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# WHEN ASKED ... CITIZEN STORIES

After releasing our first collection of citizen accounts – documenting delayed diagnoses, forced medical travel, and patients being presented with end-of-life pathways while still actively seeking treatment – we received an overwhelming response. Others wanted to share their stories. Not because they were dramatic. Because they were common.

We expanded the citizen journalism component not as a marketing strategy, but because the demand required it. Patients across Canada are living in the gaps of a fragmented system – particularly those with complex brain and spine conditions that fall between specialties. These individuals often require diagnostic imaging and expertise unavailable domestically, forcing travel to the United States at personal costs ranging from \$50,000 to over \$100,000 simply to confirm a diagnosis.

The stories multiplied because the problem is systemic.  
Fill the Cracks has since evolved into a structured, multi-pronged initiative:

## 1. Direct Patient Support

We operate as a coordinated group fundraiser assisting patients with diagnostic travel, imaging, and treatment planning when access does not exist within Canada. This reduces forced medical migration and financial devastation.

## 2. Systems Review & Infrastructure Development

We are building a multidisciplinary committee of healthcare professionals, nonprofit leaders, and advocates to formally assess system gaps. Our recent call for professional applicants generated hundreds of responses – demonstrating both the scale of the issue and the readiness for reform. This committee will produce structured recommendations to strengthen referral pathways, diagnostic access, and inter-provincial coordination.

## 3. Network Strengthening

We support and collaborate with existing nonprofits already serving these patients, ensuring funds and infrastructure reinforce the ecosystem rather than duplicate it. The citizen stories remain central. They are not anecdotal appeals; they are pattern recognition tools. They reveal repeat failures in access, infrastructure, and coordination. They humanize what policy language abstracts.

Our growth in social engagement and community participation is translating into operational momentum. The movement is no longer awareness-only – it is implementation-focused.

Your partnership enables:

Direct support for patients currently displaced by system gaps  
Development of evidence-based structural reform  
Scalable models of coordinated access

Strengthening of nonprofit and clinical collaboration

This is not charity for rare cases. It is proactive investment in healthcare resilience.  
The cracks are visible.

With strategic partnership, we can close them.

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# THROUGH THE EYES OF ANOTHER – We Witness

## BEYOND MIGRAINE: A STORY OF SALLY



**“I Was Passing Out the First Week.”**

**Rebecca Klassen on The Day That Changed Everything**

Rebecca Klassen does not begin her story with the stroke. She begins with the bathroom floor. “I felt severely concussed right away,” she recalls. “Not just shaken. Altered.”

Within days of her car accident, she went home from work feeling unwell. Hours later, she was violently ill, vomiting repeatedly before passing out. She woke up on the floor beside the toilet. That was her first drop attack. “It wasn’t fainting,” she says. “It was like my system shut off.” It would not be the last.

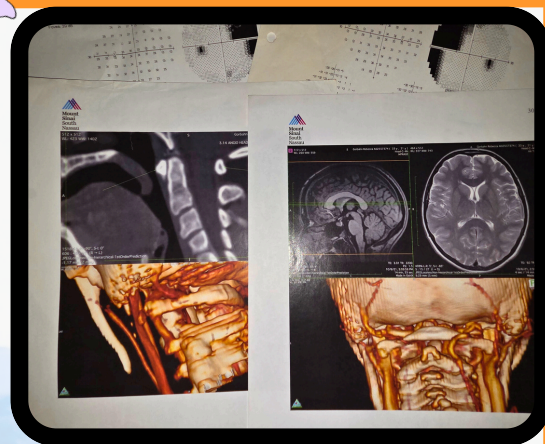
At first, doctors assumed concussion. But her symptoms did not behave like a simple head injury. She experienced crushing headaches that worsened when upright, nausea, instability, and strange neurological shifts. Eventually, she began losing vision. “That’s when we knew something was seriously wrong.”

The diagnosis was a spinal fluid leak. Low cerebrospinal fluid pressure can cause what physicians call brain sag — a downward shift of the brain due to loss of buoyancy — leading to severe headaches, vomiting, visual disturbances, and neurological instability. “For months, my body was functioning on low pressure,” she explains. “Everything felt wrong when I was upright.” She underwent a blood patch, bed rest, and caffeine therapy. The leak eventually sealed. “We thought I was in the clear.” She wasn’t.

After sealing the leak her symptoms changed again. “When it swung high, that’s when things got scary.” After prolonged leakage, the body can overcompensate, producing excess spinal fluid. Drainage regulation can fail, leading to elevated pressure. That was when she began permanently losing parts of her vision. The pain was the worst she had ever experienced — worse than seventeen spinal injections. “So much pain you don’t scream. You just bury your face in a pillow.” Fluid began draining spontaneously from her nose. It was no longer just low pressure. It was dysregulated pressure. And through it all, the drop attacks continued.

“They were happening from the beginning,” she says. Standing too long. Standing still. Turning her head while sitting. “I would just go down.” There was no warning. After she dropped, severe muscle spasms followed. “My fingers curled in. My feet tightened. My shoulders pulled. My neck stiffened. It looked like when you kill a spider and the legs curl under.” It wasn’t seizure-like shaking, but rigid, reflexive firing. Later, when brainstem compression and vertebral artery compromise were identified, the pattern made sense. “The brainstem controls posture and tone. If blood flow is compromised, the body misfires.” Head position. Upright posture. Compression. Drop attack. Spasm. “That wasn’t anxiety,” she says. “That was neurological.”

During this period, her cognition deteriorated. “The sentence in my head wouldn’t come out properly.” She walked unsteadily. Words came out wrong. Her partner often translated for her. They believed months of pressure instability had caused severe concussion-like damage. Later, she would receive confirmation of vascular Ehlers-Danlos syndrome, a connective tissue disorder that weakens arteries and ligaments. It runs in her family; some relatives have weakened left heart function. But at the time, the structural instability beneath everything had not yet been fully recognized.



**FINDINGS:**

Unchanged CT angiogram appearance of the head and neck compared with October 5, 2021.

Again seen, the left internal carotid artery is generally slender compared to the right with focal narrowing in its cavernous segment where the opacified lumen diameter measures 1.5 mm.

Also unchanged is a small aneurysmal dilation superior to left orbital fissure, which connects to a large cortical vein in the left MCA territory and a small vessel arising from the cavernous sinus, its precise origin not clearly seen,

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# THROUGH THE EYES OF ANOTHER - We Witness

## BEYOND MIGRAINE: A STORY OF SALLY-CONTINUED



"I just wanted my brain back," she says. She traveled to the United States for functional brain mapping. Her scan showed measurable dysfunction. During treatment, something shifted. "On day four, the hum in my head stopped." Her language returned. "The sentence in my head matched the sentence coming out of my mouth." But while there, physicians noted cranial-cervical instability. They warned her that this was more than a spinal fluid leak or concussion. She might one day need a fusion.

Back in Canada, she attempted to pursue surgical referral. However, dynamic compression can be difficult to demonstrate in standard supine imaging. "When you lie flat, gravity changes," she explains. "At that time, the narrowing didn't look dramatic enough." There was no referral.

Later, while exploring relocation to British Columbia and setting up a holiday trailer, she experienced a vascular event consistent with Bow Hunter physiology, with Eagle syndrome involvement affecting cranial nerves. "I lost movement on my right side." In the emergency department, a CT angiogram of the neck was ordered. It was debated. Who expects a 33-year-old woman to compress her own artery by holding her head upright? The scan was temporarily canceled before ultimately being completed. It showed compression. Documentation later read: "High-grade stenosis of the left cavernous internal carotid artery," with a lumen measuring approximately 1.5 millimeters, collateral circulation present, and instability at C1-C2. "The relief wasn't that I was fine," she says. "The relief was that it was real." Rebecca now lives with confirmed vascular EDS. "In vEDS, arteries and ligaments are fragile." At the cranial-cervical junction, that fragility allows abnormal movement. Even now, prolonged upright posture can trigger symptoms. "My right eye can drift outward. Pressure builds. I have to lie down." Without her neck collar, cranial nerve irritation increases, headaches spike, and she previously experienced bladder dysfunction. "The collar doesn't cure anything," she says. "It reduces compression."

After her stroke, she applied for out-of-country surgical care. The application was denied. She was told she would need to raise approximately \$350,000 privately. "This isn't rare," she says quietly. "It's just uncoordinated."

Rebecca speaks now not only for herself but for others navigating similar overlap. "We're not asking for miracles," she says. "We're asking for coordination." Because no one should wake up on a bathroom floor in the first week after an accident and spend years proving it was never "just a concussion."

### The Hard Truth

Here is what I have learned., emergency medicine is built to rule out catastrophe. It is not built to navigate overlap.

Spinal fluid leak.

POTS.

Cranio-cervical instability.

Dynamic vertebral artery compression.

Individually, each condition is known.

Together, they fall between specialties.

Neurology doesn't fully own it.

Vascular surgery doesn't fully own it.

Emergency medicine doesn't fully own it.

So patients end up owning it.



I was told I would need to raise approximately \$350,000 privately for surgical stabilization after out-of-country applications were denied. I don't believe patients should have to crowdsource survival.

### CITIZEN JOURNAL "11:39"

So, it happened again. It's a beautiful Saturday morning, the birds chirped joyfully outside my bedroom window, and other than that the house was silent.

The soft warmth of my blanket slides along my skin like silk. Finally, my pain has gone. I pulled the blankets up over my shoulder and reached forward. Blindly, I pulled the cat into my embrace, her deep purrs are heaven to my ears. Suddenly something bounced onto the bed behind me, another something crawls under the blanket right where the warmth of the cat can still be felt. Somehow my furry friend managed to sneak away.

I groaned like every morning when these creatures wake me. I tell them to go have cereal; they just giggle at me. I tell them to have bread. "But mom," says a small voice from behind me. "We had breakfast, and I was big and made lunch and now it's dark. I think we missed dinner, the clock says 11:39. My eyes flew open, the creature in my arms looks at me with a little smile. Pure love emanating from her tiny face. I glanced across the room for the clock: 11:39. What?

I both (jump?) straight up not realizing I'm tangled in the sheets, the bedroom carpet comes flying at my face. Well, more accurately, my face greeted the carpet - and trust me, the carpet was not invited. The two creatures giggled even harder, one even reminded me that my pyjamas lie at the foot of my bed by announcing they can see my butt. Again, I had torn them off during the night. Even though they were baggy on me they still had felt restricting, causing everywhere to ache. An ache so intense that it awakens you in tears, panic, and fear. It is like thousands of little ants are crawling inside of you and biting anything they can find.



### CITIZEN JOURNAL "BROWN"

Today is a little better than the last five days. I've actually got a few hours of good sleep.

I still feel weak. I made it to the bathroom and the couch with minor pain. Hot bags and ice packs are what the doctor recommended for pain management. The ice packs feel nice on my arthritis, but my fingers go purple so fast, that I find myself running lukewarm water over them. Crying the whole time because it feels like someone has put your hand through the sewing machine.

Bringing them back to life hurts so much more than the pins and needles you get for sitting on your foot. I was given a heated blanket to help. It warms my legs beautifully.

Well, sometimes. I mean sometimes it's a cheque and that's good, but I digress. I open the brown envelope, inside it has my claim number for CPP.

Oh no! Here I go again. It could be an audit. I read the page frantically. CPP has sent yet another letter saying the same thing they always say, that when I turn 65 and it becomes old age pension, I'm going to have very little income because I've been using it early. What am I supposed to do? I'm on it because I can no longer hold a job. So what are they trying to get me to do? I can't go back to work, and if I stay on CPP I am going to be a homeless senior citizen. This of course causes me so much stress, which turns into a "flare", which debilitates me. Keeps me on the couch or in my bed. Listening to all the stories my children tell me. Stories I should have been able to see with my own eyes.

I can see the happiness in their eyes, but I can also see the sadness.

### CITIZEN JOURNAL "AGAIN"

This time I don't think it was the weather. I think it was all the people at the grocery store. Trying to find parking was a nightmare, even for handy cap. When I finally found a spot, parked and got out, there was this woman watching me. She looked at me with absolute disgust. That happens often. There seems to be a social mentality that handicap parking is for senior citizens.

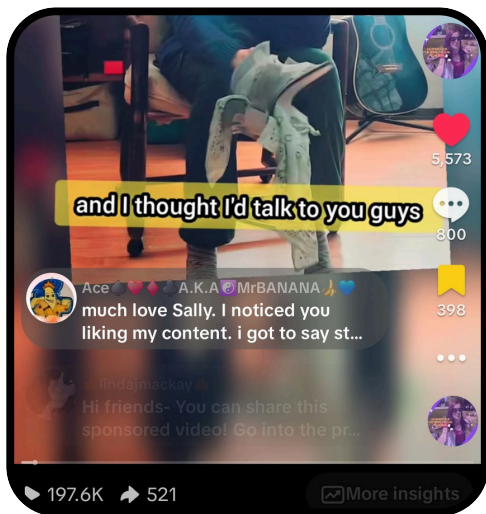
Like usual, I ignored it. As I made it slowly through the aisles, I was so nauseous. I have gotten so used to my stomach contents coming back up that I don't think about vomiting. I just swallow what comes up to say hello, letting it burn its way back down. So much better than hanging over a toilet bowl for an entire day. Each step I took in the store shot pain up my legs. I thought for sure a couple times my legs were going to give out. They reminded me of my arm this morning.



I had woken before my alarm finding my arm completely limp. Try as I might it would not move. It was like it wasn't even there. Honestly, that should have been my sign that I was coming into a "flare." After flopping my arm around with my other hand, I could move and feel it again. Sitting up I realized my legs were in a similar state.

My toes wouldn't even wiggle. I spent the next few minutes pile driving my thighs with my fists. Once I could move my toes, I realized the alarm was still beeping annoyingly. Frustrated, I stood up, a little wobbly. Suddenly a warm sensation rolled up from my chest into my head, the world tilted and began to spin. I quickly sat back down. With the dizzy birdies gone I carefully crawl-walked around my bed to shut my alarm off. Just as I'm rounding the last corner of the bed, it shuts itself off. I was mad.

here I go again



### ROLES DON'T REVERSE

Today I feel so guilty.

My husband has been gone for two days, and even though I'm fifty years old, my parents had to come stay with me while he's away. I fall a lot. Today it happened in the bathroom. My neck hurts so badly now that I can barely walk.

I keep thinking about how this is supposed to go. Parents take care of you when you're young. Then you take care of them when they're old. But here they are, still working, still worrying, still taking care of me.

They spent their retirement trying to get me diagnosed in the States. Paying for tests. Paying for treatments that were supposed to help. But what I really needed was surgery — a cranial cervical fusion — and I was told it isn't available in Canada yet.

So we did everything except the one thing that could actually fix it.

Now I feel like a burden.

Like I've taken the years that were supposed to be peaceful for them and turned them into hospital trips and paperwork and waiting rooms. And who has a hundred and seventy thousand dollars anyway?

Sometimes I lie here and think about all the things I was supposed to do for them one day. The help I was supposed to give back. The way I was supposed to show up.

Instead, they're here holding me up. I love them so much it hurts.

And I hate that love has to look like this.

### FIVE YEARS OF LEAKING

Today I jumped for joy, and I cried — all within the same hour.

I had just finished watching one of the webinars hosted by Spinal CSF Leak Canada. One of the doctors they invited spoke about symptoms I've been living with for years, and for the first time, I heard them described in words that actually fit. It was such a simple thing, just listening to someone explain what my body has been doing, but it made me feel seen in a way I haven't felt before.

For a little while, it felt lighter. Like maybe I wasn't imagining it. Like maybe all of this really does make sense to someone.

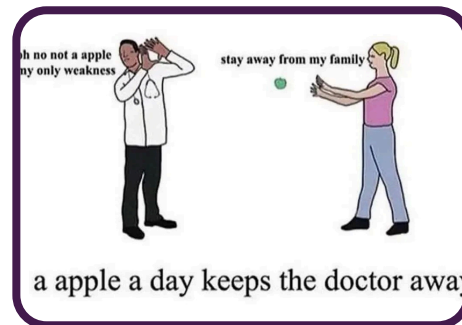
I know that right now this doctor can only help in theory and conversation, and I'm grateful for that. I hold onto the hope that one day they'll be able to help patients like me directly, here at home, with the tools they need to actually treat us.

For now, I've been told that the specialists in Toronto need me to go to the United States for more imaging before they can move forward. I wish I could go. I really do. But I can't afford it, so waiting is the only option I have.

When I watch these webinars, I feel hopeful. I feel like maybe things are starting to change. Like knowledge is finally catching up to what patients have been saying for so long.

And then I remember that I've been leaking for five years.

**FIVE YEARS OF TRYING TO MANAGE SYMPTOMS, OF PACING MY DAYS, OF DOING MY BEST TO STAY POSITIVE WHILE HOPING THAT HELP WILL COME BEFORE THINGS GET WORSE.**



### THE CHEERLEADING ENDED

Today my daughter cried and said, "It's not fair, it's not fair, it's not fair."

She's sixteen, and today we had to take her out of her favorite sport — cheerleading. Watching her lose that part of her life felt like watching something she loved slip away, and there was nothing I could do to stop it.

I never even received my own diagnosis for EDS, but when she started fainting, when her energy kept dropping, when a simple ankle sprain took nine months to heal, I knew something wasn't right.

Now I look back and see my own story more clearly.

Always getting sick.

Always tired.

Struggling to keep up with physical work.

Living with pain and low energy that no one could ever explain.

Now it finally has a name.

And now it has touched my child.

What hurts the most is knowing that the specialists who understand this condition are far away. We are in Saskatchewan, and the care we need is in Toronto. Travel, hotels, time off, appointments — none of it is possible when you are living on disability and already choosing between essentials.

So we manage. We pace. We rest. We wait.

I grieve for the things she's losing — the sport she loved, the freedom of being a teenager who doesn't have to think about her joints or her energy or how long she can stay upright.

Some days the grief is heavy. But love is heavier.

### CHURCH BRINGS DINNER

It's been four months since my divorce. I'm living with my mother and her three kids in her small two-bedroom apartment. I have POTS. My heart rate is high, and I'm exhausted. I also have MCAS, so I seem to just be sick and allergic to everything all the time.

My husband thought I was lazy, and my kids thought I was just tired all the time and sad all the time, as their teachers would tell me in conferences. My mom has EDS. She knows what I'm dealing with.

I am lucky because I have good friends and a good church community. We have visitors nearly every day. It's important because the hard things are the little daily things. And thanks to the people who come around and help doing dishes and bringing meals mean I can spend quality time with my kids helping them do their homework.

I don't know how I managed before I went back into my family's arms, and I don't know how others manage. I think I am lucky, even if life isn't much but just family.



### 4 YEARS AGO I DID TRIATHLONS

Today is a bad day. I can't get up. My eyes are shaking and my body won't cooperate, but I still have to get down to the work office to try to earn enough cash to afford my medication.

I've been waiting for disability, but it keeps getting denied because my hospital reports just say "migraines." Meanwhile, I can barely walk. My doctor keeps trying to refer me to neuro-spine surgeons, but they won't even accept my charts. I don't understand how they can say no without ever speaking to me.

When I finally did see a neurologist, he didn't know anything about my condition. It runs in my family. I also know that living in a moldy house triggered a major flare that attacked my spine. My sister had to travel to Barcelona for her fusion, and she warned me this could happen to me too.

Four years ago, I was doing triathlons. Now I can barely get out of bed.

I'm writing this because I don't know what else to do anymore. I need someone to actually look at my case, to listen, and to help before I lose more of my life to waiting and paperwork.

I am still here. I am still trying. But I can't do this alone.

### GRAVITY DOESN'T SHOW

Sitting at the airport right now, waiting to fly to Miami for my upright MRI.

This is not a trip I ever wanted to take, but it's the one we have to take.

It's just a day trip because that's all we can afford. It still feels strange that I have to leave Canada just to get a scan that might decide if I can get surgery.

I keep thinking about my kid. I can't even pick them up right now, and that breaks my heart. My sister had to move in to help, and I'm grateful, but I miss being able to just be the mom who does things without planning around pain.

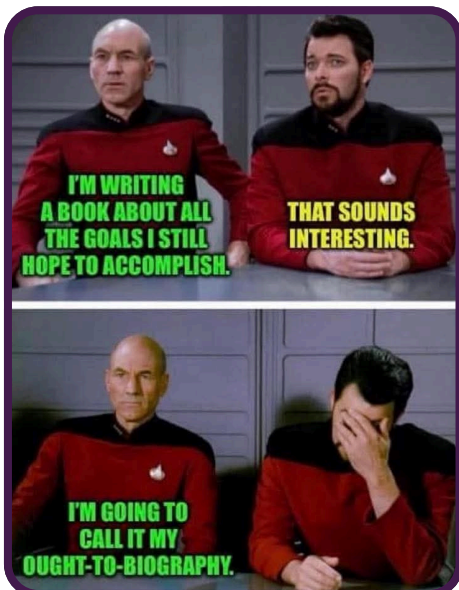
When I stand, my neck pinches nerves and I pass out. When I lie down, everything can look "normal." So this test is the only way to show what gravity is doing to my body.

Travel itself is already painful. Even getting to New York for connections was hard on my body. And I keep thinking... if this MRI shows I need a fusion above C2, I may have to travel out of the country for surgery. I honestly can't imagine how painful that would be if this is already this hard.

Boarding soon.

I'm tired, and I'm trying to stay calm, and I'm holding onto hope.

I just really hope this scan helps us move forward.



### CLEAN UP IN AISLE SEVEN

Today was humiliating.

It happened between the cereal and the canned soup. One minute I was upright, going over my grocery list and calculating whether I had enough energy to finish the trip. The next, my vision narrowed, the store noise faded, and the floor came toward me. There is no dignity in losing consciousness in public. Your body does not ask permission. It simply stops cooperating. I live with postural tachycardia syndrome. When my blood pressure drops or my heart rate surges beyond what my body can manage, I can faint. Sometimes there are muscle spasms when I'm down. It can look dramatic. It can look frightening.

It can also, apparently, look like a drug overdose.

Because I am thin and was unresponsive, someone assumed what they were seeing. Narcan was administered. When I didn't immediately "wake up normally," and when I didn't have ID on me, the tone shifted. Concern turned into suspicion. I was no longer a woman who had collapsed — I was treated like someone who had done this to herself.

But I wasn't intoxicated. I wasn't using illicit drugs.

I was a patient whose autonomic nervous system had malfunctioned in public.

The hardest part is that it isn't just strangers who make assumptions. My sudden weight loss, My balance issues, the fog in my speech — it has even led my own sister to wonder if I am secretly an alcoholic. That kind of doubt cuts deeper than anything said in a grocery aisle. When your body changes in visible ways but the cause is invisible, people reach for explanations that feel familiar to them.

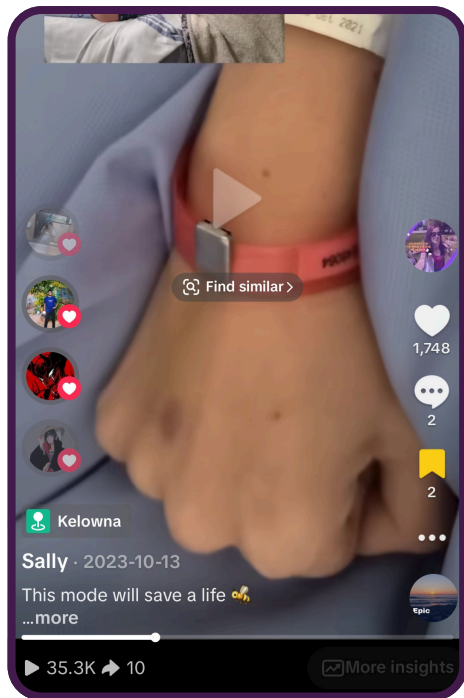
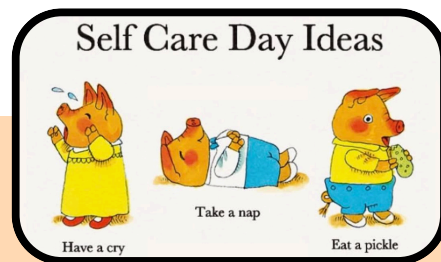
Invisible illness does not come with a uniform. You cannot see autonomic dysfunction. You cannot see the hours of effort it takes to stand upright some days. You cannot see the hydration plans, the medication timing, the quiet calculations happening in my head just to make it through a store.

You only see a body on the floor, fill in the rest with assumptions.

When I woke up, disoriented from the physiological crash, what I needed was simple: lay flat, elevate my legs, give my body time to regulate. Instead, I woke into scrutiny embarrassment heavier than the groceries I never brought home, one moment, one misunderstanding. We absolutely need overdose response. Narcan saves lives. Quick action matters. But so does dignity. Not every unconscious person is overdosing. Not every thin body with balance issues is hiding a secret addiction.

Some of us are fighting conditions you cannot see.

And when our bodies fail in public, we deserve compassion before conclusion.



### AT LEAST I HAVE THIS

I am always sore. Always a little sickly. I can't work anymore, so my husband works more than one job to carry us.

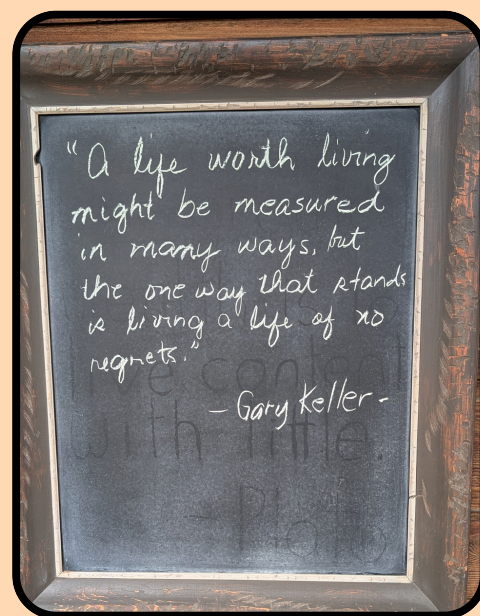
He gets up at 3 a.m. every day. Before he leaves, he sets out my medication so I don't have to manage it half-asleep. He flips my angel message calendar so there's a new page waiting for me when I wake up. It's such a small thing.

But when your body fails you often, small things are not small.

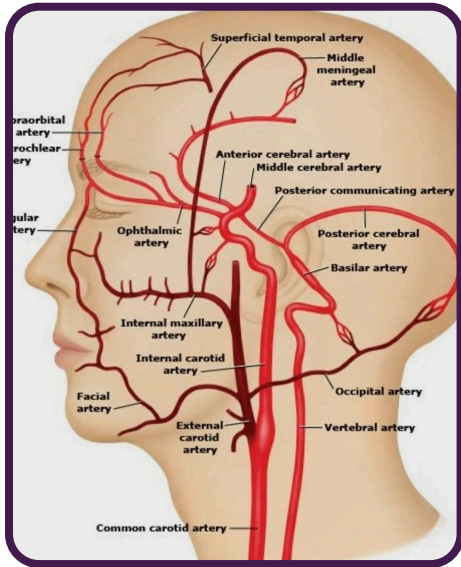
We've had many years of mostly downs. More medical than magical. More managing than living.

But every morning, at 3 a.m., someone quietly makes sure I have the best start possible.

I don't always feel strong. But I do feel loved. And at least I have this.



## DIARY LIFE OF A CHRONICALLY SICK / CITIZEN-SHARED STORIES



### ME TOO

Today I went to a brain injury support group.

I don't technically have a head injury. I have Ehlers-Danlos syndrome. I have relentless brain fog. I likely have elongated styloids, but I'm still on a wait list to see a specialist.

Some days I can't find words. Some days I can't track a conversation. It makes you question yourself.

Am I dramatic?  
Am I lazy?  
Am I losing it?

I'm so often sick that I barely leave the house. I took everything I had to go today. I know I'll be sleeping for days to recover from the effort. But it was worth it.

I met someone who understands what it feels like to live inside a brain that doesn't cooperate. Someone who didn't look at me sideways when I lost my train of thought. Someone who just nodded and said, "Yes. Me too."

For the first time in a long time, I didn't feel alone. I made a friend who knows what it's like to be me.

And that was worth the crash that will follow.



### SOLD EVERYTHING

I spent everything I had to get surgery abroad. I sold my home. I sold my car. I used up my line of credit. I came home believing I had bought myself stability.

But now I think one of the screws might be loose.

Traveling back after surgery was brutal. My body was not ready. I tried to push through because that's what you do when you've already spent everything.

I went to my doctor here in Canada. They can't requisition the scan I need. If the hardware is loose and I need revision surgery, I would have to go back to the country where it was done.

I don't have the money to go back.

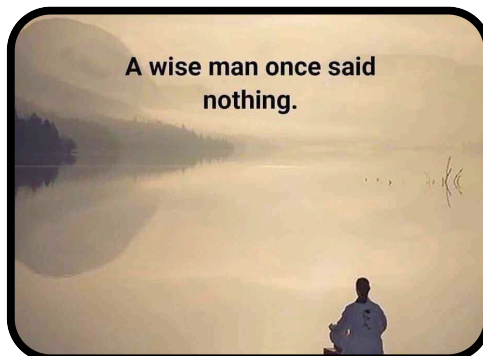
So now I lie here wondering if I traded everything I owned for a surgery that might fail now my bone fell apart.

I did what I had to do to try to save my body.

But what happens when the help you needed doesn't exist where you live?

I don't feel brave right now.

I just wish I wasn't facing this alone.



### WHAT MY MOTHER TAUGHT

I'm not sick.

I'm a police officer.

But the reason I do this job the way I do is because my mother has severe multiple sclerosis. I grew up watching her body fail her in ways she never deserved. And I never saw her as less of a mother. If anything, I cherished her more. The cuddles meant more.

The nights she read to me meant more.  
The quiet moments meant more.

I learned early what strength really looks like. It's not loud. It's not flashy. It's getting up again in a body that doesn't cooperate. It's loving your child fiercely even when you're exhausted.

Now when I go to calls and meet people who feel like they aren't enough — people living with addiction, illness, disability, or just deep discouragement — I carry her with me. I tell them about my mom.

About how needing help doesn't make you weak.  
About how being cared for doesn't make you less.  
About how sometimes the strongest person in the room is the one who keeps going quietly.  
Watching her didn't make me pity her.  
It made me strong for others.

And if I can show even one person that their life still matters — the way hers always did to me — then I know I'm doing something right.



### REPEAT, REPLAY

I'm riding home right now, and my mind won't slow down. I keep replaying everything, and I just keep thinking... how could they think that about me?

My head is pounding, that deep pressure again. My vision is off, my words feel slower, and I can feel my brain not lining up the way it should. I know what's happening in my body, but I can also feel how it looks from the outside—and those two things are clearly not being understood the same way.

I tried to sit upright, but it made the pressure worse, so I leaned back and stayed quiet. At that point, I wasn't trying to explain anything anymore, I was just trying to get through it. But I could feel it... the shift in how people were looking at me, like they had already decided what this was.

And it keeps hitting me... how could they think I'm drunk? They don't see what this actually looks like behind the scenes. They don't see the dark rooms, the silence, the effort it takes just to get my system to settle. They don't see that this is something physical, something neurological, something I am constantly trying to manage.

I can feel when my words don't come out right, when my focus slips, and I know that's the moment people start filling in the blanks. But what they're seeing is only a fraction of what's actually happening.

What they don't see is the medical side of this. They don't see what low pressure does to a brain, or how everything—speech, vision, balance—can shift all at once. They're seeing pieces, and trying to make sense of it without the full picture.

And the hardest part is, the moments I need to explain it the most clearly are the moments my brain won't cooperate.

So I sit there, quiet, letting it pass, trying to hold onto what I know is true.

Because the reality is, I am not drunk. I am not unstable in the way they think I am. I am dealing with a brain and a body that are under real, physical strain.

And I just wish people could see the difference.

### THE MAN WHO WAITED

I ran away to the mountains when the city decided who I was.

After a bad concussion, my brain never fully came back the same. Eventually, doctors began using the term CTE. The brain fog was thick. My speech would stall. I'd lose words mid-sentence. Sometimes I'd mispronounce simple things. Sometimes I couldn't keep up at all.

From the outside, it didn't look neurological.

It looked like I wasn't trying. Or that I wasn't very bright. Or that maybe I had a drinking problem.

So I left. I went somewhere that had once felt safe to me as a child — Radium Hot Springs. Mountains. Mineral water. The kind of town that feels tucked into the earth.

That's where I met Rolf.

Rolf Heer had turned a small piece of land into a world of chainsaw carvings — bears, faces, stories pulled straight from cedar. He was a former teacher, a traveler, a creator who didn't bend easily to what people thought he "should" be. His place wasn't just a business. It was a gathering point for people who lived a little differently. The first time he noticed me struggling, he didn't whisper about it. He didn't avoid me. He looked straight at me and asked, blunt and steady: "Do you have an impediment? A brain injury or something?" It wasn't unkind. It was direct.

My husband explained — the concussion, the diagnosis, the cognitive changes, the way my speech could falter even when I was trying as hard as I could. From that moment on, Rolf adjusted without making it feel like pity. He slowed his stories just enough. He gave me time to find the word. If I mispronounced his name — which I did, many, many times — he would grin, correct me gently, and let me try again.

We'd sit by the fire and he would talk about teaching, about traveling, about carving pieces before chemotherapy would make him too tired. After cancer came. After a fire took his home and much of his life's work. Loss after loss — and still he chose to build, to gather, to create.

He encouraged this community to live for themselves. Not to shrink because someone disapproved. Not to bend because someone misunderstood. He had a way of drawing people together — artists, wanderers, the quiet ones, the ones healing from something you couldn't see.

When I felt ashamed of my own brain, when I felt smaller because I couldn't speak smoothly or track every conversation, Rolf did something rare. He waited. He made room for me to finish. He let me try again. He treated me like I was still fully there — because I was.

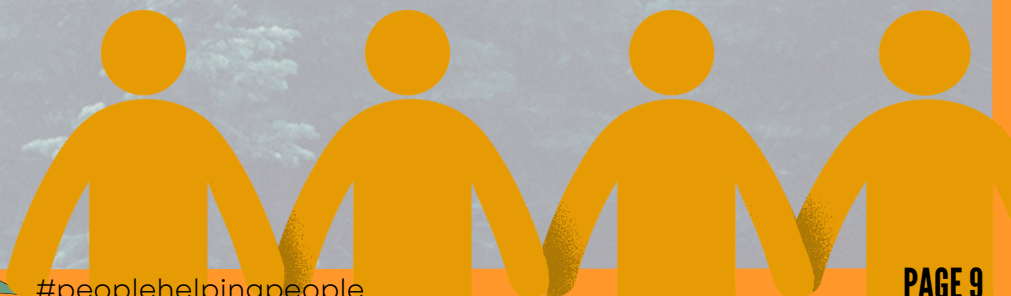
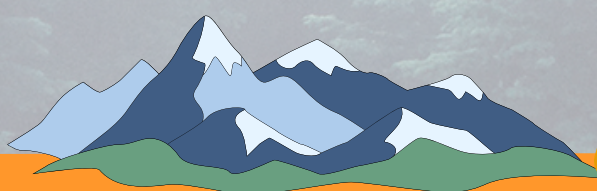
In a season when I felt judged and mislabeled, he chose patience over assumption.

When people are sick of being sick — when bodies fail, when fires take homes, when cancer drains strength — some people shrink.

Rolf didn't. He lived. He carved. He gathered.

Pulled beauty out of rough wood. And he gave other people space to do the same.

I will always remember the man who waited for my words.



# THROUGH THE EYES OF ANOTHER – Karen's Story

ONE SLIP TO A LONG ROAD OF RECOVERY, HEROES IN ALL PLACES

## Help-Care Heroes: The quiet army behind every sick person

Written by our Patients, Contractors & Volunteers

Looking after your own life is hard enough. Even when we're healthy we lean on friends, family, doctors, counsellors – we trade favours, share burdens. There's always something: the dishes piled up, the bills unopened, the unread emails we know we must answer tomorrow.

Life takes work.

But what happens when you have to look after yourself AND someone else?

What if you're sick yourself AND you're also helping someone who's sick?

What if you don't have family nearby, or the people around you are already carrying heavy loads – financially, emotionally, physically?

In a world where phones bring answers instantly, contrast that with someone who's too exhausted to lift their arm, who spends hours just trying to recover enough strength to sit up again. This isn't a tough week; this is their every day, for the rest of their life.



Picture of Karen in a satisfied smile to her friends sharing her adventure getting into the river with the help of her wheelchair while out with her family on a good day.

## Karen's Story

A Wrong Slip & Slide Costs A Family More Than \$100,000 And It's Not Over Yet...

Spinal CSF leaks remain one of the most under-recognized and under-treated neurological conditions in Canada. Patients often spend years seeking answers, with little coordinated care and even less awareness among physicians. What's changing that? Community. Karen's story is just one example of what's possible when patients lead the way. Karen's concussion came from a Slip 'N Slide accident while playing with her son. It was her sixth concussion, and this time the story didn't end after the visit to the doctor. Two months later, she suddenly couldn't walk, her head throbbed constantly, and everyday sounds and motion overwhelmed her senses.

Once an active mom and a full-time strategist for The City of Calgary, she was suddenly stuck in bed, unable to be upright, and without answers or a way forward. What followed wasn't just a string of misdiagnoses, it was a years-long fight to be taken seriously. Where the system couldn't help her, other patients did.

The accident happened in 2013. At first, doctors treated it like it was "just a headache" with dizziness. Then came a diagnosis of Lyme disease, which led to years of treatment with only marginal improvement. It wasn't until she came across references to orthostatic headaches (what she had been calling "positional head pressure") that some of the pieces began to fall into place.

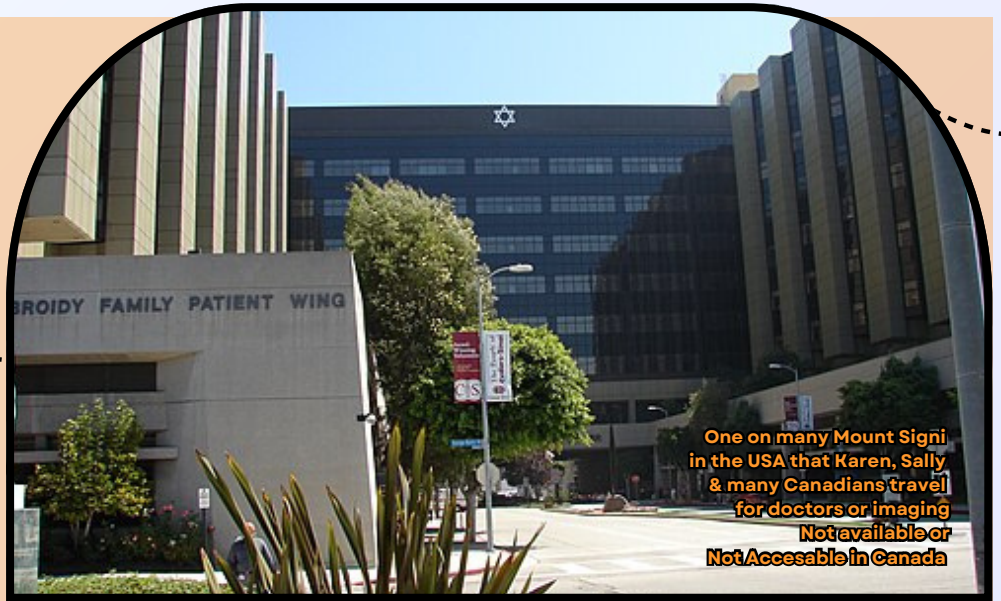
Through her own research and connections in patient communities, she started to suspect something deeper was wrong. A neurosurgeon in New York, Dr. Paolo Bolognese, was the first to suggest a spinal CSF leak. That diagnosis opened the door. Karen reached out directly to Dr. Farnaz Amoozegar in Calgary (one of the few Canadian neurologists familiar with CSF leaks) and to her surprise, Dr. Amoozegar responded. Within weeks, Karen had a clinical diagnosis and access to imaging and treatment, but the search didn't end there. When blood patches in Calgary failed, she flew to Los Angeles, paying over \$30,000 out-of-pocket for advanced scans. Suspicious leak sites were identified, but follow-up treatments back home didn't bring lasting relief.

Eleven years later, Karen finally received the golden ticket – a diagnosis of spinal CSF leak by a new Interventional Neuroradiologist in Toronto, whom she learned about through one patient who highlighted her success in a TV news spot. Karen's two spinal CSF leaks were swiftly repaired in Toronto using a technique only available in a few cities in Canada. Now she's gone from having not enough CSF to having too much CSF and learning to cope with a new condition. What helped, and kept her going, was the network she found along the way. A Facebook message from another patient led her to the Canadian CSF Leak Facebook support group, where strangers swapped PubMed links, doctor names, and practical survival tips. People who had never met in person became lifelines. It was peer knowledge, attending conferences and reading articles in order to advocate for better care that got Karen where she needed to go. It wasn't just about information – it was about solidarity. Karen said it best: "Patients shouldn't have to read medical journals to get help, but we do – and we share what we find." The deeper issue, Karen says, is that most doctors aren't trained to recognize CSF leaks – many still believe they are rare and are entrenched in old myths that become barriers to care.

Keep reading Karen's Story on the next page...

## KARENS MILES OF TRAVEL FOR ANSWERS

While awareness is slowly improving, far too many physicians dismiss symptoms or misdiagnose patients, sending them down years-long detours. Even the imaging used to confirm leaks is prone to false negatives, which can shut down care entirely. CSF leaks don't always come from dramatic injuries. Karen points out that women develop leaks during childbirth – specifically after receiving an epidural. While acute post-dural puncture headaches are sometimes recognized and treated, leaks that persist or appear later often go undiagnosed. “There are many women who walked out of the hospital thinking they were fine,” she says. “Then they get hit with a wave of symptoms months later – and nobody connects the dots.” For these patients, the trail often goes cold before it even starts. The result is a system that often rewards certainty over persistence.



Thanks to patient advocacy, diagnostic capacity in Canada is improving. Calgary and Edmonton now have imaging specialists with leak experience, and Dr. Amoozegar's clinic is no longer the only one of its kind. Some physicians are starting to pay attention – including those who once dismissed these cases entirely.

Karen sees this shift as slow, but meaningful. She points to the role of individuals willing to challenge the status quo: the doctors who answer cold emails, the specialists who conduct new research, the patients who organize care resources and fundraising campaigns, the community that refuses to let each other fall through the cracks. She continues to navigate her own uncertain path – with consultations out of province and out of country, while grateful for the opportunities offered in Calgary – but she's no longer doing it alone. “Canada is in a better place right now,” she says. “The community patient expertise is second to none. We're getting better, because we're doing it together.” The solutions to this crisis won't come from one clinic or one specialist. They'll come from networks like this one — sharing knowledge, building trust, and refusing to give up on each other. That's what keeps people going. That's what will change the system.

Doctors may not see many leak cases, but that's partly because they're not looking — and patients who don't fit the textbook picture are often told it's all in their heads. In that vacuum, patients become the educators, advocates, and case managers for themselves and each other. As Karen puts it, “We're connecting the dots because no one else is.”

Still, there are signs of progress. Canada now has more experienced neurologists, more precise diagnostic imaging options and expertise, and more options for CSF leak repairs.

Further, national networks have been established and continue to grow through Spinal CSF Leak Canada and the Medical Advisory Team. Toronto has some of the top experts in this field. They host National Case Rounds and are developing a standard of care with practicing physicians. Plus, Spinal CSF Leak Canada hosts the big annual conference and other advocacy and education events. These organizations are fairly new, and they have developed a lot in a short time frame with little funding.



On her good days, when Karen can sit up, she posts pictures of her garden tracking the birds and buds.

# A PERSONAL STORY OF THE SALLY PROJECT

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



### I THOUGHT I WAS OKAY

**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, I 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.**

On March 31, 2018, I was in an accident. The ER team 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 in Canada to get treatment - it got worse, and 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 handwritten 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 would be treated with surgery, but not in 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 had Bow-Hunter's Strokes. They were a result of the permanent damage from the leak.** It had been going on so long that my ability to hold up my 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

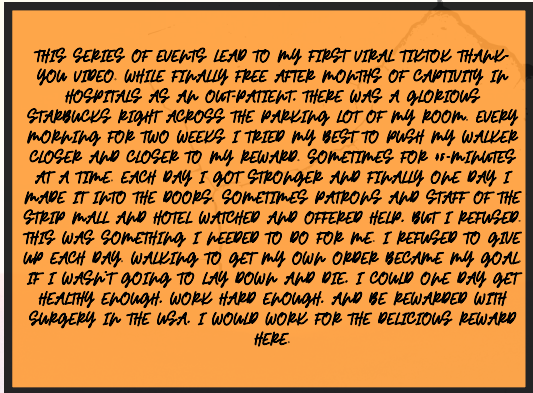
They told me I needed urgent surgery. I told them I was strong and could wait to get back to Canada. They spoke to my doctors and helped me get all the tests my Canadian neurologist requested and I was on my way home to see about a surgery to stop my ongoing strokes.

It was then we found out that Canada did not have a diagnosis and treatment plan for my condition. This led me to another group of patients who need this surgery. 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, I decided to move to the mountains and work hard on physical therapy. Five days after moving I had the biggest stroke that left me in palliative care and without the use of the 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 my friends were calling into the hospital to advocate and eventually I got approved for rehabilitation.**

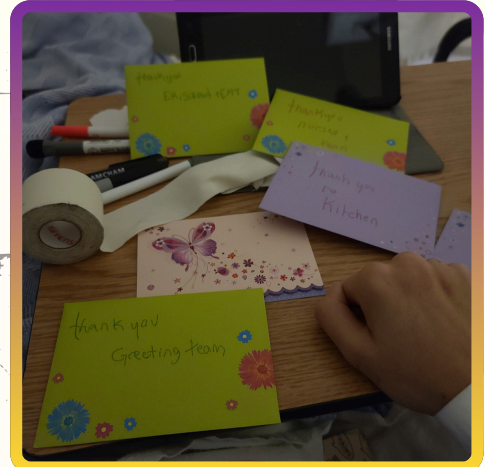


The day I finally made it there the staff took a break and sat down with me. We recorded the first TikTok video, which went viral.

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 at the start of their day.

For years friends and supporters watched me struggle, relearn to walk, travel back and forth at my own expense and with the support of others to get the diagnostic imaging and other evaluations that were 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 Palliative Care

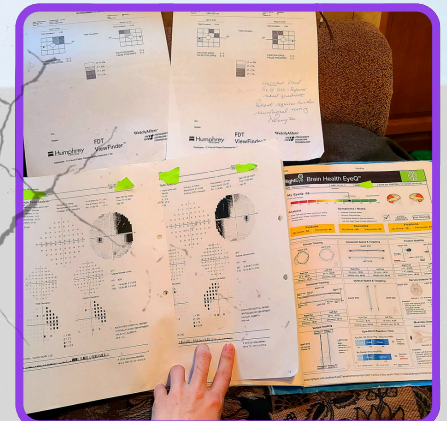
I ask myself sometimes who I would be if this accident had never happened. It is a deep and heavy question, but I am grateful for this experience. I've asked my friends if they would help, not just for me, but for all the people who have also fallen through the cracks - and they are coming through.

I grew up strong. I had to always work as a kid - on the farm, in the factory, the market, the gruelling all-nighters of heavy labour. 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 and help 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 even though it's been years of a battle, my friends are here to help me climb this mountain of a problem and see the great reward hard work brings.

**Rebecca Klassen - TheSallyProject**



Rebecca's 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.

# HELP US FILL-THE-CRACKS- Share, donate, volunteer

## What is the Vision of the future Help-Care Network ?™

BY FOUNDING MEMBERS OF THE HELP-CARE NETWORK™

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

In tandem, it will be an invaluable business-to-business network, that uplifts organizations for positive partnerships, resources, and bring 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 future charitable foundation to build programs and grants to support patients and other non-profits, organizations, and healthcare professionals that serve them.

## To leave you with a message

BY FOUNDING MEMBERS OF THE HELP-CARE NETWORK™

These stories are not isolated tragedies — they are patterns repeated across provinces and across diagnoses. They document what happens when patients with complex brain and spine conditions fall between specialties, between referral systems, and between provincial boundaries. We have raised awareness. We have completed petitions. We have spoken to politicians. We have lit Niagara Falls purple. We have shared our stories in public forums and quiet support groups alike. And yet, families are still selling homes to access care abroad, patients are still being delayed because the right imaging does not exist locally, and some are being left with choices that no one in a developed healthcare system should have to face.

The tone of these letters may feel gentle — like chicken soup for the sick person's soul — but beneath that warmth is urgency. These are not dramatic narratives. They are lived realities. They reveal a healthcare structure that is not designed for overlap, not built for coordination, and not equipped for complex connective tissue, CSF leak, and instability cases that do not fit neatly inside one specialty. This is not about impatience. It is about preventable decline. It is about access to appropriate diagnostics, trained specialists, and inter-provincial collaboration. It is about patients who are not rare — just uncoordinated within the system.

Fill the Cracks exists because these stories demand more than sympathy. They require action. Our committee is working to build pathways to diagnosis, to strengthen nonprofit and medical networks, and to identify and close the structural gaps that leave patients stranded. But change requires collective effort. Support the fundraiser. Share the docuseries. Circulate these stories. Bring them into policy conversations and clinical training spaces. Because awareness without action is not enough. The question is no longer whether this is happening — it is when enough will finally be enough, and when Canada will listen.

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



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## HELPING HANDS FOR PATIENTS

