

MOVING MOUNTAINS

WHAT TO KNOW ABOUT A MOVEMENT ON SOCIAL MEDIA THAT STARTED A NON-PROFIT, NETWORK, & TECH THAT WILL CHANGE OUR FUTURE.

Good words for Great Souls- By Rebecca Klassen

I have been suffering from a life-threatening but treatable neck injury, the result of a car accident, since 2018. Canada does not cover the diagnosis and treatment for my medical challenge or for similar patients suffering from treatable spine and brain stem injuries. In this 6 year battle we found at least 1,000 others like me, in Canada, who are being overlooked by our health care system and are left to suffer.

Despite efforts from patients, non-profits, and doctors our fellow Canadians have no hope in sight. For example, I am fight every day to stay out of palliative care. After a Bow-Hunter stroke took my right side at age 32, and I was put on palliative care with no rehabilitation, and discharge orders for hospice care for each stroke. They sent me to die.

A prescribed neck-collar is slowing down my decline and allowing me to walk again. A fusion and shunt could stop this suffering, but my condition of CCI is not treated in Canada. I and other patients rarely get a chance to even be considered for surgery because of a lack of organized government permission and training in the treatment of complex spine health in Canada.

When I started sharing my challenges and journey on social media, people were in disbelief. They've followed every step the last two years as I tried to get help in Canada. TheSallyProject on TikTok has recently exploded in support because after two years of watching, cheering my success to walk again, and trying to access this surgery through Canadian health care, I found out that nobody we know of has been approved. Not one person out of a thousand in the social media support groups we are a part of. Not one.

Thanks to the strength of social media, good friends, volunteers, and my past work as a successful cross-boarder business consultant and Executive Director, we are starting a non-profit organization that will change our healthcare system and streamline access for Canadians to the right help on their health journey. Through our newly launched non-profit the Help-Care Network™ and with its growth, an app, database, network, and a foundation. Profits from these will be used for programs to help patients stuck in the cracks of our healthcare system.

We are determined to work with the public, advocate for patients, change government policy to improve Canada's healthcare system, and support those in need on their journey. Thank you for your interest and support in our momentum for positive change and life-changing conversations. We are launching this spring our Fill the Cracks™ movement, and we look forward helping this group of Canadians and beyond. Thank you for reading this newsletter that has been created with the care of volunteers.

Rebecca Klassen, Patient & Change Maker.

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Patients needing treatment must travel to the USA, UK, AU, GER and other countries to pay, \$75,000- \$500,000USD for spinal fusions or other common treatments not available in Canada.

They are expected to individually fundraise or pay over \$120,000,000 USD to get their life back.

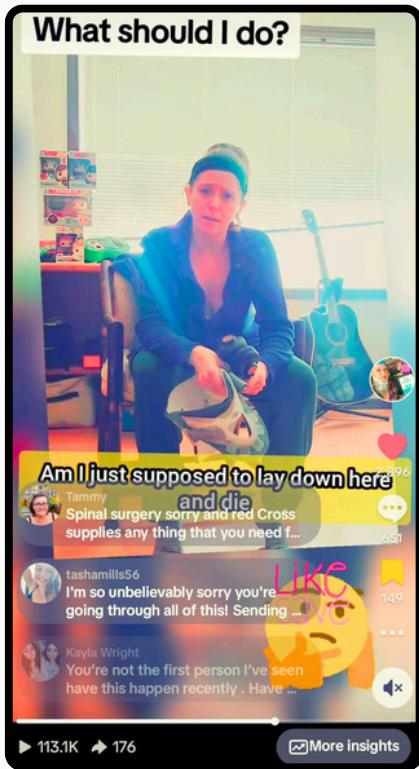
Success & Opportunity

How did we grow, Whats Next

BY FOUNDING MEMBERS OF THE HELP-CARE NETWORK™

Our initial efforts to build interest and momentum for this project are starting to pay off and is growing fast. Videos and announcements on TheSallyProject TikTok have great support and interaction, and grows each day. This has been a factor in our fast moving success.

As we launch this spring and give our supporters the action they want with our Fill the Cracks™ campaign and ongoing meetings to choose key partners, directors, supporters, researchers, mentors, patients, medical professionals, and government bodies, we have begun to develop and implement a tangible plan to build a viable non-profit and foundation, The Help-Care Network™.

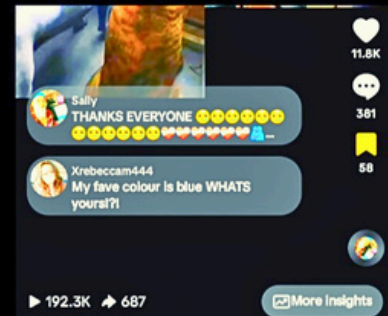
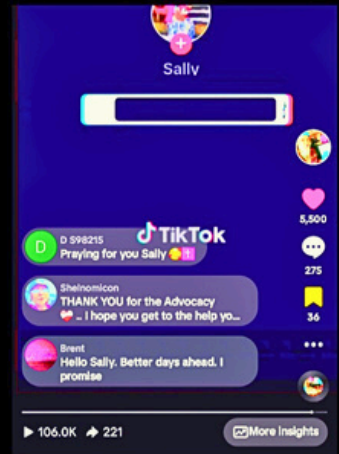
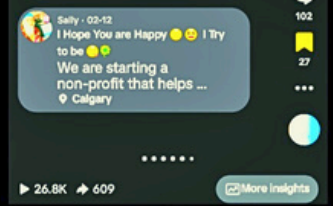


We are currently in transition of social movement to a future NPO there to be supported and useful to all Canadians and in future success other countries. We are looking for key board members and proposals for founding partners. If you, or someone you know has the skills, experience, and willingness to help, please let us know by reaching out to us via email:

thesallyproject.change@gmail.com

If you would like to join as a founding member, director of our boards or committee, sponsor, or volunteer, contact us to discuss how you can become involved in this very worthy cause.

Follow us on Facebook and TikTok and join us in launching our first year of service to patients in need, as we fundraise and campaign for this deserving community of over 1,000 patients seeking access to resources for their debilitating and life-threatening medical challenges.



"While there have been great improvements over the past several years we STILL need more research, education, and awareness about spinal CSF leak to help improve the lives of people everywhere who are affected by it"

QUOTE FROM NPO,
SPINALCSFLEAKCANADA.CA

A 6 YEAR BATTLE ENDS IN STARTING A NON-PROFIT ORGANIZATION



I THOUGHT I WAS OK

Written by Rebecca Klassen with help of her friends
When I go out it takes longer than it would for others because my smile, approachable attitude, and gratitude makes everyone want to stop and ask me, "Why are you in a neck collar?" Sometimes I joke to explain it away, but if they're really interested tell them the truth. I used to dread this because most people want to hear a happy ending, but I still have a mountain of a hurdle to jump.

My name is Rebecca. I was a successful cross-boarder business consultant and Executive Director before I was 30, and I never thought our health care would choose for me to die for lack of available treatment in Canada.

March 31 2018 I was in a accident, the ER and doctor first thought it was a bad concussion but it turned out I had a small spinal leak that had my doctors fighting for over a year to understand and treat. Sadly there are few protocols and as I was facing going blind a year after the accident. The emergency room doctors would send me home after diagnosing me with a migraine, ignoring my doctors hand written notes and calls. I had no choice but to seek private care. I fixed the leak but it left me with a terminal issue with the structure of my neck. In the US, UK, Australia, and other countries it's treated with surgery, but not Canada. As the leak continued I had drop attacks, headaches, and began losing my vision.

Once, after being unconscious for 45 minutes in the ER they consulted my neurologist, who kept asking for a contrast MRI to test a suspected spinal-fluid leak. I was told they couldn't treat me in the ER because that would be "skipping the line".

Though I privately recovered from my leak during 2020, I found out while in the USA undergoing intense cognitive therapy and brain mapping the travel and activity meant I had a Bow-Hunter Strokes. They were a result of the permanent damage from the leak. It had been going on so long my ability to hold up neck was gone and I am actively compressing my brain stem, arteries, and nerves that control breathing, circulation, and heart rate.

NOT OUT OF THE WOODS

They told me I needed surgery and urgently. I told them I was strong and could wait to get back to Canada. They spoke to my doctors and helped me get all the tests my Canadian neurologist requested and I was on my way home to see about a surgery to stop my ongoing strokes.

It was then we found out that Canada did not have a diagnosis and treatment plan for my condition. This lead me to another group of patients who need this surgery and out of all these years, only a handful seemed to be approved for surgery and there was a lot of work to get qualified to apply.

With the long road ahead and my determination to recover without surgery had me decide to move to the mountains and work hard on physical therapy. Five days after moving I had the biggest stroke leaving me in palliative care and without the use of my right side of my body.

I was told over and over to give up. Every time we asked if I could have physical therapy to walk again they told me my situation is what it is, and my options were long-term palliative or hospice. Not physiotherapy to be able to walk or use my hand again. Not the surgery that two doctors in different provinces had recommended.

I don't have much family but the ones I have and friends were calling into the hospital to advocate and eventually I got approved for rehabilitation.

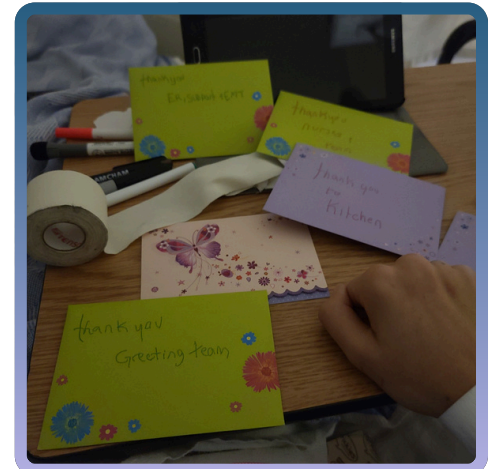
This series of events lead to my first Viral TikTok thank-you video. While finally free after months of captivity in hospitals as an out-patient there was a glorious Starbucks right across the parking lot of my room. Every morning for two weeks I tried my best to push my walker closer and closer to my reward. Sometimes for 45 minutes at a time. I got stronger and finally on day I made it into the doors. Sometimes patrons and staff of the strip mall and hotel watched and offered help but I refused. This was something I needed to do for me. I refused to give up each day. Waking to get my own order became my goal. If I wasn't going to lay down and die, I could one day get healthy enough, work hard enough and be rewarded with surgery in the USA, I would work for the delicious reward here

The day I finally made it there, the staff took a break and sat down with me. We recorded the first TikTok video, which went viral.

I kept on, showing who I am to the world. I started with small things like anonymous thank-you notes, or decorating the front doors with hearts and kudos to friends and helping non-profits so they'd have something cheerful to greet them start of their day.

For years friends and supporters watched me struggle, learn to walk, travel back and forth at my own expense and with the support of others to get the diagnostic imaging and other evaluations necessary to complete the application to still have no hope.

"I must wear this brace to live, I feel like the fable of the greek women who must wear lace around their necks or their head would fall off?,"



Thank-you letters written by Rebecca to the above and beyond healthcare in Cranbrook Palitavecare

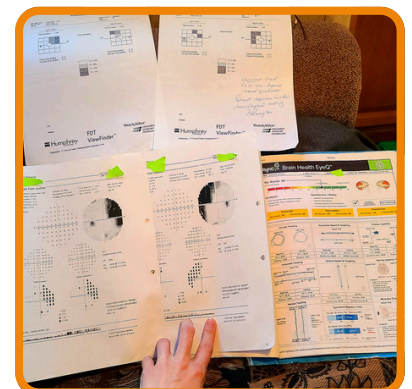
I ask myself sometimes who I would be if this accident had never happened. It is a deep and heavy question, but I am grateful for this experience. I've asked my friends if they would help, not just for me but for all the people who have also fallen through the cracks, and they are coming through.

I grew up strong, I had to always work as a kid, on the farm, in the factory, the market the grueling all nighters of heavy labor. When on my own working for myself I promised myself I would live my life to the fullest, take every opportunity I could, and have no regrets.

Some might consider my story a sad one, but I feel my life has been leading me here to start this non-profit, helping others as much as I can. I have faith that the end of my story will be a positive and successful one.

I am grateful this fall when I shared my wish to start this non-profit and change the world that tho its been years of a battle my friends are here to help me climb this mountain of a problem and see the reward and great reward hard work brings.

Rebecca Klassen - TheSallyProject



Rebecas eye charts with her Doctors handwritten plea to ER Doctors to help her after finding out she was turned away again being told its just a migraine.

All for One and One for All!

What is? The Help-Care Network™

BY FOUNDING MEMBERS OF THE HELP-CARE NETWORK™

We are currently building The Help-Care Network™ – a non-profit that support patients in finding and accessing the help they need on their medical journey through use of our apps, directory database, help line, and programs for people who have no options to help them.

In tandem it will be a invaluable business to business network, that uplifts organizations for positive partnerships, resources, and brings like minded organizations together.

The Help-Care Network™ is connecting businesses, practitioners, and non-profit organizations with each other and with trusted partnerships to grow and better serve their patients and clients in our app, helpline and database. It will act as a central resource – a hub of information and advocacy for all parties. The revenues from advertising, programs, fund-raising, recognition-awards ceremony, conferences, and social reach of this network will be used for our charitable foundation to build programs and grants to support patients and other non-profits, organizations, and healthcare professionals that serve them.

Learning More About Lost Canadians

Connections Among Conditions

Ehlers-Danlos Syndrome (EDS) is a group of disorders that affect connective tissues supporting the skin, bones, blood vessels, and many other organs and tissues. EDS can weaken the connective tissue in the neck, leading to instability.

Cranio cervical Instability (CCI) and Atlanto-axial Instability (AAI) are conditions often associated with connective tissue disorders like EDS. CCI involves excessive movement between the skull and the top of the spine, while AAI involves instability between the first and second cervical vertebrae. Both can lead to neurological symptoms due to pressure on the spinal cord and brainstem.

Cerebrospinal Fluid Leak (CSF Leak) occurs when CSF escapes through a tear or hole in the dura mater, the outermost layer surrounding the spinal cord and brain. This condition can be a consequence of surgical procedures to correct CCI/AAI or may occur spontaneously, especially in individuals with connective tissue disorders like EDS. Other causes can be whiplash, sports injury, cysts, disease.

THE FIRST HEAR ATTACK THANK YOU WAS FOR URSA IN CALGARY, AB



Prognosis

The prognosis for patients with EDS, CCI, AAI, and CSF Leaks varies significantly depending on the severity of the conditions, the effectiveness of the treatment, and the presence of co-morbid conditions. Early diagnosis and comprehensive management and in severe cases surgical intervention to can preserve, improve, save, their quality of life, these are often chronic conditions that may require ongoing management. The variability of these disorders means that some individuals may lead relatively normal lives, while others may face significant limitations.

In large proportion, the diagnosis and treatment of these conditions are not supported in Canada, leaving many sufferers to a preventable declining health and quality of life over time if they in fact survive long enough to be properly treated or even diagnosed.

Follow us on Facebook and TikTok and join us in launching our first year of service, as we fundraise and campaign for this deserving community of over 1,000 patients seeking access to resources for their debilitating and life-threatening medical challenges.

If you want to help or join our success, please contact us on Facebook, TikTok, email thesallyproject.change@gmail.com

A special thank you to some of our volunteers, professionals who helped create this newsletter.



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HELPING HANDS FOR PATIENTS

