dogs. "That's why we were

reluctant to add another dog. We were especially concerned with how much of a commitment Piglet would be," she said.

"He was a foster dog," Shapiro continued. "(But) after two months, we and he decided he was already home."

Piglet's parents were both dapple, or merle, color. Shapiro said breeding two dapple or merle dogs causes serious problems for the puppies, and each puppy born to two dapples has a 25% chance of being born with congenital ear and/or eye defects. Shapiro, who has practiced veterinary medicine for over three decades, said many times double dapple puppies are born to breeders who don't know about the potential health problems; others are born in a hoarding situation like Piglet, where the owners might not know which dog has mated with another.

Regardless, Shapiro knew Piglet was special. After adopting the tiny pup, she made him social media pages and began to share his story. The mission: To encourage spay and neuter practices, to educate about double merle or dapple breeding, to inspire others to adopt special needs pets, to raise funds for special needs rescues, to facilitate the Piglet Mindset outreach, and to "put a smile on faces all around the world."

The Piglet Mindset was created by a third-grade teacher in Massachusetts after she and Shapiro connected on one of Piglet's posts. "I ended up creating a Power Point presentation called 'The story of Piglet, the deaf blind pink puppy.' She used it at the beginning of her growth mindset lessons

and turned it into Piglet Mindset. And there it started,” Shapiro said. She corresponded with the teacher all year and made a surprise visit to the classroom at the end of the school year.

“It’s the way he approaches his life,” Shapiro said about the lessons revolving around Piglet’s journey. “He has this mindset of, he’s optimistic. He’s happy. He’s not looking at anything negative... he’s going forward. He does have his times of frustration, but he figures it out.”

“He’s a determined little character,” she said.

The Piglet Mindset lesson plans were made available for free on Piglet’s website in August, and several teachers across the country are now using them, including Worch. “I’m delighted with the response,” Shapiro said. “When I picked up that screaming little dog in March of 2017, I had no idea where this was going to go... and look at us now.”

Shapiro has also raised over \$30,000 to donate to special-needs dog rescues since Piglet’s adoption. “It’s very rewarding. I just can’t believe it.”

In the last few months since the lesson plans were made available, Piglet has been featured on E! News and People magazine. “It’s really fascinating to see,” Shapiro said. “(Piglet) has a very compelling story... He’s a character.”

Give a smile instead of a stare

Worch read the curriculum online and immediately knew the program would be a hit in her classroom. She made a ‘Piglet center’ and told parents about the Piglet Mindset during teacher conferences before school started. Before she knew it, Worch said, parents had told their children what they would be learning about during character education time in Worch’s class.

“He can’t see skin color, or disability, or anything like that,” Worch said. “It teaches compassion, understanding, and tolerance.”

Character education is a required topic in Alabama public schools, and Worch also uses the Piglet Mindset as part of

the national “Leader and Me” program. Soon, she expanded the program even more.

“They were getting so much joy out of this,” Worch said, and that joy led her to create the Piglet ambassador program. Each week, her students nominate a classmate who has shown all of the Piglet Mindset traits that week and write down why they believe that person is deserving to be a Piglet ambassador. Whoever wins each week gets to wear a special shirt with Piglet’s face on it.

“When I’m talking about this, I’m talking about love,” Worch said. “They look to their peers and not themselves for who had the best Piglet mindset.”

Worch said her students have constantly impressed her with who they chose to be weekly ambassadors. One week they chose a non-English speaking child who had just immigrated from central America; another, they picked a non-verbal classmate. “They can recognize a great leader without language,” she said.

Shapiro said she’s thrilled with the ambassador program, and now features it on her website along with the lesson plans. She is planning to expand the curriculum to include an anti-bullying section, too.

“They can see the world from Piglet’s point of view,” Worch said, adding that her kids have learned more about being inclusive with children who may be different than they are. “They know now, ‘you’re okay, let’s be friends,’ instead of being scared of what’s different.”

“I think they’ve had their hearts

and points of view molded.”

The new ambassador is announced each Friday, and Worch live-streams the announcement for parents who tune in. She said the parents get nearly as excited as the kids, commenting words of encouragement for other students and excitement when it’s their child.

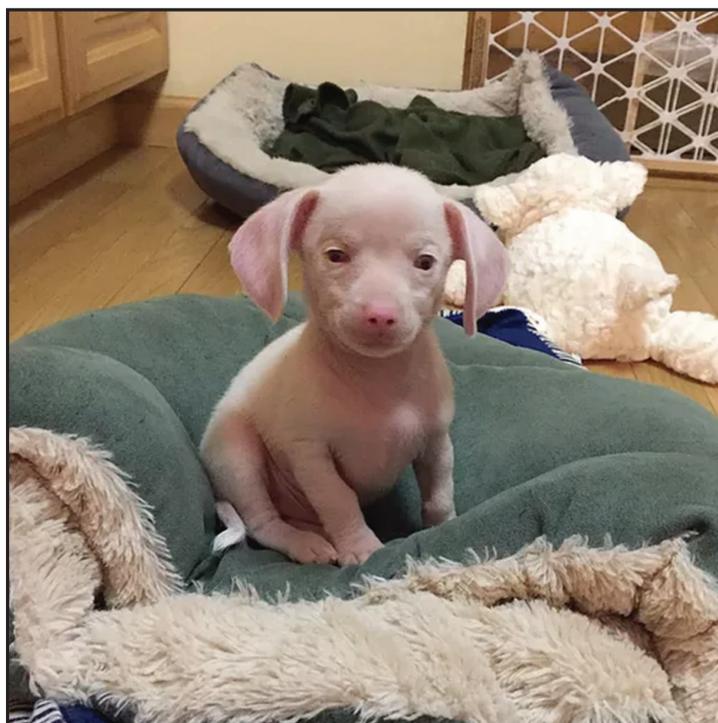
Other benefits

In addition to the character education, Worch’s students learn about English and grammar while writing letters to Piglet and other Pet Pals. Her special-needs kids and non-verbal students write to pets, she said, along with her English as a second language students. Kids who would never willingly write a sentence write pages-long letters to their animal friends, she said.

And, Worch warns her students the animals might not understand the letters if there are ill-placed periods or misspelled words.

Worch said sometimes she will talk to her students and point to animals like Irish the cat or a dog in Alaska and say, ‘Look at him, do you want to be him?’ Her students’ response?

“No. I want to be Piglet.”



I'm Deafblind Because My Mother Didn't Get The Rubella jab – Now Anti-vaxxers on Social Media are Putting Countless Children at Risk

By Emma Blackmore

Half of all parents have been exposed to negative messages about vaccinations, causing them to make dangerous decisions which could have tragic consequences.

My name is Emma Blackmore and I'm deafblind. My condition is a result of being born with congenital rubella syndrome (CRS).

I contracted rubella though my mother, who had been exposed to German measles during pregnancy. When she discovered she was pregnant, being of a young age and frightened of the response of those around her, she didn't tell anyone or receive medical support. Because of this she didn't receive the rubella vaccination and now I live with a range of complex health and medical needs.

Fast forward 31 years, and I'm now married. I work in Woodside, Bristol, at a day service which supports families and children with complex disabilities, run by the national disability charity Sense. I'm supported by Access to Work and I love my job because it allows me to help people, which has always been my ambition.

I'm happy, but my condition has caused me and my family a lot of pain over the years, and I sometimes think about what things would be like if my mother had been vaccinated and I hadn't been born with CRS.

It's why I felt so upset this week reading a new report published by Royal Society for Public Health. It reveals the extent to which false information about the vaccination safety was "breeding" on social media and

fuelling parents' fears about side effects, leading to reduced vaccination rates. For many it will come as no surprise to learn that fake news is rife online, but there are few instances where misinformation is so harmful.

The report contains the findings of surveys of nearly 5,000 people across the UK on their awareness and attitudes towards vaccines, such as MMR, the flu jab and HPV. It includes contributions from 2,600 parents, 2,000 other adults and more than



200 healthcare professionals, such as nurses, pharmacists and GPs.

It found that one in two parents had been exposed to negative messages about vaccinations, and that a fear of side effects was the number one reason why people failed to vaccinate themselves or their children.

Attitudes to vaccines were largely positive, with 90 per cent getting their children vaccinated routinely. But roughly one in 10 parents surveyed said they had chosen not to give their child the MMR jab, which protects against measles, mumps and rubella. The main reason given was

concerns over side effects.

At the same time we have seen a drop in some vaccinations in England, and a record-breaking measles outbreak that caused hundreds of infections in the UK and tens of thousands across Europe.

Put simply, the spread of misinformation about vaccine safety has seen a reduction in the number of people taking vaccinations, and this in turn poses a great risk to the public's health.

We are all influenced by headlines in newspapers and online, and it can take a long time to change people's perceptions. It's why I feel we must tackle the problem now, and put pressure on technology companies such as Facebook and Twitter to manage content more responsibly, so that reliable health sources are prioritised.

I also think we must do more to raise awareness of the effects of illness such as measles, mumps and rubella. If there was more information out there about what a vaccination prevents, and the impact that illness can have on a child's life, I feel vaccination numbers would go up. Ultimately, it's the mother's responsibility to choose whether to vaccinate or not, and we must say to them: "I know you may have concerns about what a vaccine can cause, but please also look into what it can prevent before making a decision."

I fear that there are parents out there right now, some vulnerable, feeling scared and alone like my mother, who will act as a result of receiving the wrong information, and they, and their children, will have to live with the consequences.

CDBA National Support Fund

Purpose:

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

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

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

Emergency:

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

Supplemental:

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

Criteria:

Persons Qualifying:

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

Request for Funding:

Application:

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

the application form) and include the following information.

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

How to Apply:

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



Two years ago, a few months after receiving the devastating diagnosis that our son Thomas was suffering from a Peroxisomal Biogenesis Disorder, we had the chance to go to our first conference for scientists and families, organized by the Global Foundation for Peroxisomal Disorder. We left with our suitcases to Washington DC, without knowing that we were about to experience an unforgettable first experience with our GFPD family!

It's hard to express everything you feel when you're dealing with a disease, especially when you're told that there is no cure for your child. But when you can finally be surrounded by people who really understand your journey, it's very comforting!

Thanks to the CDBA National Support Fund, the stipend from the GFPD and the Hector Savoie Foundation (a local foundation) the cost of traveling and conference fees were covered for our

family to get to the 2019 conference. We were so happy and excited!

In addition to seeing the beautiful families we had met 2 years ago, we were able to meet new families, talk with the amazing scientists behind the research, learn new tips about different aspects of the disease, be aware of ongoing research and new discoveries about the disease. The GFPD conference is a place where we are comfortable talking about different delicate topics, laughing and crying at the same time without feeling like an alien!

Not only did we learn a lot from this conference but we came back with stars in our eyes, our heads full of wonderful memories and our heart filled with hope!

Every family affected by a rare disease should have the chance to participate in an experience as rewarding as we had the chance to live at the GFPD conference!

Thank you so much again for giving us the chance to live those precious moments!

Marie-Michele Arpin, Jean-Rock, Lucas et Thomas Thériault



Device That Converts iPhone Screen Into Braille a 'Lifeline' for Deaf-blind People

By Nicole Mills



Melbourne woman Heather Lawson is both deaf and blind; to participate in an interview she requires support from two interpreters.

She places her hands over those of the first interpreter and feels via touch as he signs my questions to her.

A second interpreter translates her Auslan responses back to me.

But despite the multilayered conversation, this remarkable and independent woman's great sense of humour shines through.

Ms Lawson was born without hearing and grew up communicating via sign language.

By the time she reached her 20s, she gradually began losing her sight as well.

"It really did affect my life," she said.

A communication lifeline

A small device has given Ms Lawson, and the wider deaf-blind community, the opportunity to connect with the world.

In recent years a small display which fits in her handbag has become vital as it converts the words on her phone screen into braille.

"It's just fantastic, that technology, and I love it. It has made my life a lot easier and I've been able to achieve things."

The braille display connects to the phone via Bluetooth, allowing her to access emails, SMS, Facebook, apps and the internet.

It also makes banking and navigating public transport much easier.

"I live an independent life, and I have for a number of years, but the technology that's available now has allowed me to remain independent," Ms Lawson said.

Useful in an emergency

The machine also allows her to write notes in the phone which can be useful for communicating with taxi drivers.

She once used it to communicate with firefighters who had broken into her home to respond to a fire alarm.

"I didn't realise the firemen had broken into my house to turn it off," she said.

"We were able to communicate on my computer using the braille display.

"I get goosebumps just thinking about it. It was a great experience."

The device has 14 braille cells which change with the touch of a button to reflect the next passage of text.

"It does take a little bit more time for me to read things using those buttons but it's definitely worth it," Ms Lawson said.

Critical for connectedness

Michelle Stevens is also deaf-blind; she was born without sight and lost her hearing in her 30s due to chronic ear infections.

While she also uses tactile Auslan to process questions, her bubbly voice responds.

The self-confessed "techo-junkie" said she loved experimenting with new adaptive technologies and often shared her experience with others at AbleLink, a centre where people with dual sensory loss can improve their digital literacy.

"Technology has been absolutely fantastic," she said.

"The iPhone in particular has made a huge

difference to how I access information."

Ms Stevens said it was critical that organisations of every size ensured their online presence complied with web accessibility guidelines.



Heather Lawson says her braille display is a lifeline.

"There's nothing more annoying than you go to access an app and because the code has not been correctly written or written to follow the guidelines ... my screen reader cannot read this.

"It's a bit like me saying to people, 'turn on your computer, turn off the screen, and see how you go getting the information —



Michelle Stevens loves experimenting with new adaptive technologies.

and also turn off the sound'.

"That's how it is for us when things are not accessible."

New Mutations Causing Inherited Deaf-blindness Have Been Discovered

By Sechenov University

A team of scientists from Sechenov First Moscow State Medical University (MSMU) together with their colleagues described a number of genetic mutations causing Usher syndrome (inherited deaf-blindness).

A team of scientists from Sechenov First Moscow State Medical University (MSMU) together with their colleagues from leading scientific centers of Moscow and India described a number of genetic mutations causing Usher syndrome (inherited deaf-blindness). They found previously unstudied unique mutations in investigated DNA regions. The results of the study were published in the Ophthalmic Genetics journal.

Usher syndrome is an inherited disorder that accounts for almost a half of all cases of deaf-blindness. There are three types of the disease that are differentiated based on the level of deafness (type I - innate deafness, type II - diminished hearing that does not worsen with time, and type III - progressive decrease in hearing). According to one of the works dating back to 2010, the disease affects 3 to 6 in 100,000 people depending on the region of study. However, among American children the share of patients with this condition may reach 1 in 6,000. Mutations that cause Usher syndrome occur with different frequencies in different populations.

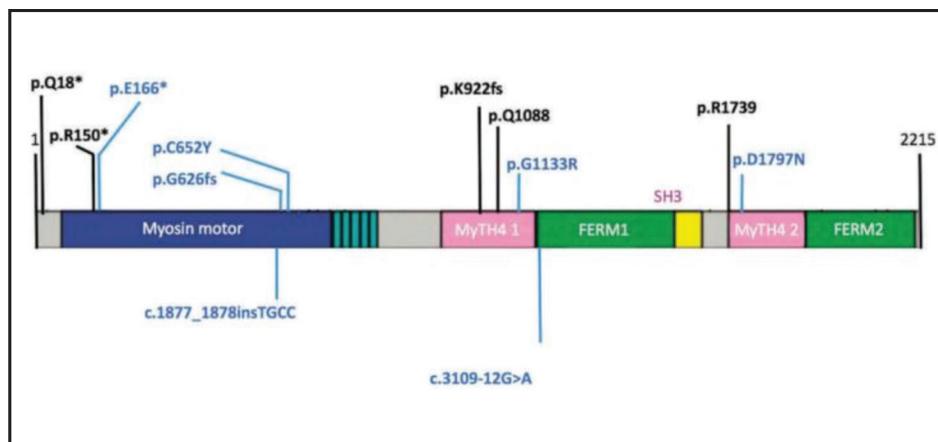
The authors of the work studied and described mutations in Russian patients with Usher syndrome. Due to the rarity of this condition the team worked with 28 patients (11 men and 17 women) 35-60 years of age in which the disease manifested when they were 1 to 18 years old. The group consisted of 21 (75%) Russians (of Slavic origin), 3

(10%) Ukrainians, 2 (7%) Jews, 1 (4%) Belarusian, and 1 (4%) Chuvash. The patients were selected according to their medical records and underwent tests to confirm their clinical diagnosis. All participants suffered from vestibular sickness and vision disorders, and 22 out of 28 also had hearing problems.

Clinical examinations of vision, hearing, and vestibular system showed that 15 and 11 patients had USH of type I and II respectively. Genetic testing demonstrated different mutations associated with the development of Usher syndrome in 23 patients. 11 patients had mutations in the genes associated with type I USH: MYO7A (8 people; a gene that codes a protein in charge of cell movement and intracellular transportation), CDH23 (1),

Russian patients was lower than in other countries, and the frequency of mutations in MYO7A in charge of type I USH was very high.

"While analyzing the databases of mutations associated with Usher syndrome we understood that some of the mutations we had found were completely new. Unfortunately, they would not help recognize the disease on earlier stages or with higher probability, but would be able to confirm the diagnosis. The search for new genetic variations associated with the syndrome may help identify new targets for specific therapy. However, this is not happening in the near future," said Prof. Dmitry Zaletaev, a chief research associate at the laboratory of Medical Genetics, Sechenov University.



PCDH15 (1) (genes that code signal proteins playing a role in the work of retina and inner ear), and USH1C (1) (a gene that codes a protein playing a role in the development of retina and inner ear). MYO7A displayed 11 mutations, 6 of them have not been described before. 2 new mutations were found in the PCDH15 gene. Genetic testing confirmed around 91% of type II USH diagnoses. The USH2A gene associated with type II USH showed 11 mutations, 3 of which turned out to be new. The prevalence of type II USH in

Among the participants of the study were scientists from India, employees of Ophthalmic Ltd, Center for Ophthalmology of the Federal Medical and Biological Agency of Russia, Research Centre for Medical Genetics, Institute of General Pathology and Pathophysiology, and many others. The work was carried out with the support of So-Edinenie Deaf-Blind Support Foundation and Sensor-Tech Laboratory.

Winnipeg Man Who is Deaf-blind, Physician Protest Widespread Diagnostic Lab Closures

By Erin Brohman, Erika Rodeck

Dynacare to close 26 of 54 labs, create 4 larger 'supersites' in Winnipeg.

A Winnipeg man who is deaf and blind says the upcoming closure of nearly half of the city's diagnostic labs will make things harder for people with disabilities, but the private company that owns the labs says the changes will improve overall service.

Dynacare, a Brampton, Ont. based medical company, is consolidating 26 of its 54 diagnostic labs and creating four larger, newer and more accessible "supersites."

The new sites — to be located in Unicity, St. Vital, Garden City and Tuxedo — will be bigger and newer with upgraded technology. The changes will happen between December and January of 2020, leaving the city with 32 sites in total.

"I think it's a hell of an idiot move. Because they're not thinking. It's probably the capital, saving money? But it's going to be a massive headache," said Magnus Kincaid, who has been deaf and blind for several years following an incident while serving in the Canadian military.

He said one doctor's appointment can take up his entire day: He has to plan days in advance for the type of transit he'll take, who will accompany him and then work around their availability. Another appointment to get a lab test done will likely mean another full day of planning and relying on others, he said.

But there isn't always support available when he needs it. Last week he took a cab to an appointment at a clinic on McPhillips Street which cost a total of \$85.

"It's going to be a headache for everyone. If you are sighted, if you have all your faculties, all your senses, it's going to be a headache. But for someone like me, it's



Magnus Kincaid wants more than a 'Band-Aid' solution for folks who face more challenges in getting to appointments.

going to be a big pain," he said.

'Improve customer and employee experience'

Dynacare says the consolidation will streamline lab collection service and bring staff together — many of whom currently work alone at labs across the city.

"Our reason is to actually improve our customer and employee experience, improve the facility, improve workflow and have more sites to have blood drawn at particular sites so we improve wait times as well," said Dr. Jenisa Naidoo, chief scientific officer and vice president of clinical development and quality for Dynacare.

No jobs will be lost during the transition, Naidoo added. Blood and urine samples will be picked up from each site and processed at Dynacare's main laboratory on King Edward Street.

She said the supersites will have more phlebotomy (blood draw) stations and patients can use an app to book a time for blood work so they don't have to

wait. She understands there will be an adjustment period as many locations close.

"No patient will have to move more than a five kilometre radius because we moved strategically and we closed strategically," she said, adding the new sites will be more accessible to people with disabilities.

Naidoo says Dynacare hopes to offer a transitional home service so that patients can "get used to the idea of going to the collection site."

"House calls are a great idea," said Kincaid. "It's a good gesture, for sure, but I think they should extend it, and come up with a solution, not just a little Band-Aid."

'Unnecessary obstacle'

A physician at Citiplace Mall says the loss of its Dynacare lab will severely impact the patients, which include people with mental illness, homeless and transient folks, newcomers to Canada, elderly people and people with disabilities.

"I am upset, I'm disappointed, I'm frustrated, and most importantly I'm very worried. I worry for my patients," said Dr. Michael Hochman, family physician at Eaton Place Medical Centre.

"Primary care is supposed to be collaborative care that involves a number of providers and this is an unnecessary obstacle to providing appropriate, quality care. And I feel that this seems like a business decision and not a moral decision, from what the lab plans to do."

Given the vast number of patients he has with mental illness and addiction concerns, he said he worries that the requisitions for bloodwork and other tests simply won't make it to an off-site lab, even if it's only a kilometre away.

He also worries for his elderly patients and patients with disabilities, and the delays that come with relying on others to get them to another location.

Hochman finds Dynacare's message "slightly disingenuous" in that he believes the changes won't benefit all patients at all locations. He describes his patients as "more unwell" than those in suburban locations, and many require regular monthly to yearly bloodwork.

The Dynacare lab at Citiplace will be integrated into the Winnipeg Clinic on St. Mary's Avenue.

"It's five or six blocks, which for you or I isn't hard or very challenging, but if you're in a wheelchair, a walker, had to book now two Handi-Transits, or simply had other things to do, your labwork

may no longer be your priority."

Concerns to be handled case-by-case

Adding to his frustration is Dynacare's failure to consult, he said.

"My clinic offered this lab zero dollars rent to stay. So we extended an olive branch, trying to understand their perspective and they did not even consider it or allow a conversation."

A spokesperson for Dynacare — which took over lab company Unicity Laboratory and X-ray Services in 2017 — said conversations are ongoing with affected physicians, and concerns about patients will be handled on a case-by-case basis, but Winnipeg has an inordinate amount of labs for its size.

"Regina has only five collection sites. Saskatoon has five. Calgary has a far bigger population than Winnipeg. And they have only 18 collection sites for a population of 1.6 million. And Edmonton has 24 collection sites for a population of 1.4 million," said Dr. Naidoo.

Its seven other sites in the province outside of Winnipeg will remain open.

Change inevitable

Hochman said he's not happy that the Manitoba government has allowed Dynacare to monopolize lab services, despite the fact it has happened in other provinces too.

"It is also disappointing in a country of universal healthcare that we allow people to profit off of people's blood and treat people as customers."

But Manitoba's health minister is in favour of the changes.

"Privately owned laboratories have been part of the health system for years and years, both here and throughout the country. We are focused on results, as we continue to do the necessary work to transform and modernize Manitoba's health-care system," wrote Minister Cameron Friesen in a statement.

But Kincaid wonders how much thought went into what it will cost Manitobans like him.

"To get out of bed just to plan your day around one appointment? It's a lot at times," he said.

"Don't take anything for granted. Be grateful for what you got. Because you don't know what tomorrow may bring."



Health Minister Cameron Friesen said that Dynacare's private lab model is part of modernizing health care for Manitobans.



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To learn more visit the link from our website at www.cdbanational.com. Thank you for your support in ensuring that, "All people who are deafblind will live rich meaningful lives."

Intervenors Provide 'Independence' to North York's Deaf-blind Community

By Aaron D'Andrea

Nazar Strejko likes to play the drums.

A few years ago, the 77-year-old retiree took lessons on how to play the instrument and can do so confidently — despite being both deaf and blind.

Strejko has Usher syndrome, which is a genetic disorder that causes vision and hearing loss over time. He has some hearing using a cochlear implant but is blind.

He lives at the Canadian Helen Keller Centre's residential facility in North York and is completely independent with the help of the centre's intervenor staff.

"I can do a lot of things when I have intervenor services," he said through intervenor Lacey McMaster. "For example, today I'll be going to the gym and will do other things, too. I can go out anywhere I want."

An intervenor is professionally trained to provide auditory and visual information to persons who are deaf-blind. They act as the eyes and ears, providing information about the environment and



Nazar Strejko, 77, who is deaf and blind, laughs with intervenor Lacey McMaster after making a joke about an old portrait in his apartment at the Canadian Helen Keller Centre in North York.

surrounding circumstances to their client.

Depending on the level of vision and hearing loss an individual has, different communication methods are used, said Canadian Helen Keller Centre executive director Jennifer Robbins.

For Strejko, he uses "two-hand manual" to communicate. The sign language

uses points on the hand to identify letters in the alphabet, so the users spell everything to communicate.

"Deaf-blind people can do anything. They can participate in society, they can be active members of their communities with intervenor supports and they're just like you and me," Robbins said. "They certainly have opportunities for independence."

McMaster is one of more than 50 full-time and part-time intervenors the centre employs to look after the 16 residents in its Willowdale Avenue residence and 18 outside members who use the service.

She previously worked in textbook publishing when she decided to seek a career change and came across an intervenor program at George Brown College in Toronto.

"I thought it sounded like the most different thing possible to what I was doing at the time," McMaster said. "It looked rewarding and looked like every day would be different, which it is."

One of the biggest misconceptions



Intervenor Lacey McMaster listens to Nazar Strejko as he plays the bongos inside his apartment.

about the deaf-blind community is that they need 24-hour support.

The Canadian Helen Keller Centre is working to fight back against those misconceptions by raising awareness about the deaf-blind community, Robbins said.

“Many of them have jobs, families, but certainly with the support of intervenors

they can participate pretty fully in society,” she said.

In addition to its residential facility, the organization runs a training centre on Empress Avenue where staff provides training on technology, communication, orientation and mobility and more.

The charitable organization has grown over the years and is looking for a bigger space in North York so it can have more office space, program space, parking and, most importantly, residential space, Robbins said.

“We have people on our waiting list,” she said. “As I said to you before, we’ve been open since ’92 but we’ve only had about 12 vacancies since then.”

Sometimes when McMaster is out with a client, she finds people will ask her questions about how she is communicating with



Strejko communicates with an intervenor using two-hand manual.

someone rather than directly asking them. She wants that to change.

“They love being asked these questions, they want to engage with people,” she said. “So instead of just watching and wondering what’s going on, (don’t be) afraid to actually approach and be direct and ask those questions.”



Nazar Strejko communicates with intervenor Lacey McMaster using two-hand manual.



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The Burnout that Special Needs Parents Experience

By Heather McCain

I think most parents probably feel burnt out at some point while juggling all of the responsibilities that parenthood brings. It seems there is always a never-ending list of things to do, but never quite enough time to get it all done. Parents of special needs children have lists that are a bit longer, but still have only 24 hours in a day.

Our lists include medication administration, regular appointments, multiple forms of therapy, paperwork, unending phone calls, IEP meetings, learning to use and then using medical equipment, and so on. We often need to feed, change, or bathe our children who are well beyond their pre-school years. We need to make sure we don't run out of the medications that our child's life depends on, or diapers in a size that can't be bought in a store and must be purchased from medical supply companies. When we plan outings, we must make sure our destination will be accessible for our child. If you can imagine, I've only just put a dent in all the extra things a special needs parent must do, remember, or know.

Before anyone gets the idea that I'm complaining, I want to make sure to be clear that that isn't what this is about. I'm just sharing experiences. I understand that it can be hard for those who have not lived this life to grasp what our day-to-day routine consists of (I use the word "routine" loosely) so I wanted to try to paint a picture as I'm getting into what this is all about, which is the burnout that special needs parents experience. This is something that I personally experience, and that I hear or see other special needs parents talk about often.

I'm not talking about that exhaustion at the end of a long day.

I don't mean the needing a cup of coffee or two, or three kind of exhaustion.

I mean that deep down, all the way to



your core exhaustion that creeps into your heart and mind, the kind that's already there when you wake up in the morning.

It's when you're so burnt out that you can't even bring yourself to open a piece of mail or check your voicemail because you can't fathom adding one more thing to your list, not even a seemingly tiny task like returning a phone call.

It's the kind of exhaustion you feel as you wake up to change a diaper and bed sheet in the middle of the night, like you have for the past 9 years. Or 20. Or 42.

It's letting go of careers and plans.

It's feeling like you have little control over what happens to your child, when you desperately want to protect them.

It's handling meltdowns like a pro in public and hiding in the bathroom to cry later.

It's watching monitors until the sun rises, even though you've been awake for approximately 29 hours already.

It's waking up at 4 a.m. to make it to your child's appointment at the specialty

doctor 5 hours away.

It's the heavy guilt of being away from your other children as you sit in the hospital with one, weighing on you like a boulder.

It's being afraid of the future but learning to live in the moment—Who will take care of my child if something happens to me? What if my child outlives me? What if I outlive my child? Breathe. My child is here with me now. Enjoy this moment.

It's falling into bed thinking, "how can I keep doing this every day?" Then, getting up the next morning to do it again.

It when our health suffers, mentally and physically. Depression and anxiety are common in parents of special needs children, and lifting a growing child and equipment such as wheelchairs takes a toll on one's body over the years.

The burnout is real. I'm not telling you about it for pity, I'm simply sharing the reality of many with you. And it has nothing to do with how much we love our children. Trust me, we love them so

much that we put their every need above our own. We love them so much that we wouldn't trade being their parent for the world. Know what else? You will probably never recognize how burnt out we really are on the inside when you see us with our children. That's because you will see us playing peek-a-boo, or beaming with pride over them, or kissing their soft cheeks over and over just soaking in all the love they offer. You hear the praises

we give them and how we gush over every little thing they do. The burnout is real, but so is the unconditional love between us and our children.

You see us in the moments that keep us going, the moments that make all of the hard parts worth every second. But rarely does anyone see us at our most vulnerable, so rarely does anyone notice how burnt out we are.

The next time you see a parent of a special needs child, instead of saying, "I don't know how you do it" (trust me, we're not even quite sure how we do it), or "I couldn't do what you do" (trust me again, you could if it were your child), consider smiling and telling us we are doing a good job. Sometimes, that's all we really need to hear to keep on keeping on.

The Grief of a Special Needs Parent

By Heather McCain



It's so early that it's still dark outside. My husband wakes our son up and lifts him over the rail of his bed. He begins to change his diaper while I gather his outfit and medication for the day. We then feed him breakfast, and let him practice eating finger foods. Then we brush his teeth, clean his face, and dress him.

My husband then begins to walk him to the car, but my son decides he doesn't feel like walking and plops on the ground, refusing to budge. So, my husband lifts him from the ground, carries him to the car, and straps him into his carseat. I double check that his stroller is in the trunk and then run back inside because I realize I forgot the bag with his diapers, change of clothes, sippy cup, and toys.

You probably think I'm talking about my infant or toddler by now, but I'm not. My son will be fourteen in just a few months. Getting him up and ready for the day has been a daily routine since he was born. My son depends on my husband and I for nearly every need. Since he is non verbal, we have to be very aware of his cues that he needs or wants something - facial expressions or actions that we have learned mean specific things.

The other day, I got together with a friend who's son is just a few days older than mine. Her son is outgrowing his parents, and he is a football player. I enjoyed hearing about what he is up to, and was so proud to hear about his accomplishments. That night as I

diapered my son and then wrapped my arms around his tiny frame I couldn't help wondering, though. Would our boys have had sleepovers and been great friends? Would my son have played football, or any sport? He loves balls of all kinds, maybe he would have played basketball, or baseball...

Then, I pull myself out of it. I wonder sometimes, but ultimately I always know that he is exactly who he is supposed to be. There is no other version of my son - there is only the child I once imagined while he was doing flips inside of my belly - the healthy version - and the child that IS. Because, of course we don't imagine our children being born severely disabled. We don't even want to think about our child suffering, much less imagine it.

This is the grief of a special needs parent - the quickly passing moments when something, or nothing, makes us wonder, what if? What if my child could talk? What if my child could walk? Most heartbreakingly, for some, what if my child had lived?

And that's okay. It's alright to wonder. It's alright to grieve. Because once that moment passes, we look at our child, just as they are, and wonder how in the world we got lucky enough to be their parent. That is the joy of a special needs parent.

Lessons From Charlotte's Web

By Frances Jablonca

Lesson #4

Not everyone knows dogs can't speak English!



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

I grew up having pets in the house. My mother loved German Shepherds in particular. Her father had bred and trained them as service dogs while she was growing up. She'd even tried her hand at breeding them a few times when I was a child. Cats, too, were always in the picture at our house as early as I can recall. I remember them walking across the kitchen counters, sitting in the sink, batting at the water droplets that dripped out of the faucet. Our large dogs were always up on the couch, keeping us children company while we watched TV programs. We appeared to be a pretty relaxed household; nobody seemed overly bothered by all the animal hair in the house.

While raising our own three children, we didn't have pets until they were school age. Charlotte's difficult first years with her high medical needs kept us pretty

busy. Furthermore, we quickly discovered that her older sister and younger brother had allergies to fur bearing animals. Charlotte, with all her Charge Syndrome related complications, oddly, didn't. Not wanting a totally pet free house, we eventually acquired hamsters and fish that were contained in cages and aquariums. However, contrary to the excitement her two siblings had about having pets, Charlotte did not engage with these small creatures. I had wondered, could it have been that her lack of fine focus was a significant factor to her indifference? Being such an animal person myself, I was grateful to one of the intervenors that worked with Charlotte, for gently and thoughtfully exposing her to her own larger pets. Linda had 2 dogs and two cats, so when Charlotte went over for visits and sleepovers, Linda made it a goal to facilitate interaction between Charlotte and her animals. While still not ecstatic about either, Charlotte seemed to tolerate cats somewhat more than dogs. I thought that the fluidity of movement with which cats moved was perhaps a factor. Most dogs tend to be enthusiastic greeters and often they startled and destabilized Charlotte (whose balance was already compromised) with a whack from a long wagging tail, or a wet nose and slobbery kiss to her face out of nowhere.

Still, I felt we needed our own dog, with the hope that we could instill some enthusiasm and affection in Charlotte for animals. As an aside that has some relevance, Charlotte hadn't naturally cuddled dolls or stuffed animals at the same age as her sister. When

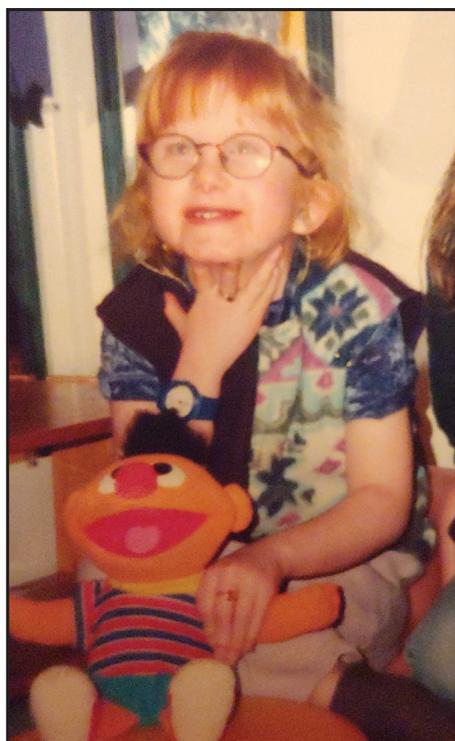
she did begin to mimic or develop the act of cuddling, depending on your view of whether this is a learned or innate behavior, what was unusual in Charlotte's case was her perception of what to cuddle. She seemed to understand that one is inclined to cuddle long rectangular shapes - the human body roughly being such - and the first thing she held in a cuddle position was a knife, then later



Pets provided hours of entertainment for Charlotte's siblings



a ladder-shaped toy! I conjectured that her lack of visual acuity hadn't taken into account the significance of the human face, or in the case of stuffies, even an



Large, color-contrast face like Ernie were her favorites

animal face. Eventually however, she did develop either the knowledge or skill to cuddle dolls. Her favorites always had very colorful, defined features; thus, it was Bert and Ernie dolls that were her babies. So, my thinking was that perseverance in the pet department couldn't hurt. Maybe in the future she might even want to use a guide dog. Then one day, while I was at her hairdresser, I overheard another client mentioning that they needed to get rid of two of their larger of four dogs as they were moving into an apartment. My ears perked up. This seemed to be the perfect opportunity to acquire a mature, non-shedding, trained dog. A few days later, I brought home our new Wheaten Terrier, Molly. And Dublin, her brother, went to my sister's home. Molly was a calm and sociable animal. She was a big hit with Charlotte's siblings, but Charlotte remained indifferent. She didn't appear to see what the big fuss was about having a dog in the house. She didn't care to pet her, or touch her in any way, nor make eye contact with her when Molly came close to her to greet her and be with her. The soft feel of fur may not have had the pleasurable sensation for Charlotte that

it has for many of us. Or maybe she just wasn't an animal lover!

Then an incident occurred a few months after we got Molly that was a big 'aha' moment for me about Charlotte's perception of pets. Charlotte had come home after school. Molly had gone to the door to greet her gently, her stubby tail not a potentially destabilizing threat, and went back to lay down in the kitchen. Charlotte, as usual, had not patted or acknowledged her and joined me in the kitchen. I gave Molly a pat and told her what a good girl she was. Charlotte must have been watching me carefully, because she turned to me and signed to me, asking, "what do you and Molly talk about?" and added, "I can't see her lips moving, she has so much hair on her mouth!"

I was floored! Had she really not known that a dog can't speak human languages? Did she wonder if all of our smaller pets had been able to speak? How did that important bit of info not get related to her? She had the awareness that our lips moved when we spoke, though she didn't lip read. She obviously thought that Molly had answered back, but just couldn't see her lips forming words.

Her question at once made me feel incredulous that this concept, which seemed so obvious that it shouldn't need explaining, was indeed knowledge that we take for granted in the hearing and world of perfect eyesight. And, at the same time, I felt a pang of sorrow so deep that it still brings me to close to tears, knowing that she was so reliant on others to fill those gaps. And also, how much trust she had to have in those around her to tell her about her world, albeit such seemingly simple things which we don't need to explain to our other children.

Sadly, Molly passed away after 2 years. But being ever hopeful that Charlotte just needed another opportunity to bond, but with a puppy this time, we came upon Louie, a small-breed cross, and took him home at 7 weeks. Charlotte didn't buy in with him either, unfortunately. Size was

not the issue here.

Regardless, the rest of us made him a welcome member of the family, but I continued to ponder Charlotte's apathy towards animals, or at least pets. One, that a pet needed my time and attention (especially if I was having meaningful conversations with it) which meant that there would be less time for me to interact with her. If this was the case, I could hardly blame her. She was utterly dependent on me as her primary caregiver to fill in all the voids in her world. Of course, she would feel somewhat resentful towards a dog taking up what compromised time I already had for her because of how much time basic living takes up. Secondly, how many more gaps in knowledge did she have that we were unaware of?



Why do I need to hold this dog?

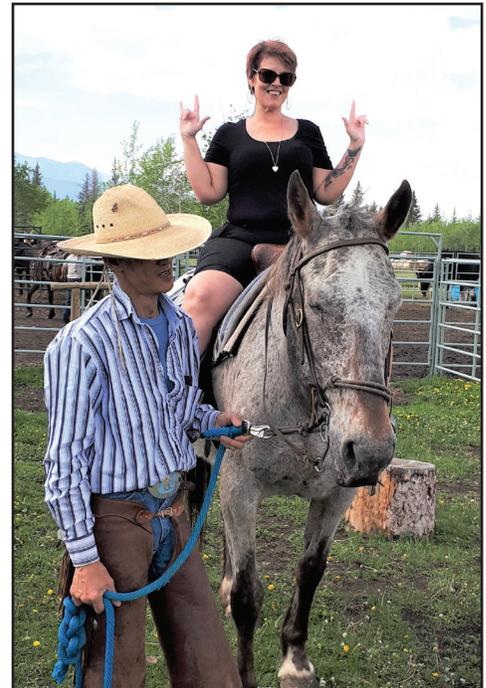
I am not sure if I had discovered the real reason that Charlotte didn't care for dogs. But that little event was a reminder that incidental learning doesn't occur naturally for deafblind individuals and therefore experiences need to be constantly planned into their life at home, at school and in the community. Families need to have the strong support of human resources because it is a big job. The more people who have input into communicating and teaching a deafblind child, the more rounded he/she will become and hopefully more of those knowledge gaps can be filled.

CDBA Chapter News

CDBA Alberta Frances Jablonca, *President*



CDBA AB Chapter held its 3rd Charlotte MacKinnon Memorial Wagon Ride in June at the Rafter 6 Ranch outside of Calgary, complete with campfire cook out. We were blessed with perfect weather – blue skies with just the right amount of cloud and a refreshing breeze to keep us and our trusty horses cool.



Throughout the year we continued to support our members with funding support for intervention and accessibility technology. At our 2019 AGM in Calgary last November, we welcomed Cheing Lo as our new Vice President. As well, we said farewell to our Board Secretary of 2 years, Kellie Cornforth and our Vice President, Julie Bierman, both of whom are owed a debt of gratitude for their hardwork and valuable input to our Chapter Board. We look forward to working on strategies to continue to serve our deafblind community in Alberta.

CDBA Chapter News

CDBA British Columbia Theresa Tancock, *Family Services Coordinator*



2019: A Year in Review

This past year has been a good one for CDBA-British Columbia. We continue to support children and youth with deafblindness through our two main programs, the Early Intervention Program and the Intervention Program. Through these programs, we are able to also offer Youth Transition support and fun-filled family activities and workshops.

Our Early Intervention Program supported 40 children, birth to 5 years old. This included home visits, daycare and preschool visits, educational workshops for families and professional teams and collaborations with other organizations and professionals.

Our Intervention Program supported 40 children and youth, ages 2 – 5 years, during the Spring Intervention Program, while the Summer Intervention Program, supported 57 children and youth and

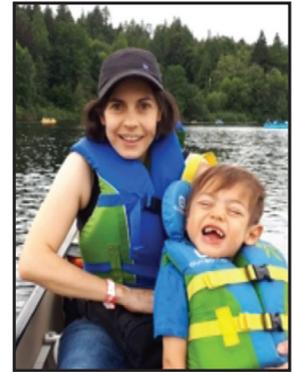
employed 65 Intervenors. We are now looking forward to our

Winter Intervention Program, which has 40 children and youth registered. Our Summer Recreation Program welcomed many children and their families to fun-filled venues, such as Science World, the Vancouver Aquarium, a water park and train rides, paddle boats and carousel rides and, of course, bowling. This is such a wonderful opportunity for children with deafblindness, their families and Intervenors to network and socialize.

The Youth Transition Program involves our participation in school transition meetings, facilitating PATHs and Representation Agreements and supporting families through their child's youth to adult transition.



This year we were also very fortunate to receive one-time-only funding from our funder, the Ministry of Children and Family Development. This funding allowed us to better support our Early Intervention Program, offering more direct service to our families, as well as our newly developed Sensory Clinics. Through this funding, we developed our own Snoezelen Tent, which was explored during our two Family Network Workshops. The children with deafblindness, their Intervenors and their families explored the Sensory Tent and other sensory activity centers, created experience books and participated in art therapy. The parents participated in informational workshops and sharing sessions with other parents. Our goal is to offer more Sensory Clinics throughout BC, as the benefits to the children, their families and Intervenors is fantastic!



Bowling continues to be the family activity of choice for us in BC. We offered Bowling Fun Days throughout the year and again incorporated it into our Deafblind Awareness Month and AGM Fun Day. This year, we collaborated with the DeafBlind Planning Committee, which increased the number of participants and fun! We also celebrated the blue lighting of two of our Lower Mainland buildings with dinner and a photo!

Our hope this year is to enhance Intervenor education, acquire further funding for youth transition support, enhance support for adults with deafblindness, increase deafblind awareness and, above all, continue to have fun!



CDBA Chapter News

CDBA New Brunswick Kevin Symes, Executive Director



It has been a busy few months here at CDBA-NB in Fredericton.

In August, consumers, intervenors and staff got to get on a bus and travel to St. Andrew's. We spent the morning browsing the local market, having lunch and then boarded a catamaran to go whale watching. We got to see 5 humpback whales that day, along with porpoises, seals and other unique sea creatures.

In September, once again, our Annual Camp was held in Richibucto, NB. This year's theme was Disney, where the cabins and tent were decorated in all different Disney characters. With 60 people in attendance, it was a weekend of laughter, activities, yummy food, catching up with old friends and making new ones. We saw a wonderful performance by Atlantic Cirque, who also showed us how everyone can be part of a circus with all of our unique abilities. Saturday night, the consumers, intervenors and staff got to dress up as their favorite Disney character, we saw Gus, Twiddle Dee and Twiddle Dumb, Queen of Hearts, Elisa and many others. Our camp spirit

award was given out and lots of fun was had while dancing the night away. It was another wonderful weekend for all and lots of memories made.

Our Snoezelen room continues to be busy as well. Some of our consumers and intervenors meet each Thursday for a time of fellowship, crafts, movies or playing games. Other consumers come in throughout the week on their own time with their intervenors to enjoy. It also has been busy with outside agencies coming in with their consumers to enjoy the many benefits of our room.

It was with great sadness that our past president Michael Stewart Sr. passed away on October 25th, 2019. Michael had a huge impact on CDBA-NB during his years of service and contributions. Michael will be sadly missed by all.

CDBA-NB would like to wish everyone a Healthy and Happy New Year!



Fredericton client's apple picking.

Matthew enjoying strawberry picking.

Dressing up as favorite characters.

Owen and Marissa cool off at Wilmot Splash Pad.

CDBA Chapter News

CDBA Saskatchewan Dana Heinrichs, *Executive Director*



Program Admin Assistant

CDBA SK Chapter has received funding for a new position. The addition of the Program Admin Assistant position has already been beneficial by assisting the Residential Program Coordinators in areas such as scheduling, training and the set-up of new employees. Also, assisting the Executive Director with things like payroll, reports, hiring and financial management. As time goes on, the role will evolve to meet the needs of the agency and fill in the gaps to continue building a strong leadership team.

At Kerr this fall, the ladies had lots of time to enjoy being outside, and loved their new Sensory Garden. They took good care of the lawn, their pretty flowers, and relished the nice weather until the very last day.

They were thrilled to attend the wedding of one of the management team, and dressed up every Saturday for a few weeks after, hoping to do it all again!

They participated in many fun days at Cosmo, doing some neat art activities when the contracts ran low, they made cards and Christmas Tree ornaments in anticipation of the holiday season.

The highlight of the year so far has been going to GLOW in Saskatoon, an interactive light display - some hanging, some on the ground they could step on, some flashing, some touch or motion sensitive, topped off with a fun visit with Santa.

The ladies are back to work at their volunteer work placements at Royal University Hospital now that the renovations are complete, and they really like their new work area in the just-opened Children's Hospital.



Healing with Occupational Therapy

After living in a state of anxiety from unknown causes for 3 years, EB was retreating more and more into a world of her own. Despite our attempts with many different treatments like: holistic and traditional, along with many different support styles - we just weren't making any progress. The situation was really effecting her quality of life and she could no longer participate; no more work, no more grocery shopping, no more dancing, No More Fun!

Then we found Thera-play...

An Occupational Therapy center that specializes in children's therapies. We contacted them to ask about treating an adult with global disabilities. The answer was 'absolutely', they have two therapists that specialize in this field.

So the process was started and although it took close to a year to gather all the information and history – you would have to say it was worth the wait.

Working weekly with our therapist on self regulation and engagement, the changes have been amazing. We are back to work and we have started grocery shopping again. She communicates her needs more effectively and seems happier over all. We still have more work to do and may never see the person she once was but this new woman is simply amazing. Hurray for Thera-play!

The Christmas season is here, which is a wonderful time to give back to the community. The Michael's Manor Individuals and Intervenors are making Christmas baked goods and delivering them to their community partners they work with, along with our neighbours. It is so great to live in a kind accepting neighbourhood like we do, so what better way to show our appreciation than hand delivered sweets.

Lots has been going on at Michaels Manor and this fall the plans for the perfect gift for a loved one began. So, before the weather turned too cold, Intervenors got creative and did a fun photo shoot in the park as a gift for his parents. They turned out fantastic and everyone enjoyed a day full of laughter and making memories.

As the Individuals needs change due to health or other circumstances it is always great to have the opportunity to find new programs to meet their needs. This fall one of the Individuals was able to volunteer with Street Cats Rescue Program, delivering flyers around the city.

First Global Report on Deafblindness

www.senseinternational.org.uk



The World Federation of the Deafblind (WFDB) has published the first ever global report on deafblindness in cooperation with Sense International, supported by the International Disability Alliance.

The report examines whether the rights of persons with deafblindness as recognised in the Convention on the Rights of Persons with Disabilities (CRPD) are being met by governments across the world. Despite impressive achievements by individuals and specialist organisations, regrettably the report finds that overall the issues faced by persons with deafblindness have largely been ignored and persons with deafblindness are being 'left behind', contrary to the principle underpinning the Sustainable Development Goals (SDGs).

Key findings

The report shows that around 0.2% of the world's population is living with severe deafblindness. Analysis of prevalence data also found that 2% of the world's population lives with 'milder forms' of deafblindness.

The research found:

- Persons with deafblindness are more likely to be poor compared to people with other types of disabilities and compared to persons without disabilities.
- Families and households that include persons with deafblindness are more



likely to be in the bottom 40% in terms of their socio-economic status.

- Persons with deafblindness are ten times less likely to be employed than non-disabled people, and 30% less likely to be employed than persons with other types of disabilities.
- Children with deafblindness are 17 times less likely to be in school than non-disabled children, and twice less likely to be in school compared to children with other types of disabilities.
- Between 20-75% of persons with deafblindness have additional impairments.
- There is a high prevalence of depression amongst persons with deafblindness, but low access to mental health services.
- Children with deafblindness are less likely to live with both parents.

- Persons with deafblindness are less likely to be married.
- Persons with deafblindness report a low quality of life and experience restrictions in participating in a wide-range of activities.

Case studies in the report provide insights into what is possible when persons with deafblindness are listened to, have access to health, education and training, and are supported to participate fully in the life of their community.

Recommendations

The evidence contained in the report confirms there is a disability and development gap. While the adoption of the SDGs in 2015 demonstrated a growing momentum for change based on inclusion, concerns remain that national development efforts will continue to exclude persons with



Abul runs a shop in his village due to similar work by Sense International in Bangladesh.



deafblindness.

Recommendations of the report are centred around seven key areas; pre-conditions for inclusion, social protection, education, health, work and employment, political participation and social participation.

Report Methodology

Persons with deafblindness from across the world contributed to the report. The

statistical research was led by a team from the London School of Hygiene and Tropical Medicine.

The statistical research was led by a team from the London School of Hygiene and Tropical Medicine. The full report is based on prevalence estimates of deafblindness for 22 countries, in-depth analysis of 11 countries, an academic literature review, surveys and case studies. In total, over 97.6 million people were included across the 22 datasets. This represents the

largest population-based analysis of deafblindness conducted to date and includes evidence from a variety of regions and country income groups.

Next steps

The WFDB, in coordination with Sense International, aims to publish follow up reports every four years until 2030, to monitor progress on realising the rights of persons with deafblindness according to both the CRPD and the SDGs.



Renew your membership or become a member of CDBA at

www.cdbanational.com/become-a-member

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In Memory of Michael Stewart Sr.



L to R: David Brown, President CDBA-NB; Michael Stewart; Kevin Symes, Executive Director, CDBA-NB

Michael Stewart Sr. of Harvey, New Brunswick passed away quietly on October 23, 2019 in a local hospital while being treated for an undisclosed illness.

Mike, as he was affectionately known, became part of the CDBA New Brunswick family in 2001, when his son Michael Stewart (MJ) began to receive Intervention services. He joined the CDBA-NB Board of Directors, served as Board treasurer and then as Chapter President. In 2006, Mike received the CDBA-NB Community Volunteer Award for all his hard work and dedication. He and his family played a major role for many years fundraising at liquor stores in Fredericton and participating in Bowl-a-thons. In 2008 and 2013, Mike received the CDBA-NB Board Volunteer Award.

For many years Mike played a major part in CDBA-NB/PEI's annual camping experience for deafblind consumers, intervenors and families. He picked up donations, recruited volunteers for camp, assisted with cooking, barbecuing, clean up and more. Mike also served as President of the NB

Deafblind Center of Excellence until it merged with CDBA-NB a number of years ago.

Mike attended many conferences on behalf of the NB Chapter- the DBI World Conference in 2003 in Mississauga, Ontario and in 2008 a Parent Conference hosted by Sense Scotland, as well as workshops/retreats hosted by CDBA-NB.

In the CDBA-NB Chapter brochure, "Who we help ... And what we do", Mike's son is quoted:

"I am determined to keep my independence. CDBA-NB has done so much for me that I can't describe in words. CDBA-NB has done so many great things that have turned my life around. When I was 12, before I received CDBA-NB services, I was too shy to go out in the public to socialize and meet new people. For the past 10 years or more, I have been receiving CDBA-NB services, and I have gained a lot of confidence in my ability to lead an independent life. To be honest I can't be sure I would have my Proctorship in residence, if it hadn't been for CDBA-NB teaching me how to communicate with hearing people more efficiently"

In May 2019 Mike received an honorary lifetime membership in CDBA-NB (shown below). Our thoughts and prayers have been extended to his family on behalf of his legion of friends and colleagues at CDBA. Rest in peace.

CDBA National Cherry Bulmer Award

This award is presented to an individual, group of individuals or an organization that has made an outstanding volunteer contribution to the Canadian Deafblind Association at the National and/or Chapter Levels.

This award has been named after Cherry Bulmer in recognition of the passion, enthusiasm and commitment to which she dedicated her time and effort to this organization.

For more information and Nomination Form, contact the CDBA National Office info@cdbanational.com





Canadian Deafblind Association 2019/20 Board of Directors



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All people who are deafblind will live rich meaningful lives.



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