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Edition 45, No. 2 Summer 2022

## Intervention



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## Connecting the World One Stitch at a Time: Yarn Bombing

Throughout June, large trees, fronts of buildings, fences, and lampposts in community spaces around the world were decorated with vibrant knit and crochet squares – a form of street art known as yarn bombing – to raise awareness about deafblindness.

Regions from countries like Africa, Argentina, Australia, Brazil, Canada, Croatia, France, Germany, Greece, Guatemala, India, Ireland, Italy, Paraguay, Switzerland, and the United Kingdom to name a few, took part in Deafblind International's (DbI) second yarn bombing movement. Participants fostered connections and united a community with individuals, service and advocacy groups in the field, DbI members and partners, and the wider global public.

By coming together to yarn bomb objects in as many cities and countries as possible, this unique awareness initiative connected the world one stitch at a time.

Check out #DblYarnBombing2022 on social media and learn more about Dbl at www.deafblindinternational.org.















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The Canadian Deafblind Association (CDBA) was formerly known as the Canadian Deafblind and Rubella Association (CDBA). "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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## **Message From the CDBA National Board of Directors**

Carolyn Monaco, President



Welcome to the summer issue of "Intervention" magazine! We want to draw your attention to a few things that have earned our attention in recent months.

The first surrounds the announcement of the "CDBA Wayne Turnbull Memorial Scholarship" about which we are very excited. Established earlier this year, this scholarship honours the legacy of Wayne Turnbull, who was deafblind and a Board member of both CDBA National and the CDBA Alberta Chapter. Wayne was a lifelong advocate for individuals who are deafblind and their Intervenors. The scholarship will be awarded to a deserving student in any area of Intervenor Studies through an accredited educational institution, whether the program is offered in-person or online. More details are provided on page 24 of this issue. For an Application Form, go to the CDBA National website <a href="https://www.cdbanational.com/awards">www.cdbanational.com/awards</a>.

The second is the virtual **CDBA National AGM** scheduled for Saturday, September 24, 2022 via Zoom. CDBA members will be receiving the agenda, registration and program information via email at the end of August. All registrants will receive a Zoom invitation the week before the meeting. If unable to attend, we strongly urge you to complete the Proxy Form, then scan and email it to CDBA National Office info@cdbanational.com.

Finally, the **18th Deafblind International World Conference** is coming to Ottawa, Ontario from July 22 – 28, 2023, the first time this prestigious event has been held in Canada since 2003. The Conference will be a hybrid affair, which means you can attend in person, or virtually! Visit their website www.deafblindnetworkontario.com.

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## HOLD THE DATE! 47th ANNUAL GENERAL MEETING

## **CANADIAN DEAFBLIND ASSOCIATION (National)**



Saturday September 24, 2022, 1:00 pm – 3:00 pm EST Virtual meeting via Zoom

Look for Registration, Program & other information to be posted in the coming weeks www.cdbanational.com

## **Editorial From the National Executive Director**

Tom McFadden



As we and the world around us slowly emerge from the pandemic, Canada's charitable sector, and that includes CDBA, is taking stock of COVID's impact, particularly with regards to donations and fundraising. According to the respected Veritas Foundation, the results are a mixed bag. Revenues in the sector, particularly from donations and fundraising, fell sharply in 2020 but recovered nicely towards the end of 2021 and into the spring of 2022. Going forward, CDBA National will continue to search for new ways to address the economic challenges ahead.

#### Inside this issue

With that, I welcome our readers to this summer 2022 issue of "Intervention". Within its pages, we once more spotlight the unique Deafblind Awareness Month initiative of Yarn Bombing which connected the world "one stitch at a time"; the 9th installment of "Lessons from Charlotte's

Web" continues to educate with a realistic "lived" focus on growing up with deafblindness, as does an inspirational piece about the plight of a deafblind child in Africa.

From the world of amazing, we learn how an engineer with a passion for special needs communities developed a robotic signing arm for those who are deafblind, and how a 15-year-old digital artist created an NFT (non-fungible token) collection "Spark" and released it on the anniversary of famous deafblind author and activist Helen Keller, about whom we disclose some little-known facts.

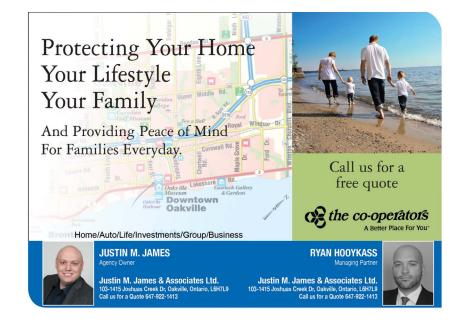
We also share with readers a heartwarming book by a deafblind Catholic priest (Usher Syndrome) that offers greater insight into the lives of the deafblind community with insightful and hilarious stories, as well as how the family of a child born with CHARGE Syndrome has navigated through many challenges in search of appropriate resources by "thriving through connections".

#### June 2022 as Deafblind Awareness Month

June 2022 marked the 8th anniversary since the Senate of Canada recognized June as Deafblind Awareness Month. In addition to the many celebrations and proclamations in towns and cities across this country, the focus by CDBA chapters was on "Yarn Bombing" - a Dbl global initiative that inspired immense interest in more than 20 countries around the world. For the first time in 3 years, the Senate hosted a "meet and greet" on June 16th in Ottawa attended by representatives of service organizations in the field of deafblindness.

I leave you with this thought: One can learn much about a person by the quality of friends he keeps...Author unknown

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## Deafblind Former Catholic Priest Cyril Axelrod Launches His Third Book

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The room was filled with laughter as he shared heart-warming, insightful and hilarious stories from the book.

Cape Town - With the launch of his third book, deafblind former Catholic priest Cyril Axelrod hopes to show a life filled with colour and adventure, as well as a greater insight into the lives of the deafblind community.

Axelrod, the author of And the Journey Begins, launched its sequel, Still on that Journey, at Park Inn by Radisson, Newlands, on Wednesday.

Turning 80 next week, he was born deaf and has ministered to deaf and deafblind communities across the world, including South Africa, China and the UK.

In 1980, Axelrod was diagnosed with Usher Syndrome, which leads to progressive blindness, and became

completely blind in 2000. Axelrod uses his hands to interpret the sign language used by a speaker or through his communication assistants.

"I was born with Usher Syndrome, which is progressive blindness through retinitis pigmentosa. I didn't realise that until I was about 50, but I have been blind for 22 years completely, and it progressed from when I was 50."

The room was filled with laughter as he shared heart-warming, insightful and hilarious stories from the book.

"It's full of life to show that I am full of life. I wondered why I should continue, but I came to realise that the book would broaden awareness of deafblindness for all people," Axelrod said.

"It's very important to accept disability. "Remember that disability in itself is part of the gift of life. It gives you the opportunity to become aware that disability is something to help you to open your eyes and ears to understand what others need from you, and also it helps all people to change their views.

"Most people are afraid of disability – change that. Help them to feel comfortable with disable people," Axelrod said.

In November 2013, Axelrod was awarded the Officer of the Order of the British Empire by Queen Elizabeth II for work done in developing training programmes for Deafblind persons, and rehabilitation services with Deafblind people.

Axelrod also summited Machu Picchu in Peru while completely deafblind, with the help of guides over the five-day journey.





Cyril Axelrod, 79, chatting to supporters at the launch of his new book, 'Still on that Journey'.

"Just before I became blind, I remember that in London I could see a candlelight and it became dimmer. That was the last moment of my sight. The candle flame became dim and that was it," Axelrod said.

Now, he paints from memory using string and glue to outline the images he intends to paint.

Editor and publisher Larry Kaufmann said: "I have known him for nearly 50 years, and I have been a very close friend of his, and one thing I realised just

by interpreting for him with people was how much he inspired them.

"I said to him, 'you must not limit your outreach to other disabled people, because we all need your message'. And from that moment, he started expanding his horizons, and that's when he started writing books for people who have never been deaf or blind to give them some experience of it."

DeafSA Western Cape Provincial Director Jabaar Mohamed said he was left with goosebumps as Axelrod shared anecdotes from the book - all filled with humour and insight.

"He gave us a lesson that nothing is a limitation... Cyril had reached so many ambitions, spreading words around the world about deafblindness and what he is capable of doing. He is such a good role model!."

Still on that Journey is available online for R200 including postage at Redemptorist Pastoral Publications (rpp.org.za) or at orders@rpp.org.za.



## **SAVE THE DATE!**

The 18th Deafblind International World Conference is coming to Ottawa, Canada on Saturday, July 22 to Friday, July 28, 2023!

With the theme of "Global Connections: The Future in Our Hands" the conference will be a hybrid affair, which means you can attend in person, or virtually!

Our hope is to connect with more people than ever before. As more information becomes available you can stay informed by visiting

our social media channels and our website at deafblindnetworkontario.com/. Canada welcomes you to join us in our beautiful national capital, Ottawa, Ontario in 2023. Let's stay connected, the world is at your fingertips.

## **Thriving Through Connections**

Donia Shirley sites.ed.gov



Donia Shirley, Vice President of the National Family Association for Deaf-Blind and parent of Jaxson, a child who is deaf-blind.

When a baby is added to a family, invisible bonds often quickly form with others who have children the same age. For families who have children with complex support needs, that community can seem out of reach, especially when they have a child with a low incidence disability such as deaf-blindness.

A few days after our 6-week-old son Jaxson was transferred to our local children's hospital, we started receiving diagnoses. We learned he was deafblind; he was profoundly Deaf and had colobomas (an eye condition that cannot be completely corrected). The medical

team eventually informed us that Jaxson had CHARGE Syndrome.

We did not know anyone who had a child with a disability and felt lost. The community we had built when we had our older son, people we could call on about changing diapers and warming milk, didn't understand our new situation. We now had a child with a tracheostomy and medical issues who was deaf-blind, and we didn't have anyone to turn to.

We decided to look for information about CHARGE and immediately found the CHARGE Syndrome Foundation. Within a few hours of registering, I received an

email from one of the staff members. This was an incredible moment and one of the first times I realized that having connections with other families would be vital for our family's survival.

After connecting with the foundation staff member, I looked on social media and found another family who had a child with CHARGE. Connecting with a mom who had a young child with CHARGE who was thriving gave me hope for Jaxson. Seeing a child with CHARGE who was walking, communicating, and doing all the things his doctors told us he might never do was a big moment and motivated us to keep going in those early days.

Jaxson spent his first six months in the hospital, and during that time, he received inpatient therapy services. Early on, there was a moment when I recognized that our role in his care was critical. We were working on having him hold his head up, and when he finally met this huge milestone, the occupational therapist acknowledged his hard work and what we were doing with him daily to help him develop.

The more I learned about how to support Jaxon's growth and development, the more I realized that our family would be his biggest champions, working to advocate for his future. If we didn't join him in his hard work and connect with other families and professionals who could help us, he wouldn't be able to reach his full potential.

At 6 months old, Jaxson was released from the hospital, and we started working with the early intervention system. Unfortunately, none of the personnel we encountered had experience with a child who was deafblind. I set out to find resources, such as a teacher of the visually impaired, a teacher of the deaf/hard of hearing,

and the state deaf-blind project—the Florida and Virgin Islands Deaf-Blind Collaborative. The project helped us find the resources and services Jaxson needed.

Without support, it's hard to find your footing. Making connections with families is like a snowball effect: You start to feel more connected the more you build relationships. Suddenly, you have a community, and those supports and relationships are vital to helping the whole family thrive.



I learned the most about deaf-blindness once I found and began networking with the National Family Association for Deaf-Blind (NFADB). NFADB educated us about the services that Jaxson would need and provided access to

professionals who helped us learn about effective strategies for children who are deaf-blind and showed us ways we could replicate them in our work with Jaxson.

Over the years, we have encountered a lack of qualified professionals and, as a result, decided to withdraw Jaxson from the public school system and create a learning environment for him at home. Thanks to support from the Family Empowerment Scholarship, we put together a terrific educational team of therapists, teachers, and individuals

who work with Jaxson. They see him as an individual and not a specific diagnosis. Since starting his homeschooling two years ago, Jaxson has made tremendous progress. He can now write, identify,

and spell about 80 words, communicate using sign language, and recently taught himself Braille (without explicit instruction). He has an amazing speechlanguage pathologist. She's taught herself braille and sign language to

support Jaxson more effectively. He is thriving, our family is thriving, and we have found our footing.

We wouldn't have been able to come this far without the support, knowledge, and connections we found through family organizations, our state of Florida's deaf-blind project, the Texas School for the Blind and Visually Impaired's online resources, and the National Center on Deaf-Blindness. No one prepares you to have a child who is deaf-blind or who has CHARGE. We knew nothing before we connected and engaged with other families and the people at these organizations. Thanks to those connections, we are now confident in our ability to be strong advocates for Jaxson. It truly is all about the connections—for us and for Jaxson.

## **Canadian Deafblind Association National Support Fund**

### **Purpose:**

The purpose of this National Support Fund is to provide CDBA members living in Canada who are deafblind with another funding option 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
- Other services or equipment resulting from specialized or unique circumstances

The funds provided are short term and are to supplement other sources of funding. They are not intended to replace funding which may be otherwise available nor are they to be of an ongoing nature.

#### **Emergency**:

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

#### Supplemental:

will be defined as—adding to other funding sources which may be insufficient to cover Intervention Services during short-term hospital stays or specialized education or recreational programs, the cost of such programs or specialized equipment etc.

### **Criteria for Funding:**

Persons Qualifying:

- Those individuals who have been identified as deafblind and/or in a deafblind service program.
- 2. The individual or their immediate family must be a member of CDBA for a minimum of six months

prior to the submission of the funding application.

### **Application for Funding:**

Requests for funding may be received from any source on behalf of any qualifying individual from across Canada. The application form is available for download on the CDBA National website www.cdbanational.com or by contacting the CDBA National office info@cdbanational.com or by calling (866) 229-5832. Requests must be submitted in writing.



## **Lessons From Charlotte's Web**

By Frances Jablonca

Lesson #9

Blindness Doesn't Mean You Don't Notice.



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.

Recently I had a memory come up on Facebook that inspired this lesson. It was a photo of Charlotte that I had posted in the early months of grieving her passing. She was around 5 in the photo, sitting on a wicker couch on our back deck, dressed in a whimsical outfit that was one of my favorite hand-me-downs from her older sister Madeline. She was also wearing the cutest pair of yellow kid's plastic sunglasses, complete with a Sylvester the Cat shape on the nose-bridge. She looked adorable, but more notably for my story, the lenses of the sunglasses were poppedout; she is only wearing the colorful frames.

My memories of Charlotte's "popped-out lenses phase" then came flooding back and I then found more photos with different pairs of her signature look and began to reflect on this quirky phase she went through. She did use sunglasses with lenses as well when out in the sun since

she was very sensitive to bright conditions. Her pupils couldn't properly contract. This was due to her colobomas, which means her irises didn't properly close in a full circle, leaving a gap at the bottom of her irises. Thus, her pupils had a keyhole shape to them, a common defect of Charge Syndrome

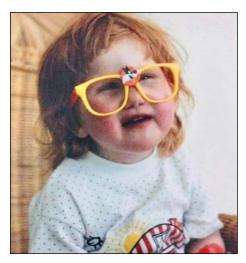
Charlotte's fascination for eyeglasses started when she was a toddler. She was medically stable by then. Her heart medication was effective and her G-Tube kept her nourished and growing and she was showing quite an interest in eating now. Her oxygen levels were still frightening low, hovering at the low 80 precent, until the time she would have a two-part open heart surgical procedure.

Despite it all, life was pretty good. We were all learning ASL and were delighted at how interested she was in socializing. She would happily roll or crawl into



Can I borrow your glasses?

anyone's lap to interact with them, and she was especially intrigued if they were wearing eyeglasses. She would sweetly lift the glasses off the visitor (Rob and I didn't wear glasses) who was holding her and gently place them correctly on her own face with no hesitation or difficulty. Everyone was happy to oblige, although the length of time they would indulge her depended on how bad their visual acuity was.



If a person happened to hand them to her upside down, she instantly righted them and slipped them onto her face. I thought for sure she would have needed more time to problem solve the upside-down aspect of the slim, almost colorless wire arms curving upright. It amazed me that with her difficult optics she was still able



to manipulate those subtle relationships of space and shape. Normally, because of her poor vision, she was attracted to larger objects of highly contrasting colors.

Then life became all about the eyeglasses. She just really wanted to wear glasses. Wire-rims were all the rage then. All the important people around her were wearing them. Her older sister Charlotte would insist on trying on her aunts', uncles' and grandparents' glasses on, and pretty much anyone else's who came by sporting

eyewear. Eventually, we decided it might be prudent to find a substitute for her, rather than risk a costly potential mishap with someone else's essential mode of vision. Somehow the idea surfaced that we could offer her a budget-friendly alternative - her children's sunglasses with the lenses removed. Thankfully she didn't insist on the wire rims.

She would eventually be prescribed glasses by the ophthalmologist for her very mild astigmatism. Unfortunately, there was no prescription that could rectify the real culprit for her 20\200 20\200, legally blind vision, the afore-mentioned colobomas.

I was so pleased that she was obviously expanding her learning circle and not stuck with emulating only me - her main role model for so much. (You can read about her relentless, but flattering, stalking of my footwear in Lesson #3). Also, it was encouraging to see how she was both observant and coordinated. Parents of



I have my own glasses so now I look like you



children with special needs will relate to how grateful one is for every accomplishment our children have with such difficult and complex challenges. Nobody can ever really predict for us what they will be able to achieve in their lifetimes. And eventually she would be quite adept at a plethora of fine-motor activities such as

playing cards, cutting up vegetables for salads, manipulating her computer magnifying program, participating on Facebook, and operating her own cell phone.

Her ability to orient the upside-down glasses so easily, probably shouldn't have come as a surprise to me as she was already using this spatial and directional awareness to learn sign language. She had, after all, started signing 'mom' by 9 months of age. (Oops! I think I am bragging now!) But bear with me here as I comment on how Charlotte observed that people could have accents in ASL, and moreover, that she would facilitate those accents. The first time I noticed that she signed 'mom' 2 ways, was when I saw her sign it differently with her Intervener. Linda was a professional interpreter who worked as an assistant with Charlotte 3 to 5 mornings a week when Charlotte was 3 years old. (We were so fortunate to have such a strong ASL role model at Charlotte's young age to build and develop her language.) In Linda's presence, Charlotte would sign 'mom' precisely how Linda did, which was slightly different from how I had learned and taught Charlotte. Our family signed mom with our open hand perpendicular to our faces, but Linda had her hand positioned parallel to her face.

Her aunt and uncle, one of the wire rims couples, whom she adored, also had some idiosyncrasies with their basic signs, which Charlotte recognized were unique to them.





Everyone I love has glasses.

With my sister, Charlotte would always sign the color 'pink' exactly how my sister signed it, with her middle finger tapping her lip and the rest of the fingers down in a fist. Basically, it looked like how one might give someone 'the finger'. Rather, 'pink' is made by signing the letter "K". where your middle finger touches your lip and your pointer finger is in front of that finger. Her uncle had an 'accent' too, when he signed goodnight, which did not escape Charlotte's attention. Uncle Brian would flop his right hand off and down to the left, instead of the typical straight-ahead motion and down below the horizon. It was guite humorous to watch her sign goodnight the typical way to each family member, until she came to Uncle Brian, where she would flop her hand goodnight sloppily off to the left. Besides observing these subtle details, what an excellent communication skill she was practising.

Noticing can mostly certainly happen, regardless of what we presume and when we might least expect it to.

## Plight of a Deafblind Child in Africa

Simate Simate

www.newsday.co.zw



MANY people do not know that there is a disability called deafblindness. It is a unique and dual sensory disability that arises from a combined loss of the sense of hearing and the sense of vision.

It restricts the ability to access visual and auditory information, communicate and to move and locate objects in one's environment. As a result, people with deafblindness lead isolated lives and little is known about them, especially in Africa.

For instance, there are hardly any available statistics on deafblindness and specialised services to support the functioning of deafblind people are poor in Africa and other countries of the global south.

A child with deafblindness in Africa usually lives like an outcast. To begin with, limited child health care services means that parents do not usually notice that their child has a combined sight and hearing loss.

Many times, only one impairment, usually the visual impairment, tends to be apparent. If they happen to detect both impairments, it is usually at a much later stage and by this time the child will have suffered the consequences of their misconception about their disability. Stigmatisation and labelling is common in many families where disability is still conceived as a misfortune.

When the couple realises that they have a disabled child, mothers are typically abandoned to raise the children on their own. This is a serious problem in several countries where there is no social protection and the mother has no established source of income.

Unlike most fellow children with deafblindness, I was lucky enough

to have an educated, working and caring father who supported me in my education. By the time he died, when I was doing my junior secondary school, he had built a foundation for my upbringing.

My disability nevertheless haunted him. I would hear my parents whisper their helplessness and despair when I lost a great deal of my hearing and sight at the age of 10 and 15, respectively. It was a miracle to them that I continued to pass at school despite my deteriorating senses of sight and hearing. This is what encouraged them to keep me in school. They concentrated on enhancing my ability, rather than limiting me because of my disability.

Severe congenital deafblindness is usually mistaken for mental disorder or hyperactivity because of a deafblind child's inability to perform visual and auditory tasks performed by their peers.

Mind you, this is Africa where there are still several myths about disability and its causes. This includes the belief that disability is caused by witchcraft and is a source of abomination to the family. Such myths usually make a family withdraw their child from the public eye when they discover that their child has deafblindness, a strange and perplexing disability.

Extreme home confinement of deafblind children isolates them from peers and deprives them of information and communication. This is how I developed the habit of talking and smiling to myself even when there are people around me. It is embarrassing when people around you discover that you are in your own world and communicating with imaginary friends.

This behaviour can be addressed by actively involving deafblind children in outdoor activities that promote self and

community identification of deafblind people.

Outdoor activities also build peer relationships, stimulate intellectual development and promote health through physical exercises.

Similarly, home confinement of deafblind children with the view of protecting them from harm and peer abuse can result in overprotection.

I managed to overcome home confinement despite the difficulties of communication and it helped me to learn and work in mainstream society, which I encourage many parents of children with mild and moderate deafblindness to do.

I have a difficulty in accessing visual and auditory information because I have post-lingual acquired deafblindness. But, for children with severe congenital deafblindness, communication — especially with their mothers and caregivers is a serious problem.

Such children may communicate through body movements, gestures, facial expressions, vocalisation or use of objects.

For instance, a child may cross their legs to communicate to people the intention to go to the toilet. A child may communicate being thirsty by holding a cup. But the caregiver may not perceive or comprehend what the child's behaviour means and fail to address these needs.

Competent communication partners, including caregivers and teachers, are essential in providing intervention to deafblindness. But few professionals working with children specialise in communicating with deafblind children and adults in Africa.

Although there is very little information about deafblindness in Africa, it is nevertheless common knowledge that children with severe disabilities are at a higher risk of abuse and neglect.

Deafblind children are unlikely to learn activities for daily living as a result of communication problems with their caregivers as well as restricted physical mobility. Thus, activities such as eating, dressing, bathing and toilet skills are difficult for deafblind children.

This exposes them to high risk of abuse because of their inability to detect, resist and communicate or report abuse as a result of their dual impairment. Moreover they are usually confined to their homes.

These children's inability to perform activities for daily living also makes them become completely dependent on their caregivers who, in many instances, perceive them as a burden. Deafblind children who live with step-parents or non-biological parents are at even higher risk of maltreatment.

I was brought up by one biological parent and by a step-parent and did not experience as much abuse as other deafblind children because my disability was moderate during my childhood and I could perform all activities for daily living.

I could also detect, resist and report maltreatment during my childhood. This experience transformed me into a disability rights activist.

To this effect, I studied for a Master of International Human Rights Law at the University of Leeds and Master of Arts in International Child Protection at King's College London.

I have incorporated my knowledge of human rights and child protection and communication for deafblindness in my advocacy for inclusion of children with disabilities, particularly deafblind children in Africa.

Deafblind people who depend on their sense of touch to access information and communicate are the most excluded and under-researched groups in society.

The attainment of the sustainable development goals will remain an illusion for deafblind people in many countries especially in Africa if they continue to be invisible and excluded from policy and social services.

I responded to the gap of scholarly knowledge and lack of intervention concerning deafblindness in my country by completing a master of pedagogical sciences in communication and deafblindness in 2020 at the University of Groningen in the Netherlands, alongside a PhD in Education Policy Studies at Stellenbosch University, which I am yet to complete.

My scholarly work has enhanced my capacity to advocate for inclusion of deafblind people in Africa.

I am the co-ordinator of the Deafblind Zambia Programme (DBAZ) and secretary of the Africa Federation of the Deafblind (AFDB).

The DBAZ is collaborating with the Norwegian charity, Signo, and the Finnish charity, Abilis Signo is supporting inclusive education in Zambia and Malawi, while Abilis is providing advocacy capacity to AFDB members.

Apart from Zambia and Malawi, Lesotho and South Africa are the two southern African countries that have formed advocacy groups for deafblindness inclusion and are collaborating with the DBAZ.

As part of raising awareness about deafblindness in Africa, the AFDB will host the World Federation of the 6th Deafblind General Assembly and the 12th Helen Keller World Conference on Deafblindness in May 2022 in Nairobi, Kenya.

I will present my study findings on intervention to deafblindness to promote meaningful communication among deafblind peers in Zambia.

Simate Simate is a Zambian living with deafblindness. He is a disability rights advocate for the inclusion of deafblindness in Africa, national coordinator of the Deafblind Zambia Programme and secretary of the Africa Federation of the Deafblind. Simate holds master's degrees in arts, international human rights law and pedagogical sciences. He is also a Canon Collins PhD scholar in education policy.

## **Author-Advocate Brings Message of Inclusion to Palomar College**

Palomar News www.palomar.edu



Haben Girma, honored by heads of state and named a White House Champion of Change by President Barack Obama, urges the importance of access to higher education.

SAN MARCOS — The award-winning author and advocate Haben Girma spoke on overcoming ableism and signed copies of her book, "Haben: The Deafblind Woman Who Conquered Harvard Law," during a visit to Palomar College on Monday, March 14, 2022.

The first Deafblind graduate of Harvard Law School, Girma visited Palomar to host a hybrid in-person/virtual event that provided off-site access via Zoom for those who could not attend in person.

Girma shared a variety of personal anecdotes, such as learning to surf, looking for work in Juneau, Alaska, meeting President Obama, and attending Harvard Law.

"There's a myth that there are two types of people—dependent and independent. But that's not true, we're all interdependent," she said. "Inclusion is a choice—it's the small and big decisions we make to make our communities more inclusive, and when you choose inclusion, you model it for everyone else around you."together. It is wonderful to see them live independently of their father and I, while continuing to be the same happy and confident people we have always encouraged them to be."

The Watsons are looking forward to Scott and Ian visiting for the holidays.

Along with sensory holiday traditions, like music from the Little Drummer Boy, holiday movies, a visit from Santa, a bright, twinkling Christmas tree, and a delicious dinner with loved ones.

"We plan to have lots of Christmas music and Christmas lights of course, while creating new memories," said Paula.

The early evening event, entitled, "Disability & Innovation: A Conversation with Haben Girma," was held at the Brubeck Theatre and co-hosted by the Disability Resource Center (DRC) at Palomar College and MiraCosta College's Student Accessibility Services (SAS) department.

"It is an honor to hear from Haben this evening about breaking down barriers and the importance of investing in accessibility," said Superintendent/ President Star Rivera-Lacey. "I've been a fan of Haben's for a long time. Thank you to our colleagues in the DRC at Palomar, as well as the Student Accessibility Services team at MiraCosta College—it's because of their dedication that this event is possible."

During her time in Alaska, before discovering her passion for law and advocacy, Girma said she had trouble finding work, even though her resume was strong and she had no problem getting interviews.

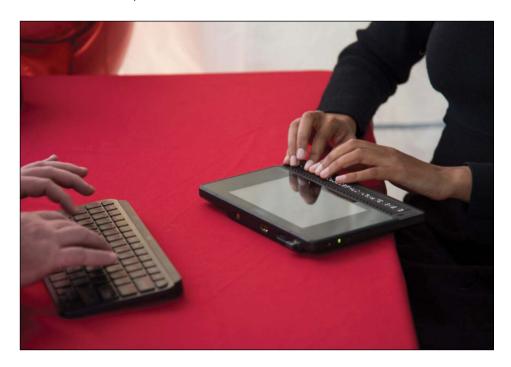
"These were tactile jobs, they did not require sight—washing dishes, folding laundry," she said. "These employers assumed a Deafblind person couldn't wash dishes. And if I couldn't get a job as a dishwasher, what else would I be able to do?"

Later, with an interest in surfing, she was told, "We've never heard of a Deafblind surfer." As she told the story on Monday, a video of Girma surfing played on the screen above her head.

Of her time in the lvy League, Girma recalled her first encounter: "They told me, 'We've never had a Deafblind student at Harvard Law School before.' I told them, 'I've never been to Harvard Law School before.'

"If you've never had a disabled person

in a program, that's a sign there are barriers—barriers to access, such as stairs, or social barriers," she told the audience at Palomar, which included "Haben is a true champion of disability justice, and we are honored to have her with us tonight," said Shauna Moriarty, Director of the DRC at Palomar.



many students and educators. "So look for barriers at all levels, and do the work to remove those barriers so we can have inclusive communities."

During her presentation, Girma also demonstrated the technology she uses to communicate and engage with audiences—including her interactive braille computer.

Before heading outside to sign books and pose for pictures with students, Girma challenged her audience to be agents of positive change: "Many disabled people don't like the word 'inspiring' because it's often a disguise for pity," Girma said. "But I don't mind the word 'inspiring' when it's used for action. What are you inspired to do?"





## 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. Thank you for your support in ensuring that, "All people who are deafblind will live rich meaningful lives."



# CENTURY PINES GOLF CLUB

35th Annual "Lend-a-Hand" Charity Golf Classic raises much needed funds for Canadian **Deafblind Association** 











It was a superb day for all concerned, as the golfing community finally works its way back to a greater degree of normalcy post-pandemic, with no masking and indoor dining. On Tuesday, June 28th a turnout of 18 golf teams enjoyed a terrific day on the course for the 35th annual "Lend-a-Hand" Charity Golf Classic, generously supported for the third time by The Cooperators. This year's event was held at the beautiful and expertly manicured Century Pines Golf Club in Troy, Ontario.

The fun-filled day saw golfers enjoy a "classic" continental breakfast and BBQ buffet lunch, along with amazing raffle table prizes and some healthy on-the-course competition, including a hole-in-one challenge and professional long drive champion. CDBA sincerely appreciates the hard work of its 3 dedicated volunteers all day long - Kim McFadden, Amanda Scott, and Sawyer James.

#### **TOURNAMENT WINNERS:**

Winning Team: Justin James, Robert Sclissizi, Mike Watson, Colin McCoy 2nd Place Team: Ryan Hooykaas, Andy Dorn, Dan Bulario, Kyle Campbell 3rd Place Team: Ed McCormack, Joe Bardaro, John Bulhoes, Jim Crabtree

Most Honest Team: Chris Merry, Raechel Molony, Carissa Gopie, Cherisse Corradetti

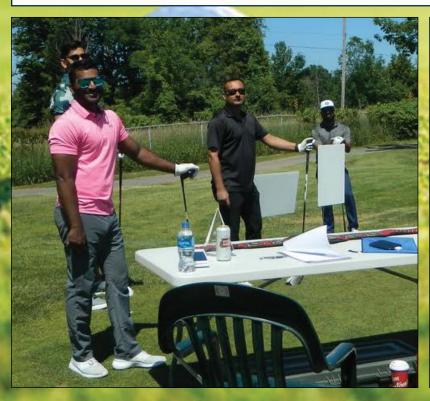
Ladies' Closest to the Pin: Sarah Walker Men's Closest to the Pin: Nick Teti Ladies' Longest Drive: Chris Merry Men's Longest Drive: Kyle Paolini

#### CDBA National is very grateful for the generosity of the following Major Sponsors:

**Platinum:** Justin James & Ryan Hooykaas, **Gold:** Niagara Vintage Wines, **Silver:** The Cooperators, **Bronze:** Westridge Benefits, **Breakfast:** Tire Resort, **Lunch:** Paragon Home Capital & Turtle Bay Pools and **Carts:** RM Realty

CDBA National also gratefully acknowledges our **Golf Hole Sponsors** as well as those who kindly donated prizes for our raffle table. We also wish to sincerely thank **Golfers Green's Lorraine Ferrari** for overseeing our hole-in-one challenge competition, and **PLDA Long Drive Champion Kelly Rudney** for conducting the very entertaining hole-in-2 competition.

This year's event raised over \$15,300. These funds will go towards a wide range of activities for persons who are deafblind and their families, carried out by CDBA National through its National Support Fund. Since this tournament started in 1987, it has raised more than \$690,000 for Intervention services and emergency supports for persons who are deafblind and their families.





## Options and Opportunities for Those Who Are Blind or DeafBlind

The Lighthouse for the Blind Inc

www.seattletimes.com



John Cashion works on the production floor. The Lighthouse for the Blind, Inc. employees make aerospace parts, office products and other machined products.

People with any disability have an unemployment rate more than twice that of those without a disability. Only around one-third of working-age adults with significant vision loss is employed between the ages of 21 and 64, according to the EEOC.

"The largest barrier is societal/employer attitudes and misconceptions about the capabilities of individuals who are blind or DeafBlind," says George Abbott, CEO and president at The Lighthouse for the Blind, Inc., the single largest U.S. employer of DeafBlind employees and the largest employer west of the Mississippi of people who are blind.

Blindness doesn't limit employability — only access to visual information resulting from damage to the eye, ageor disease-related degeneration, or the brain's inability to interpret messages sent from the eyes. According to the EEOC, between 6.6 and 10 million people are blind or visually impaired. DeafBlindness is a combination of hearing and vision loss.

The DeafBlind community prefers this capitalization usage."DeafBlind is its own cultural subgroup, even within the Deaf community," explains Employee and Community Services Vice President Amy Koehl. "That's why there is not a hyphen because it is one element, not

two separate things...it's bigger than the sum of its parts."

The Lighthouse for the Blind, Inc. creates increased diverse, sustainable, and meaningful employment opportunities for people who are blind, DeafBlind and blind with other disabilities in the Puget Sound region and over a dozen other locations served. The Lighthouse for the Blind, Inc. employs more than 70 machinists who are blind and DeafBlind to produce parts for various aerospace manufacturers. The organization also creates office products, hydration equipment and other products for the federal government and U.S. military.

Recent government contracts awarded to The Lighthouse for the Blind, Inc. allowed the organization to expand to six new locations on military bases where they sell their manufactured products, in addition to thousands of other products; two stores sell transportation products and services and the remaining four offer office and other workplace supplies. Store positions are fully accessible to people with disabilities — for example, providing access to screen magnification and screen-reading software.

Large monitors, speech output and refreshable braille displays help employees who are blind and DeafBlind independently operate machines to produce precision aerospace parts. People with low vision or using a cane can navigate production workspace floors by following clearly defined pathways created from raised, high-contrast lines.

More job opportunities open up if employers make accommodations relying on often-simple changes and assistive devices. "Some hiring managers assume a blind person may require expensive accommodations," Abbott says. "This is rarely the case."

Abbott notes that workplace accommodations or necessary equipment depend on the individual's needs, work environment, and job responsibilities. A few examples:

A small gooseneck lamp to focus light on the user's task.

A larger computer monitor or screenmagnification software.

Screen-reader software so the user can hear computer text aloud.

Raised dots or pieces of tape on a copy machine, printer or microwave to locate important buttons by touch.

More digital and wireless technology devices are becoming available to help people communicate and participate in the workplace.

"Braille translation software along with braille embossers allow the conversion of text from documents and spreadsheets into hardcopy braille," Abbott says. "There are so many wonderful tools to meet just about any need," he says.

Everyday devices can also be crucial for the blind and DeafBlind. "The smartphone and a wide number of apps have become extremely helpful tools for researching information, using rideshare services, identifying currency, planning and monitoring walking and public transit routes, and so much more," Abbott notes.

The Lighthouse for the Blind, Inc. has helped many employers bump up their accessibility game, ranging from large corporations to smaller businesses. Guidance offered included blindness awareness training, creating a moreaccessible cafeteria layout, providing

website usability feedback, getting braille on signage and assessing the best access technology for computer installation.

The Lighthouse for the Blind, Inc. also offers employable skills through its Computer Training Program and introduction to assistive technology. The program teaches eight different courses, including basic keyboarding skills, Microsoft Office, iPhone with VoiceOver/Siri, and refreshable braille displays.

"It might be hard to imagine that people with visual impairments can perform in the workplace like anyone else," Abbott says. "But this is because hiring managers do not understand the techniques, adaptations and technologies that are available."



Roger Poulin, an instructor at the Technology Training Center, provides instruction in assistive and mainstream technologies to DeafBlind employees and community members.

## **Engineer With a Passion for Special Needs Communities Develops a Robotic Signing Arm for Deafblind People**

Alena Kuzub

news.northeastern.edu



Samantha Johnson, bioengineer and founder of Tatum Robotics, vividly remembers meeting a DeafBlind person for the first time.

She was in her sophomore year at Northeastern University, taking an American Sign Language class, which required her to learn more about the local Deaf community by attending local Deaf events. At one of the events, she met a DeafBlind woman.

"I thought it was truly like magic how they could somehow understand [what was being communicated] purely into their hands," Johnson says.

DeafBlind people communicate via tactile ASL with the help of a partner or an interpreter, holding onto their dominant hand while the interpreter signs. Signing with the woman, Johnson immediately thought of a robotic device that could sign for DeafBlind people. But she didn't have the time or skills to develop such

a device during her sophomore year, so she stored the idea away in her head.

Last month, however. Johnson, who is now 23 years old and a 2021 alumna of the College of Engineering with a combined bachelor's and master's degree in bioengineering, was announced to be the first place winner of the 2022 Innovator Awards given out by the Northeastern's Women Who Empower platform in the young alumnae graduate category for developing a robotic arm that can sign in ASI.

The award came with a \$22,000 cash prize that Johnson is planning to spend on further research and development, as well as on costs to hire DeafBlind consultants to help brainstorm ideas and evaluate prototypes.

Johnson grew up in Hudson in Central Massachusetts and describes herself as an optimistic person with high energy, who checks in on everyone and makes sure that everybody is happy.

"I really do see that we can accomplish anything we set our minds to," Johnson says. "I can work for 20 hours a day, especially if I see progress being made, I can keep going."

Johnson started working with special needs students in middle school as a part of a conversation club that helped them practice making eye contact, asking questions and showing active listening.

In high school, Johnson was one of the first members to join a unified track and field team, where special needs athletes competed alongside abled partners. This experience allowed her to learn more about the impact of assistive technology, including wheelchairs and prosthetics, which gave students the abilities they otherwise wouldn't have had, she says.

"I decided to do bioengineering with the assumption that I either will do prosthetics or assistive technology," says Johnson, who still works as a life skills aide for adults with disabilities after work.

Johnson revived her idea of creating a communication device for DeafBlind people in her last year of college. In 2020, she was supposed to work on her thesis in a lab but all the labs closed due to COVID-19 pandemic along with the university. Instead, Johnson transitioned to working on the thesis at her small studio apartment.

She set up 3D-printers, bought soldering irons and started building a signing hand in collaboration with the Deaf-Blind Contact Center in Allston. She designed all of the parts herself, 3D-printed them, assembled them and started writing code. After the initial prototypes had been built, her father Todd Johnson, a software engineer, took over developing software for the hand to make it sign.

To ensure the device is the most effective, Johnson enlisted help from Northeastern's Institute for Experiential Robotics and its director Taskin Padir; assistant professor in biology Jon Matthis and his motion capture software project FreeMoCap; associate professor in bioengineering and thesis advisor Chiara Bellini; and assistant professor in chemistry and chemical biology Mona Minkara. She also established

collaboration with the New Dexterity group at the University of Auckland.

"Samantha employed a truly experiential approach to her project," Padir says. "Rather than looking for an application for a technology, she identified an unmet need within the DeafBlind community and set course for her project to make an impact. This is the recipe for success."

He also notes that Johnson is a true entrepreneur and go-getter, able to attract talent and motivate her team toward the goals of her project.

By the time Johnson graduated Northeastern, she had created a handwrist system that could fingerspell words texted to it from a computer. Johnson looked for jobs but none of the options involved working directly alongside disabled communities, which was important to her.

In a turn of fate, the Canadian National Institute for the Blind saw an article about Johnson's work and offered her a small grant to continue working on a robotic arm. This allowed her to start her own company, Tatum Robotics, and move to a new space at MassRobotics, an innovation workspace in Seaport.

Tatum Robotics currently has one full-time employee, a linguist and fellow Northeastern alumna Nicole Rich, two graduate co-ops, and a large number of volunteers, Johnson says. Her father continues to be the lead software architect and her mother, Tammy Johnson, who is an accountant, helps manage the finances.

"We are hoping that once we get funding, we can bring on a few more employees, especially get more DeafBlind folks on staff," Johnson says.

Since the thesis project grew into a real business, Johnson has formed collaborations with the Perkins School for the Blind, National Technical Institute for the Deaf and Helen Keller National Center. She brings in DeafBlind collaborators as frequently as possible to better understand tactile ASL and the needs of the community.

Tatum Robotics currently continues to work on a low-cost, anthropomorphic robotic hand that will fingerspell tactile sign language and a safe, compliant robotic arm so that the system can sign more complex words and phrases. They are creating a user interface and gesture recognition software with the help of some Northeastern clubs, so that DeafBlind people can respond back and have two-way communication all by themselves, similar to video relay services that sighted but Deaf, hard-ofhearing and speech-impaired individuals use in real-time via a sign language interpreter.

"We are bringing in native Deaf and DeafBlind signers to come in and sign so we can actually map their signing motions right to our robot," Johnson says.

Brian Mansur, program director at the Deaf-Blind Contact Center, says he sees a lot of potential in the devices Johnson is working on. They would make things like reading newspapers and emails,

going online, texting with a friend or even watching movies accessible to DeafBlind people.

"If you have somebody come in and try to sign into their hand all day, the task is too tremendous to get every bit of information," Mansur says. "They can touch a robot wherever and whenever and get nuances and changes that are occurring in the language because the language is always evolving."

DeafBlind people would become more employable with these communication devices, Mansur says.

He emphasizes how committed Johnson and Tatum Robotics are to the project.

"It is very impressive. I haven't seen anybody that dedicated as of yet," Mansur says.

Johnson has received positive feedback from other engineers and entrepreneurs, and they often suggest focusing on other bigger audiences or more lucrative markets, Johnson says.

"The technology itself is novel," Johnson says. "What we are doing could do more than benefit DeafBlind people."

But for now she prefers to focus on the DeafBlind community, which has been historically underserved, and, maybe, expand to other sectors later.

"We can really make such an impact on the lives of these people who currently don't have any means of communicating. And this could be the first," Johnson says.

## How do I become a member of CDBA?



Becoming a member is very easy; you may either download a copy of our membership form at www.cdbanational. com/become-a-member or complete the membership form online.

Once completed, please mail, or scan and email your form. Memberships may be paid by cash, cheque, or credit card.



## Deafblind Teen Artist Creates NFT Collection to Spark Passion and Discussion

Alexandria Slater uk.news.yahoo.com



Ava Jolliffe's Spark is one of the first NFT collections of its kind – a 250-piece profile picture collection to spread awareness about deafblindness

### A Deafblind teen artist from Lancashire has created one of the first NFT collections of its kind to spread awareness about her disability.

The 15-year-old digital artist Ava Jolliffe has been doing art since she was three years old, when her condition took away her vision and her hearing.

She is now releasing her NFT (nonfungible token) collection 'Spark' during Deafblind awareness week, which begins on the anniversary of famous deafblind author and activist Helen Keller's birthday.

Preston-based Ava has a rare degenerative condition she became ill with at three years old which severely affects her vision and has left her profoundly deaf and a wheelchair user.

Despite the challenges, Ava uses her art as a form of communication and escapism, to overcome her frustration, and advocate for the disabled community.

### Ava's digital artwork

Her mother Laura Jolliffe shared how proud she is of Ava and everything she has achieved despite the barriers she faces on a daily basis.

She said: "She's deafblind, she's 15, she lives in the North West, and she's a woman.

"So, trying to get any footholds into the artistic community is difficult.

"It's difficult for her to be taken seriously so I get really frustrated but she has achieved so much for herself and society already.

"Life is frustrating for her but this is her love and her passion."

Ava Jolliffe,15 year old digital artist

Ava's independence is difficult for her and she has someone sat with her all the time in school.

"Even the gossip in the classroom about who's kissing who has to be fed back to her," says her mum, Laura.

"This is the one thing she has control over in her life, the one thing where she's independent and can go away in her room and do her own art."

The 250-piece NFT connection titled Spark is run by Deafblind UK charity and Fungii Studios to spread awareness of deafblindess and raise funds for the cause.

NFTs are unique forms of digital data - often photos or other digital artworks - owned by one person which can then be sold or traded online.

One of the NFT pieces from Ava's

#### Spark collection

Ava's artwork is bright, vivid and cheerful and because her vision is so poor it has to be colourful.

She channels her frustration and anger about society's inequality and injustice into her artwork.

Laura continued: "It's about the fire in your belly that you get when you have a moment of realisation. We want to spark passion in people and discussion. It's all about that beginning bit of the spark that turns into activism and change."

## Another one of Ava's digital drawings

Deafblind Awareness Week runs from June 27 to July 3 and the charity Deafblind UK is encouraging us to get "in the know" about deafblindness, during the week so we can all be more deafblind aware.

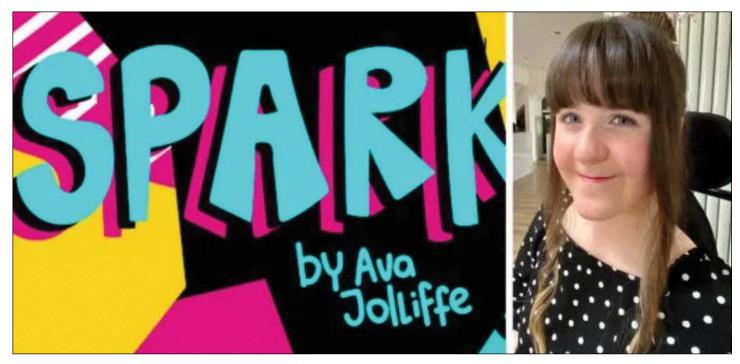
However, Laura stressed that it's important to "stay engaged" after awareness week because social media makes it is "easy to become like a trend" and then move on to the next movement.

"We've noticed there are a lot of people asking how to say please or nice to meet you, and it's amazing. It brings that little spark of loveliness to Ava.

"People are becoming more comfortable with it, and that's the thing we need to get to - people getting comfortable with people being disabled because we're all the same just a little bit different.

"But this is about trying to send a consistent message about disability and getting away from fashionable trends. Even things like sign language - it isn't a fashion for the deaf community.

"It's trying to get away from faddism because it isn't a phase, it's her life. So, we're just trying to say to people



Ava Jolliffe's Spark is one of the first NFT collections of its kind – a 250-piece profile picture collection to spread awareness about deafblindness

these people are out there, these people deserve equal respect."

Deafblindness affects around 400,000 people in the UK, and it affects everyone differently, some people need to make small changes to the way they go about everyday life and some people will rely on others for communication and getting about.

## Ava on Britain's Best Young Artist programme

Laura shared that Ava is blessed to have her talent because otherwise, "what else would she be doing?"

Life is extremely hard for deafblind people so Ava's artwork "gives her a wonderful sense of challenge, ambition and worth."

At 13, Ava became the youngest artist to hold an exhibition at the Garstang Arts Centre for her drawings that she created to communicate her feelings before she learned sign language.

Since then, she has designed Christmas cards, featured on BBC programmes, and is now currently working on a children's book. Drawing takes Ava a long time so digital art gives her the right tools by allowing Ava to zoom in and focus on minute details.

#### **Spark NFT Collection by Ava Jolliffe**

Laura continued: "She's sick of people talking down to her because she's disabled. She really wants to show that people like her are a formidable force.

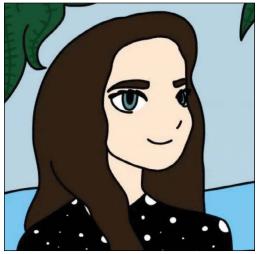
"Her work is impactful as it makes people challenge their own thoughts and opinions on how they perceive deafblind people and what they can offer.

"She proves stereotypes wrong, and she's shown society that deafblind people can achieve great things."

Shirley Scotcher, Director of Fundraising and Marketing for Deafblind UK said: "Ava is an extraordinary human being, and we love working with her.

"She is a shining example of how with the right support and determination, we can all achieve what we set out to.

"We hope that all those who may be struggling with sight and hearing loss, take the time to reach out to Deafblind UK on 0800 132 320 to learn about how we may be able to support them, to live a meaningful life, full of hope for each future."





Lancashire Telegraph: Ava's digital artwork



#### CDBA WAYNE TURNBULL MEMORIAL SCHOLARSHIP

### For students enrolled in an Intervenor Program of Study



Established in 2022, the Canadian Deafblind Association Wayne Turnbull Memorial Scholarship honours the legacy of Wayne Turnbull, who was deafblind and a Board member of both CDBA National and the CDBA Alberta Chapter. Wayne was a lifelong advocate for individuals who are deafblind and their Intervenors.

### Eligibility:

- Awarded to a deserving student in any area of Intervenor Studies, whether it be online or in-person, through an accredited educational institution
- Applicants must reside in Canada; however, the program of study could be outside of Canada
- Previous award recipients are not eligible to apply again

#### **Amount of Monetary Award:**

- \$2,000 Canadian towards tuition fees
- This award is payable to the post-secondary educational institution of the recipient's choice

#### Award based on:

- Two letters of reference submitted directly from the referee to the scholarship committee—one academic/professional, one personal
- Proof of school registration status
- Completed application form
- Letter of intent from applicant (what is your motivation for taking this course of study)

### **Application Deadline:**

- Application form and all support documents must be submitted by May 31<sup>st</sup>
- Decision on application will be made on or before June 30<sup>th</sup>
- All applicants will be notified of approval or denial by July 15<sup>th</sup>

Contact CDBA National for an Application Form info@cdbanational.com

All people who are deafblind will live rich meaningful lives.

CDBA National—1860 Appleby Line, Unit 14, Burlington ON L7L 7H7
With Chapters In: British Columbia, Saskatchewan & New Brunswick

## **News From CDBA British Columbia**

CDBA British Columbia Theresa Tancock, Family Services Coordinator



So, what have we been up to on the beautiful west coast of Canada? It has been an extremely busy few months recently, to say the least. On top of our usual Spring Virtual Recreation Program activities, Flowers, Flowers, Flowers and Easter Fun, we have other items to note.

Our fiscal year end had two sensory clinics as 'bookends' – one in the Lower mainland in

Langley and one on Vancouver Island in Nanaimo. Our sensory clinics take on many forms: weekend events for our Early Intervention Families, one-day events for all families or as an additional activity at an event.

Our black sensory tent is 10x10 with walls and inside we have different strings of lights, lighted and/or vibrating toys, a vibrating mat, tactile objects and a projector. It is designed for one (sometimes two) individuals at a time to allow sensory exploration – often a calming result.

Our clinic in Langley was a weekend event for the families of children with deafblindness, birth to 5 years. It

consisted of a room for the Sensory Tent and other sensory stations, a room for the siblings to play and socialize and a room for the parents to share, problem-solve and learn.

Intervenors were hired to support the children with deafblindness and sitters were hired to support the siblings. This allowed the parents time to network with the other parents and participate in the two workshops that were offered – "The Impact of Hearing Loss on Communication" and "The Impact of Vision Loss on Communication". For many, this is the first



time engaging with other parents of children with deafblindness. Our clinics are also an opportunity for Intervenors to network and learn from each other.

Our clinic in Nanaimo was a one-day event, to allow families of children birth to 19 years across Vancouver Island to come together and network. Intervenors and sitters were hired here as well to allow parents time to learn about the Children's Low Vision Project of BC, Experience Books and Youth Transition.

So much is gained with parents, their families and Intervenors coming together to share experiences, tools and stories, so it gives us such pleasure to offer these well-rounded programs.

CDBA-BC has also begun offering a new online training program for our Intervenors. The staff of the Minnesota Deafblind Project has graciously allowed us to present the Open Hands, Open Access Modules as a training format for our Intervenors. We are offering two modules at a time and upon completion, the participants will receive a Certificate of Completion from CDBA National. One cohort was completed earlier this year and we are offering the same modules to another cohort for our Summer Intervenors. So far, this new program has been well-received and offers a great solution to our lack of training options for our Intervention Program Intervenors.

In conclusion, I wish to thank the Province of BC and the many communities (Nanaimo, New Westminster, Mission, Richmond, Surrey, Vancouver and Victoria) that made proclamations of June as Deafblind Awareness Month, to line up with the work of Deafblind International (DbI) and the National Deafblind Awareness Month Committee (NDBAM). We also had several BC landmarks light up in blue, City of Penticton classes of KVR Middle and Penticton Secondary Schools yarn-bomb their front fence and the City of Burnaby displayed the yarn-bombed 'Little Bo-Peep and her Sheep'! It is so very encouraging to see so many communities, organizations and individuals come together across Canada in support and awareness of deafblindness.







## **News From CDBA New Brunswick**

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



We all made it through another New Brunswick winter and now we can enjoy the summer months. It will be another busy summer. The CDBA-NB Board of Directors have been busy working on updating all of CDBA-NB policies, with approval of the final drafts taking place in June, at the Board of Directors meeting. We do have open positions on the CDBA-NB Board of Directors. If you know of someone who might be in-terested in working with CDBA-NB Board of Directors, they may get into touch with me. Over the next few weeks, the CDBA-NB office staff will be getting the updated policies out to the Intervenors.



We are also planning a summer day trip for the

clients and Intervenors. More infor-mation will be made available in the coming weeks.

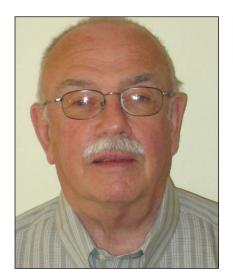
It is looking like Covid-19 is slowly moving behind us, however, we still need to be cautious. All the events will still be outdoor events this year. We do ask that Intervenors, continue to wear their mask while with their clients when they are in large crowds.

I would like to thank all of the clients and Intervenors who took part in the Deafblind International Yarn Bombing event this year. Hopefully, over the next few years we can hold other events across New Brunswick, to help bring awareness of Deafblindness. You will see in this newsletter that DBI will hold the 18th, Deafblind International World Conference in 2023 in Ottawa, Canada. This will be a large event bringing peo-ple from all over the world to Ottawa.

I would like to thank all the CDBA-NB staff, Intervenors and Board of Directors for all their work that they do. CDBA-NB's focus is to ensure that all of our clients' needs are met and that they have all the best opportunities. I would like to also thank all of those who make donations and support CDBA-NB.

I would like to remind the families of CDBA-NB clients, that we are here for them as well. If at any time that CDBA-NB can support you, please feel free to reach out.

Have a great summer and I hope to see you all on the day trip!!





## **Douglas James Page**

December 24, 1937 - March 21, 2022

It is with great sadness that we announce the passing of Doug Page after suffering a stroke while in the Colchester East Hants Health Centre, Truro, NS. Doug was a faithful husband to Alma for 64 years and a loving father to Troy and Darren. Doug and Alma began their married life in Lawrence Station, NB where he taught Vocational until 1965 at which time he accepted the position of Vocational Director at the School for the Deaf and later accepted the position of Manager of School Services until retirement in 1994. Doug dedicated his life to serve Jehovah God in 1966. He has been a faithful witness, serving first in St. Stephen congregation, later in McAdam and then in Amherst for 57 years. Doug is survived by his wife, Alma (Sypher); sons Troy, Ottawa and Darren (Pattie) Huntsville, ON; grandchildren Donovan and Bryce, great grandchildren Grayson, Jerikko and Deacon. Doug was predeceased by his adoptive parents, James and Dorothy Page of Fredericton, NB an infant daughter Tammy Marine, grandson Amide, daughter-in-law

Jenny and in-laws Dale and Ann Smith. During the 2018 Annual General Meeting Doug and Alma, who were retiring from the Board, were presented with a "key" to CDBA-NB (Doug received a key on a key chain and Alma a Key pendent). They were also given a family lifetime membership to CDBA-NB and a video slide show was presented showing their years with CDBA-NB. CDBA-NB greatly appreciates Doug and Alma for their hard work, dedication and commitment to CDBA-NB.

## **News From CDBA Saskatchewan**

CDBA Saskatchewan Leanne Kerr, Executive Director



I am starting to get more comfortable in my new role here at CDBA-SK. It has definitely been a huge learning curve for me, but Dana, our former Executive Director, has been very helpful during this transition.

Because of the Covid pandemic, we have been very cautious about attending large group gatherings and spending time indoors at public places. We welcomed spring with open arms as that meant more opportunities to spend time outside and attend outdoor gatherings. The CNIB hosted a barbeque in the park in Prince Albert, so some of the Individuals made the trip up there for the day. A few even have some family members in that city so they were able to stop by and enjoy some time with their loved ones. Some of the Individuals at CDBA attended a CNIB Deafblind Awareness event with guest speaker Ryan Riehl who is deafblind and a competitive water skier. It was a great event with prizes, crafts and snacks as an added bonus!

Our annual Lend-A-Hand Golf Classic was held on June 1 and was a huge success. We changed venues this year and held it at the Legends Golf Club in Warman with Taste of Ukraine catering the supper. We received so many positive comments about the tournament and the meal despite the excessively windy day. Our volunteers held on through all of the wind so that all of the golfers could play the games and have a fun day. We had so many sponsors and businesses donating, but it would not have been as great of a success as it was without the continued support of MacDermid Lamarsh Law Firm. At the end of the day, we raised \$22,656 to help improve the quality of life for Individuals living with deafblindness.

This summer, the ladies at the Kerr house have started to attend church again. They were so excited to be able to attend in person as they have not gone in over 2 years. Planning is underway for several day trips as well as overnight camping trips for the Individuals over the summer. We are so fortunate to have so many parks and lakes close to us that we can enjoy all summer long.



One of the teams golfing in the Lend-A-Hand Classic



The Deafblind awareness event held by CNIB



Leslie relaxing on the deck



Alex enjoying the sunshine in a park



The charcuterie board Norrie won

## What's Going on Here?: Yarn-bombing at Brampton City Hall and Gage Park

Sabrina Gamrot

www.thestar.com



Have you walked through Gage Park or City Hall recently and seen knit objects wrapped around fences and trees?

If so, you have just seen some yarn-

bombing, a street style form of art that uses knitted, loomed or crotched yarn swatches to create a tactile installation in public spaces.

The pieces come from the Deafblind Community Services (DBCS), which has created the installations to promote awareness for Deafblind Awareness Month.

The agency has joined a global campaign to build awareness and knowledge about people who are deaf and blind throughout the month of June.

Deafblind is a combination of hearing and vision loss. More than 465,000 Canadians are deafblind, with roughly 211,000 living in Ontario.

Each piece was made by someone who is supported by DBCS while the actual knitted pieces symbolize the coming together of individuals who are deafblind, friends, families and community members.

Yarn-bombing across trees, lampposts, fronts of buildings and fences can be seen across Ontario as DBCS and Deafblind Ontario Services (DBOS), have created displays in multiple locations including Sudbury, Ottawa, London and Peterborough.

Dragging your hand across one of the displays reveals different textures and surfaces, allowing those to experience the art physically.

## This is Why Mississauga and Brampton Parks Have Been 'Yarn Bombed'

Karen Longwell

www.insauga.com



Parks in Mississauga and Brampton got a burst of colour in a yarn bombing this month.

The Riverwood Conservancy in Mississauga, and Brampton City Hall and Gage Park are both targets of the so-called explosion.

Yarn bombing is bright and colourful display of yarn art. It can involve wrapping trees, fences or any object in crocheted or knitted yarn pieces. Other names for the colourful art include "yarn storming", "guerrilla knitting" or "kniffiti."

While yarn bombings sometimes have a political message, the reason behind the Peel wool take-over is a good cause.

And this time it comes from Deafblind Community Services (DBCS), Canada's leading provider of specialized support and emergency services for people who are deafblind.

June is National Deafblind Awareness Month in Canada. The yarn bombing project aims to raise awareness and show support for Canadians living with deafblindness. Communities across Ontario have come together to create beautiful yarn bombing displays.

"These displays are about creating a sense of belonging and drawing attention to something that is ignored by so many," the DBCS states.

About one per cent of Canadians live with deafblindness and require the support of intervenor services to be as independent as possible.

However, these services are currently only available in three provinces — Ontario, British Columbia and Saskatchewan.

## Grimsby 'Yarn Bombs' Spin Attention Toward Deafblindness Awareness

Chris Pickles

www.wellandtribune.ca



Grimsby is a little more colourful than usual.

That's because of a yarn bombing project designed to raise awareness of the issues the deafblind community face across Canada.

The main yarn bomb was installed in front of the Grimsby Library and Art Gallery, covering "Two in One (Imsby)," a sculpture designed to be a community piece that would be repainted every few years. Two smaller yarn bombs have been placed outside the Peach King Centre.

Yarn bombing is a form of art that involves knitted yarn typically wrapped around objects in the community.

The Grimsby initiative started in March when the town received a community grant to mark seniors month in June and decided to partner with Deafblind Community Services (DBCS) in the

yarn bombing project.

Krista Bowie, recreation supervisor at the Town of Grimsby, said it was an "opportunity not only to have fun and create, but to support (DSCS)."

The town distributed knitting kits across the community and in all, there were 160 participants who knitted 2,400 squares for the project in Grimsby.

Marion Petersen, who participated in the project, estimates she sewed 350 squares. "I got carried away," she admitted.

There were so many squares the town was able to donate some to other areas, including Hamilton, and leftover squares will be made into blankets to distribute to the homeless community and to women's shelters.

The yarn bomb is designed to attract the eye of passersby and have them

engage with the art and then learn about the deafblind community.

"Everyone coming into the building has asked what it is," said Alex Hartstone, art gallery manager. Staff are then able to raise awareness of the deafblind community.

"It really has been heartwarming to see (participants) get behind this initiative," said Tammy Taylor, manager at DBCS.

Individuals living with deafblindness usually use the help of intervenor services: professional staff members who often live with individuals and act as a "bridge, through communication" to everyday life, explained Taylor.

They use sign language, largelined notes, print on palm (which involves drawing the letters onto the palm of a hand with a finger)

and British two-hand manual (whereby the intervenor manipulates the hand of a person with deafblindness to spell out different letters).

Intervenors are crucial in "allowing (individuals with deafblindness) to be active members of society," said Taylor.

Although it is estimated over 460,000 people live with deafblindness across Canada, Taylor admits that intervenor "services are not equitable and accessible across the country." The services are available in only three provinces: Ontario, British Columbia and Saskatchewan.

"The goal, ultimately," said Taylor, "is to see all Canadians access intervenor services no matter where you live."

# Helen Keller Day 2022: Little-Known Facts About the History's First Deaf Blind Person and Disability Rights Advocate

Aditi Ratti

www.latestly.com

This day is observed as a holiday by international organizations, especially those blind and deaf. It is generally known for the fashion show held on June 27 annually for fundraising purposes. Helen Adams Keller was born on June 27, 1880 and was the first deafblind person to earn a bachelor of arts degree.

Helen Keller Day is the birth anniversary of Helen Keller, who was an American author, political activist and lecturer. It is observed every year on June 27.

As you observe Helen Keller Day 2022, we at LatestLY, have curated a list of 5 things that you must know about Helen Keller.

## Became deaf and blind due to childhood illness

When Helen was 19 months old, she was detected with acute congestion of the stomach and the brain. It is now known as scarlet fever or meningitis. A few days after her fever broke, her mum realised that Helen had lost her hearing and sight as she wasn't

responding to the dinner bell or a hand wave.

#### Mark Twain was her best friend

Helen and Mark met in Cambridge School for young ladies when she was 14 years old.

Helen started to recognise Mark with his scent as he smoked 10-20 cigars a day. They stayed close friends until Mark's

She belonged to the Socialist Party of America and helped find the American Civil Liberties Union.

## The U.S currency has an image of Helen Keller

Helen appears as an old woman sitting holding a book on the rocking chair in the Alabama state quarter (part of the 50 states quarter program).

## The Bollywood movie Black is inspired by Helen Keller's life

The director of the movie Sanjay Leela Bhansali read Helen's autobiography and visited the Helen Keller Institute for the deaf and blind before writing and directing the film. The film

was premiered at Cannes and both lead actors won Indian film fare awards.

Helen Keller was history's most famous deaf-blind person and an inspiring author, and activist. On Helen Keller Day 2022, you must know these unknown facts about her.

Wishing everyone Happy Helen Keller Day 2022!



death 16 years later.

## Was a member of the Socialist Party of America

A big part of Helen's life was focused on politics. She wrote essays about her socialist views and supported industrial workers' rights, women's suffrage and birth control. She has also been investigated by the FBI several times.





Visit georgebrown.ca/C158

Do you have a passion for helping others? Are you creative and a good communicator? You can make a difference by becoming a Deafblind Intervenor at George Brown College in just two-semesters.

#### Program highlights:

- Semester 1 delivered fully online, Semester 2 delivered both in-person (first seven weeks) and online (last seven weeks)
- Learn to work with children and adults with deafblindness
- Develop American Sign Language (ASL) skills adapted to accommodate for vision loss
- Study professionalism, values, ethics, health & aging
- Interact with deafblind community members virtually and in-person
- Field experience may be completed across Canada in your community through George Brown College partnerships



## Canadian Deafblind Association 2021/22 Board of Directors





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