inspire

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Tumour Foundation of BC

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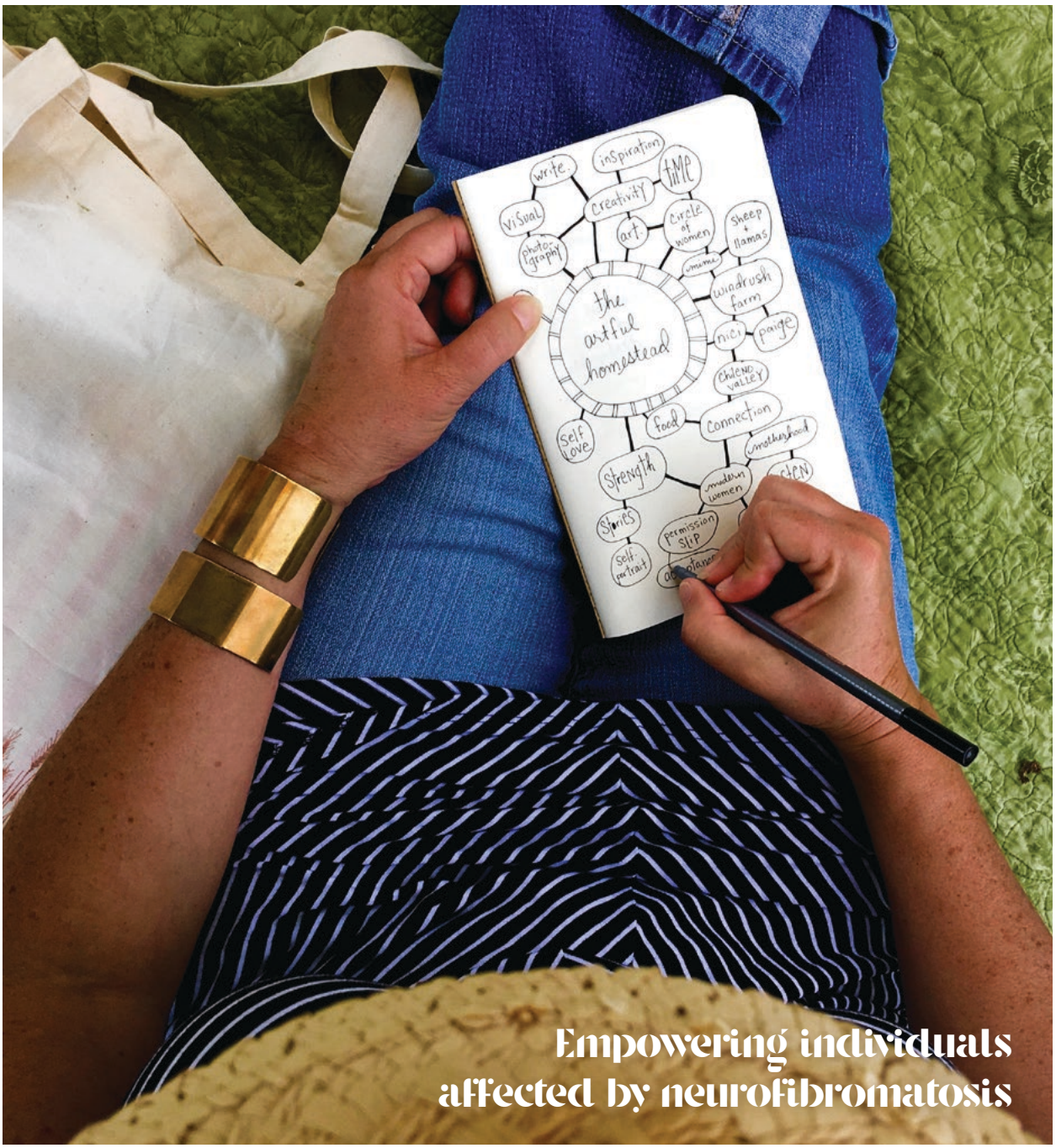

Empowering individuals affected by neurofibromatosis

Make an impact

Making a difference doesn't need to involve a big time commitment or a large monetary gift. A small donation or volunteering a few hours can make a significant impact to the children and families living with neurofibromatosis (NF).

As the only charitable organization in BC serving the NF community, the demands of our programs continue to grow.

Learn how you can help us empower families at:
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TOGETHER WE CAN MAKE A DIFFERENCE!

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Cover image by Maggie Easton

FROM THE EDITOR

DESIRÉE SHER

The challenges of living with a disorder that has a myriad of symptoms and complication, and no treatments or leaders in care, makes the NF journey a particularly arduous adventure.

We have prepared this seventh edition of *Inspire* with the goal of easing that burden a little for you.

The NF journey isn't one you can prepare for, but it can be made easier when not completed alone.

Inside this edition, you will find courageous voices sharing powerful stories of fear, loss, resiliency, and hope on their NF journeys. Through connections with others, we become stronger and better equipped to navigate the twists and turns that are part of living with a rare disorder.

We hope this issue reminds you that you are not alone on the NF journey. There are over two million people worldwide battling NF. Here are some of their stories. May they shine a light on your path!

Tumour Foundation of BC

EMPOWERING INDIVIDUALS WITH NF

IT TAKES A VILLAGE: THE POWER OF CONNECTION

MAYA KENNEDY

Through my many years volunteering with the Tumour Foundation of BC, the one theme that consistently arises for me is the importance of community. Every occasion I've helped with (whether it be the annual symposium, Cocktails for a Cure, or any number of the Tumour Foundation's community events) has proven to me the power of people coming together.

When living with or supporting someone who suffers from an incurable disorder such as NF, everyday can feel like a struggle. Doctors' offices become sources of anxiety when your physician is no longer able to offer certainty and instead looks to you for guidance. It is in this fear and feeling of hopelessness that the importance of connection rings true. Having someone to share your highs and lows with is valuable on its own. But the benefits of community spread far beyond the immediate relief of sitting down to chat with someone.

Getting involved with the Tumour Foundation means being connected to people who are experiencing the same stresses and successes as you. But what makes connection so valuable?

Besides the benefit of discovering solidarity, social connection can improve our own sense of resiliency and empowerment. A study consisting of 14,000 seniors in Pennsylvania found that individuals with high levels of connection and socialization were physically healthier and even had higher cognitive functions than those without.[1] Another study found that when individuals felt supported by their neighbourhood, they were more tolerant to pain, possessed a greater sense of purpose, and had a lower risk of anxiety and depression.[2] Resiliency researcher Eliot Friedman even credits a lack of social connection to be as detrimental to our health as smoking and obesity.[2] Even science shows us that when we reach out for support, we improve the lives of ourselves and those around us.

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[1] *greatergood.berkeley.edu/article/item/how_social_connections_keep_seniors_healthy*

[2] *greatergood.berkeley.edu/article/item/four_ways_social_support_makes_you_more_resilient*

Photo by Mark Cruz on Unsplash

Of course, looking beyond the scientific evidence, the emotional benefits of connection are clear. When people come to the Tumour Foundation, they find comfort in discovering answers. Whether it's parents navigating the same challenges for their children at school, or patients comparing courses of treatment, we're delighted to offer a space to share ideas and fears; one where people can share their challenges and celebrate each other's wins. When a parent tells us that the symposium gave their family much needed hope, or a patient exclaims that they've "never felt so connected with people before this event", we know that the Tumour Foundation's power is more than what scientific studies, or the number of attendees at each event could ever express.

So the next time you see an invite to a Tumour Foundation event, think twice before saying no: saying yes could mean finding connection, improving your health, and welcoming a lifetime of support and positivity into your life.

Maya Kennedy is a grade ten student currently at TREK, a one-year leadership and outdoor adventure program. She has been volunteering with the Tumour Foundation for over five years and has participated at events far and wide between. Working with the Foundation has fuelled Maya's desire to eventually enter the field of medicine. In her spare time, Maya is a competitive swimmer, loves rock climbing, and lazy days with Netflix and her dog.

Photo by Helena Lopes on Unsplash

NF1 IN THE SPOTLIGHT: OPTIMISM, FASHION, & FOLLOWING YOUR DREAMS

AN INTERVIEW WITH AROOJ AFTAB

Arooj Aftab sounds wise beyond her years from the moment we hop on the phone – so much so that I almost don't believe her when she says "Yeah, I'm 23."

A fashion blogger, influencer, and stylist, Arooj is known online for her distinct baggy clothing style and put-together outfits. Though I had followed her Instagram at **@vogue_wonders**, where Arooj currently has over 10,000 followers, I wasn't sure what to expect when we spoke. I shouldn't have been nervous. From the moment we get on the call, her positive energy and sunny outlook was clear: Arooj seems to find inspiration everywhere she looks. "I find inspiration in what I read, what I see, what I look at, magazines, fashion trends already out there, and more – I try to find as much inspiration as I can on a daily basis to help people on my platform."

For Arooj, helping people goes well beyond sharing her stylish, well-curated outfits. While her fashion sense is inspirational already, Arooj is particularly remarkable for how she uses her fashion platform to raise awareness around neurofibromatosis type 1 (NF1), which she is personally affected by. Particularly in the modelling industry, which has a history of favouring certain body types, being honest about her condition has been an incredibly brave and impactful step that has allowed Arooj to help people both within her home country of the UK and well beyond.

"My main style consists of oversized fitting clothes which I share on my Instagram. But in working in the fashion industry [in roles spanning from scouting to digital content], I want to show that no matter what you've got, you can be who you want to be. I've always been interested in fashion and intrigued by the way clothing fits on our bodies, and how it becomes a representation of who we are. It's not just about clothing – it's about expression."

Arooj didn't start off using her platform this way – originally, it was simply to share her own style.

"I once saw someone hashtag 'outfit of the day' on Twitter and I thought, 'Hmm, I could do that.' So I started posting my different outfits. But then as my NF grew, my clothing sizes got bigger, but nobody knew why. I just became known for oversized fits and wearing menswear."

Arooj eventually became shortlisted for a *Cosmopolitan* Award for her sharp style sense. And yet, while this was exciting, she couldn't help but regret that no one following her platform knew the true story behind her baggy attire. "It was then I started to feel like I couldn't accept it; I felt like a bit of a fraud – because no one knew my real story. I felt like I was hiding. I wanted to achieve something but I wanted to be authentic as I achieved it."

Of course, sharing one's condition can be a stressful and daunting task. For Arooj, it was also empowering: she hadn't anticipated how many people she'd reach and touch through her message.

"I shared my story online – it was scary. I was more scared sharing it to Instagram than I was doing a documentary, for some reason. With the documentary I was part of, it was pre-filmed. Online, I wasn't sure how people would respond in real-time. But honestly, it was incredible. My direct messages went crazy. I got so many followers; I received so much support from people relating to me: some people with NF and some people who didn't have NF, but who understood how I felt and thanked me for being so authentic.

Even to this day I get loads of messages and they're all so much more positive than I was expecting. A weight was lifted off my shoulders."

NF is often a hidden condition – so many afflicted by it hide the fact that they have it, which can lead to a lack of general awareness about it. Even though NF1 is found in roughly one out of every 3,000 individuals, there are few public figures who have admitted to having the genetic disorder. Arooj has given many people with NF a woman to look up; a figure in the public eye who is going through the same challenges they are. "I've had people write me saying 'Wow, I've never seen a person with NF in the mainstream media.' It's kind of crazy to me, because so many people deal with it. For me, I'm just happy I can use my voice to spread the word. When British *Vogue* mentioned me in an article, it meant a lot to me – to see huge publications pick up my story and share it with their readership has been amazing. More people are learning about what NF means and how common it is."

Still, Arooj is incredibly humble when I congratulate her for her bravery and for setting an example for others. "I'm not perfect", she admits. "What works for me might not work for everybody else. I think the first step is trying to accept your condition, and knowing that it's not the end. The first stage for me has always been acceptance; understanding myself and my needs. For those newly diagnosed, I would just remind people to not let NF put up barriers for who you want to be in the world. We are so much more than our conditions as people. We have so much more to achieve."

In terms of her own achievements, Arooj shows no signs of slowing down. "I've just wrapped up another piece for a big fashion magazine, a video on diversity and confidence. I'm also

working with some charities, and a few projects on the horizon. I'm moving to London soon and have a lot of exciting work coming up there."

Through it all, she finds important ways to take care of herself. When asked what she does to nurture happiness, she states: "Anything with creative arts, writing, keeps me going – I love arts and imagery. Writing down how you feel always helps: always be reflecting. Looking back on your writing shows how you're working towards your achievements, how you're chipping away. I find time to go to galleries, go for walks – but I think you can make anything into your happiness. It doesn't have to be just one thing."

It also doesn't have to be too planned, or part of a routine. Rather, Arooj speaks to the importance of generally trying to take it day-by-day.

"I don't necessarily have a routine. I think each day we learn, we see what's good for us, what's not good for us. I try to get an early night, but it doesn't always happen. You can't always know what the future holds, so I take it day by day. My advice to others is: take each day as it comes, but don't have expectations. Be grateful for your experiences and opportunities and stay positive. When you're positive you can be the best person of yourself, and not let anything stop you".

"It's always mindset over matter" Arooj explains. "It's easier said than done, but if you can start developing a stronger mindset, the world is your oyster. The minute I get up and be positive and do things, my life will change. I've tried to take on an attitude of recognizing how lucky I am – how lucky I am for healthcare, and for the life I do have. I'm lucky to have great friends, great family – and lucky to have a voice."

Of course, there are challenges. There are good days and bad. But building a community online, an extended network of supporters and friends, has helped Arooj stay strong and keep moving forward.

"One thing I want to be clear about" Arooj states "is that I haven't beat NF – I've just accepted it. I'm not some superwoman who has suddenly overcome it. What I have tried to do is be open with it. Accepting and overcoming are two different things: but what has helped me is hearing stories of other people and knowing that I'm not alone."

Brittany McGillivray is an editor and content strategist based in Vancouver BC. She has an MA in New Media and Digital Culture from the University of Amsterdam and a BA in Literature from McGill. As an avid reader, writer, and aspiring poet, she cares most about community, feminism, and giving a platform to all voices.


there are no blocks
on the path.
the blocks ARE
the path.
- zoe wild
"the mental anguish of moderation"
- annie grace, author
HOME podcast
every thought
is a deed.
gratitude list
day 343 sober
january 12, 2016
1. sobriety
2. no hangovers
3. clearer skin
4. new friends
5. my health
6. focus in my life
7. early mornings to myself
8. high speed internet ... finally!
9. artistic geniuses like Bowie
10. mantras
11. my MAC computer
12. hip sobriety school
13. texting w/ hilary
14. laura as accountability partner
15. my sponsor
16. Step 4 in process
17. acceptance
18. surrender
19. joy
20. grace over drama (g.o.d.)
21. my search for a higher power
22. A.A.
23. my past
24. today
25. HOME podcast
26. Since Right Now podcast
27. instagram community
28. art supplies
29. juicing
30. my LIFE.

GRATITUDE: A PRACTICE TO APPRECIATE THE PRESENT

MAGGIE EASTON

We've all heard that gratitude is important – but what, exactly, does it mean to practice having it? Gratitude comes in many forms, from saying thank you when someone goes out of their way to do something for you, to actively paying attention to the little moments that make up your day – both the good and the bad. In its simplest form, it is appreciation: an emotion of feeling thankful. Although it sounds fairly basic, the positive practice of gratitude has recently become a popular topic of psychological research. Studies have found that when practiced with intention on a regular basis, gratitude can improve mental and physical wellbeing.

Tammi Salas knows a thing or two about gratitude. For starters, she's been keeping a gratitude journal for four years, a routine that has supported a drastic change in her attitude, a shift in perspective, and allowed her to feel grounded and in the present moment. Tammi is an abstract artist, podcast co-host of **The Unruffled Podcast**, writer, creative conversationalist, and self proclaimed perfectionist in recovery. Her process involves using watercolors, pens, pencils and even collage to create a landscape for her daily gratitude list. Tammi has published a gratitude journaling guide titled *My Daily Gratitude Practice – How I Got Started + Found My Visual Voice*, which outlines her approach to gratitude journaling and offers examples of her lists to motivate and inspire.

Choosing to be grateful is sometimes easier said than done – and no matter what challenges you're dealing with, journaling can feel like a daunting and time-consuming task. However, creating a gratitude list is a simple yet powerful tool to relieve anxiety and cultivate a sense of purpose. Writing down what we are grateful for can help center us, slow down our thoughts, and guide us in finding contentment in our current situation. When our minds are positive, we are more resilient to stress, and our bodies may build stronger immune systems and have a higher tolerance for pain.

I had the pleasure of getting to ask Tammi Salas a bit more about her gratitude journey and here's what she had to say:

WHY DID YOU START A DAILY GRATITUDE JOURNAL PRACTICE?

In early sobriety, I was invited to start a daily gratitude practice by my sponsor. She suggested I write 30 items for 30 days. At first, I completely resisted, but figured I could do anything for 30 days. By the end of the month, I was completely hooked.

HOW DO YOU FIT GRATITUDE JOURNALING INTO YOUR SCHEDULE?

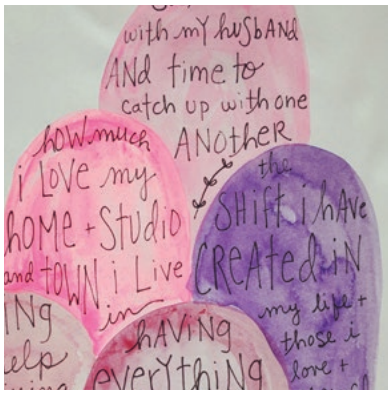
On a good day, it's part of my morning routine, along with prayer, meditation, and creating simple artwork while having my morning cup of tea. When my morning routine isn't possible, I carry my notebook with me throughout the day and add items I'm grateful for as the day unfolds. It's an important practice to me, so I make time for it.

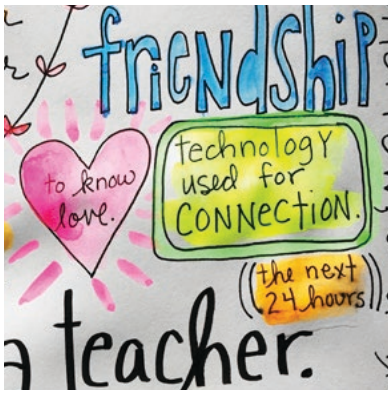
WHAT ADVICE CAN YOU GIVE SOMEONE WHO FEELS LIKE A DAILY PRACTICE IS TOO OVERWHELMING?

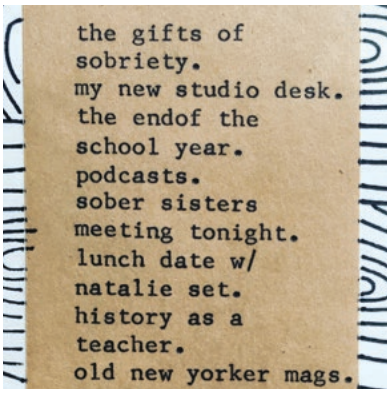
Start small. You don't have to write 30 items like I did initially, but you can certainly find five things to be grateful for. Keeping it short and sweet is a great way to start and if you stick with it, your lists will surely grow over time. You can also carry a notebook in your bag and jot things down when you have a moment. You could also keep a small notebook on your nightstand and wake up 10 minutes earlier each day to capture your gratitudes before you even get out of bed. I'm part of a gratitude circle with eight other women. Reading their lists helps to inspire my lists, too. Find a gratitude accountability partner and text them your list every day. It's a beautiful way to get to know someone on a much deeper level. I highly recommend it.

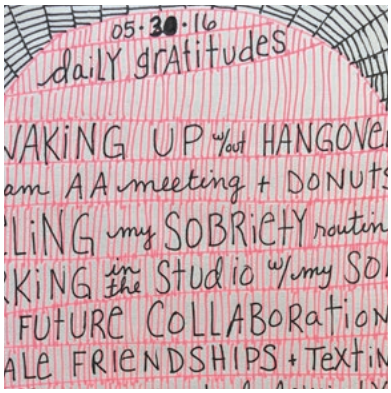
HOW HAS DAILY GRATITUDE JOURNALING IMPROVED YOUR EVERYDAY HEALTH AND MENTAL WELLNESS?

For me, having a consistent daily gratitude practice has helped to keep me grounded, along with a solid morning routine. I think gratitude is contagious, and it absolutely inspires me to find more gratitude in my life. It offers a fresh perspective and a shift in consciousness. It changes the way I view the world and my place in it. For years I suffered from anxiety and self-medicated with alcohol. Once I got sober, I had to feel all my feelings without drinking them away. I still suffer from low-grade anxiety and sporadic, debilitating panic attacks, but now I have a tool that I can use every single day that helps to create a firm foundation from which I start my day. Waking up early affords me the peace and quiet I crave and creates fertile ground for my spiritual practice, which includes creating a gratitude list.









You can read more about Tammi Salas and her creative pursuits on her website tammisalas.com. She has recently published her Proof of Life 60-page Gratitude Journal, a 6 x 9 inch full color booklet filled with her artwork to use as a foundation for your own gratitude lists. You can also check out the hashtag #tammisgratitudetribe on Instagram where there are currently over 3,000+ lists in inspire and motivate you to start your very own practice.

THE IMPORTANCE OF STORYTELLING AND LIFE WITH NF

AN INTERVIEW WITH STACEY KINLEY

IMPORTANCE OF STORY TELLING

I wanted to share my experience with NF because it's so important to share your story, especially for people with NF. My daughter Mackenzie who has NF1 has a very visible tumour and I worry she will be teased at school. If you have a child with cystic fibrosis, people understand what that is and won't be scared of it. But Mackenzie doesn't look like everyone else, and we don't want her to hide because of it. I don't want her to grow up without confidence. She's beautiful and kind and wants to be friends with everyone. We want to encourage her friends and people to ask questions about her. We want to show people that there's more to Mackenzie then just her epilepsy and NF.

Stacey is a mom from Alberta who opened her heart to share he family's journey with NF.

ON HER CONNECTION TO NF

We have two girls: Mackenzie and Hazelyn. Mackenzie turns four in one week and has NF1 from a spontaneous mutation. When Mackenzie was two days old, she began to have seizures while we were in hospital. As I've worked with adults with disabilities, I recognized the seizures when they first happened. But I didn't want to be the stereotypical, panicked new mom and I just wanted to go home. So I didn't say anything to the doctors; only my husband. The lactation nurse noticed the seizures. She was the one who encouraged me to say something. The paediatrician reassessed her a few weeks later and she told me, "Since Mackenzie is awake you can drive her. If she wasn't awake, we'd get you an ambulance. But they're waiting for you at the hospital." I was trying so hard not to cry, looking at the ceiling, trying to compose myself. We drove to the hospital, and the rest seems like a blur. They did an MRI and saw that she has cortical dysplasia. They'll never know if the epilepsy is a cause of NF or separate, but we treat them separately regardless. We were told that if she didn't get control of the seizures by the time

she was six months old, she would have infantile spasms. And those began before she was even two months old, which led to brain surgery before she was 13 weeks old, to resect the area of her brain that was having seizures. While the surgery did stop her spasms for just over a year, she began to have seizures caused by another part of her brain. She's now been diagnosed with refractory epilepsy, as she hasn't responded well to a variety of medications. Her seizures come and go now. We're grateful for the times when there are no seizures, as this is when she can develop and grow. The seizures have become a part of life now.

ON FINDING TREATMENT

When Mackenzie was three months old, we noticed an abnormality beside her right eye. As it grew with her, her neurologists assured us it was nothing to worry about. But at nine months old, I noticed spots on her. This was when we first heard from our pediatrician that Mackenzie may have NF. We went to a geneticist and discovered six months later (which felt like forever) that she did have NF1. Since then, Mackenzie has had two debulking surgeries to try to resect the mass that surrounds her eye. While the eye surgeon was determined to fight and remove this tumour, other doctors discouraged the surgeries as it only "angered" the tumour.

I read about MEK inhibitors, but we were unable to get selumetinib in Canada. We tried trametinib last January at Toronto Sick Kids and we were there for nearly five weeks. It took nearly a year for me to convince Mackenzie's doctors to help us get her into the trial. We were put in touch with a social worker who helped us find funding to relieve the financial burden of travelling across the country so frequently. We now go to Toronto every three months for follow-ups.

Mackenzie has one tumour around her artery, and another tumour on the left side that goes around her carotid artery, up to her jaw bone, around her ear, and into her arm, shoulder, near her spine, and the top arch of her aorta. She has another tumour at the base of her skull. We've seen a shadow on her heart during echocardiograms. But there's nothing to be done to it, unless her lips go blue or we see any other major signs. The drug has made a very minimal decrease in actual tumour growth, so now we're monitoring her and are going without the drug to let her enjoy her summer.

ON THE MEANING OF MILESTONES

I had to tell my husband one day that we have to grieve. He didn't understand. Mackenzie was alive, what was there to grieve? But I told him that there are certain aspects of parenthood that we need to grieve, given Mackenzie's diagnosis and ongoing struggles, and we need to find a way to do that together. We don't know if she will be able to get married, finish school or, at that time, even walk. We came into parenthood thinking we knew what our milestones were going to be, but now we don't. He finally

realized what I was trying to say and said he didn't want to think about that. But we have to so we are prepared for milestones that may not come. So now we celebrate everything! Everything comes at a different pace, but every milestone of Mackenzie's comes with celebration, hoots and hollers (I'm sure our neighbours think we're crazy). She didn't walk until she was two years old, but she does now. She's in the process of developing her speech with the help of a speech pathologist.

ON HAVING A SECOND CHILD AS PARENTS WITH NF

Now that we have a second child, we're constantly monitoring and analyzing our youngest for signs that something may be wrong, despite the doctors saying there's only a 1% chance that she has NF. It really takes a conscious effort to not be anxious or overly critical all the time. We had an appointment with our youngest daughter's pediatrician, and our doctor asked if we had any questions. I said, "What's normal now?" She began to explain what seizures look like, but I understood that. When your child is having upwards of sixty seizures a day, it isn't hard to identify them. I wanted to know what normal looks like now for us. And she had no answer for us at first. But she helped explain what movements indicate a trip to Children's [Hospital] and what are just regular movements (because they can be hard to distinguish).

Hazelyn's milestones now are surrounded with more happiness then McKenzie's. When Hazelyn smiles, we're so happy to see this milestone. But with MacKenie it was "there's a smile but she should have smiled months ago" and it was filled with much more sadness. Now we're just able to enjoy these moments.

ON SELF-CARE

It's hard to find time to myself. My husband and I went away before Hazelyn was born, and we try to make time for date nights. But I try to make time for other moms too. I try to be there for the moms whose children are recently diagnosed and are overwhelmed by the medical system. In fact, just being there for them is therapeutic for me. Being able to help someone find those necessary resources that I couldn't is gratifying for me. Being able to talk to moms is gratifying because I didn't do that. I stayed inside all day with the windows drawn after I first had Mackenzie. There was a permanent divot in my couch from just sitting and nursing her all day long. I stopped taking care of myself. I put on weight and now I'm not as active. The stress alone of having a child with NF is really tough on you emotionally and physically. I didn't care about what I ate, and even going for a bike ride wasn't fun when Mackenzie didn't have enough muscle tone to be in the bike trailer without me feeling guilty.

ON IDENTITY AND NF

We didn't want to tell people that Mackenzie had epilepsy for the longest time. We didn't want that to be a part of who she was, or how she was identified. But we know now that NF is a part of who Mackenzie is, and in order for our family and friends to understand our struggles, they need to know the whole story. One time, I was talking to my co-worker about Mackenzie and unintentionally said that **we** have epilepsy, our family. But she understood. Because Mackenzie's epilepsy affects more than just her – it's a part of our family and who we are.

RESILIENCY

People ask how we do it, with all of Mackenzie's struggles – but you just do it. That's what parents do. Parents with NF understand that you have to take it one day at a time, one diagnosis at a time. Because if you do it any other way, you're going to be drained emotionally and you aren't going to able to care for yourself and your kiddos.

Interviewed by Desirée Sher

IN CONVERSATION WITH CAROLYN SMYTH

A NURSING PERSPECTIVE

Registered nurse Carolyn Smyth had been working in genetics for 8 years, and nursing for 14, when she saw a job posting for a neurofibromatosis coordinator at the Birmingham Women's and Children's Hospital NHS Foundation Trust. She decided to apply.

She had just completed a genetic counselling course at Great Ormond Street Hospital, so she had plenty of notes on different genetic conditions to help her prepare. "I ploughed through [my binder], thinking this would give me some great information for applying for the job . . . and there was nothing mentioned about it. I read on the company website that [neurofibromatosis] was the most common, least known, genetic condition, and I thought, it really is." Luckily, she got the job.

In her work, Smyth educates patients, their families, and their teachers and employers about NF. "NF's one of those conditions that's really common," she says, "but awareness is quite low, and people really struggle to get appropriate help, and the drugs they need."

SPREADING THE WORD ABOUT NEUROFIBROMATOSIS

Starting with newly diagnosed patients, Smyth offers one-on-one reassurance and education. "We'll get a referral, contact the family, and chat to them to see that they have the information they need. Especially if there are any complications, it's helpful to give them a bit of time to talk about things – to say, 'I can come see you at home, we can talk through this.'"

She also liaises with teachers of students with NF to ensure they are fully informed about their needs and can set them up for success. "My own son actually has ADHD and Asperger's. That taught me just how difficult it is for a parent to talk to a school – even if you feel that you know the condition, or you feel that you're quite eloquent.

"I'm approached by parents all the time, asking me if I could go into school and talk to the teacher. Sometimes their reception is absolutely magnificent, and they're incredibly helpful, and sometimes we don't get a particularly good reception. The teachers and the special education needs coordinators have a really tough

Photo by Fraser Cottrell on Unsplash

job, and they've got a lot of kids in their class. It might be up to half with special needs, and various different issues. So I know it's not easy, but it's definitely not easy being the parent of a child with learning difficulties, either.

"I feel really passionate about [building understanding]. A big part of what I do is going into schools and sharing whatever information I have with parents, because I think it starts with the parents understanding. I know for me, with my child, once I understood that there were certain things he actually could not physically do, and he wasn't being lazy, and he wasn't being difficult, that the dynamics changed immediately. It was still really hard, but I understood more, and I felt I could be more supportive of him."

Educating the educators continues at the university and college level. "We're able to speak to student support and explain about NF. . . If their handwriting's bad or it's very difficult for them to write, we may be able to get somebody to scribe for them and things like that, so it can make a big difference. We can get them extra time in exams, if that would help them."

A NEW STANDARD OF CARE

Nearly 20 years since Smyth began working in the field, she still finds that public awareness in the UK is quite low. "On the ground, I still find it really difficult. Many, many people just haven't heard of NF." However, plenty of useful research is under way, and the options for treatment have significantly improved. Two clinics specializing in complex NF1 are now operating, one in London and one in Manchester, giving patients a much-needed chance to consult with physicians who are experts when it comes to their condition.

"It's a brilliant resource for parents and children, because often, they will otherwise get seen by medics who don't have a great deal

"I ALWAYS SAY TO THE CHILD, 'HAVE YOU HAD PROBLEMS WITH THIS OR THIS?' AND THEY'LL SAY, 'YEAH.' AND I'LL SAY, 'DO YOU KNOW IT'S NOT YOUR FAULT? THIS IS MOST PROBABLY ASSOCIATED WITH NF AND THE LEARNING DIFFICULTIES ASSOCIATED WITH IT. SO WE CAN HELP WITH THIS.' I THINK THAT'S IMPORTANT FOR THEM TO KNOW."

of knowledge about NF. At least we know that if they go to one of these two centres, they're going to see somebody who's an expert. All the teams who are involved, whether it's neurosurgeons or plastic surgeons, ENTs, or speech and language, have a good understanding of NF.

"Generally, all [patients] need is a referral from their GP, which makes it so simple. They'll do the appropriate scans, any investigations that they need, and then they'll start treatment. In most cases, they'll come back to us for their care. [The clinic] might see the patient again in a year's time, but generally they'll try to get them to come back to local services, because it's easier for them to be close to home.

"It's just so good to have experts that you can contact and just say, look, we're worried. Could you have a look? And they will."

There are only seven coordinators like Smyth in the UK, so she keeps quite busy. "It is one of those jobs that you're never going to finish at the end of the day or week." However, spending so many years in the role means she has become an integral part of the NF community. "Being in one place, you become quite close to lots of patients, and they do feel like family members."

Lindsay Vermeulen is a writer and editor based in Vancouver, Canada. With specialties including cookbook editing, content marketing, and copywriting, she has always been drawn to the place where food and words intersect.

PATIENT EMPOWERMENT

ISABEL JORDAN

I am increasingly seeing pieces about patients taking responsibility for our own healthcare and engaging with the healthcare system. But I wonder if perhaps the approach is too simplistic. Solutions are presented as if we are able to just step into a role of control and take the reins. I think there is more to it. In fact, I'm troubled by the use of the words 'empowered' and 'engagement', and think that we (the patients and families) need to tell those in power what those words need to mean.

Many organizations say that they want to empower patients and caregivers. The results are typically that we're put on advisory committees with no real decision-making ability. We're told to take responsibility for our health, when in fact, we're not given real access to our data, referral tracking or any meaningful, systemic ways to change how we interact with the people who truly have power in the system. We're told to be advocates for our health and our community, but how are we to do that when we're constantly at the bottom of the pile, too often the afterthought in organizational structures.

Honestly, I'm tired of it. I'm tired of lip service to the idea of patient engagement, patient empowerment, and patient activation. The way I see it, power is a limited resource. There is no empowering us until those who hold power willingly give up some of theirs; I can't take up what isn't available – that's just the simple truth.

Happily, I have found wonderful pockets of change – those who take what power they do have and slice it up so that patients and families can have our voices heard and contribute to decision making in a real way. And it just makes me want more: more in my own family's healthcare, more in creating research priorities, and in designing care. It's made me realize that in the world of disability parenting and chronic illness, I only have so much energy. I want what I do to be effective.

So, how do we do this? 10 years involved with the Rare Disease Foundation has taught me one thing: we do it together. We do it as a community – a community of patients and families, but also of clinicians and researchers that understand the value of patients' perspectives. Researchers can't do it alone, clinicians can't do it alone, patients and families can't do it alone. But if we are united in demanding better care and better research, then we will see change happen. And if the patient and caregiver perspective is front and centre in defining what exactly that means, then I know we will have been successful.

When we first started looking for a diagnosis for our son, we were so very alone. When we were in the ICU with him, we had no one to turn to for advice. But today, many years later, through the benefit of connections with other rare disease families, we know more, we advocate more, and the system we are a part of is better because of it. My son is safer because of it.

SO, AM I EMPOWERED YET?

As I said, I think patient empowerment should be defined by patients. To me, it means that we decide what good care means and we get a hand in making that happen.

So, I'm not going to say an unequivocal 'yes', but I'm better than I was 11 years ago in the PICU. And the reason I am is because of community.

So, thank you.

Isabel is the mother of a young man living with a rare disease and has become a strong advocate for patient partnership in research. She's been interviewed on radio, written on patient engagement, co-authored Patients Included charters, is a member of numerous health research teams, and has spoken at national and international conferences about patient partnership.

NAVIGATING A CHRONIC ILLNESS WITHOUT A CLINIC

COURTNEY WILLOUGHBY

Ask anyone about the challenges of living with a chronic condition, and I bet they will tell you that at least once they have struggled with navigating the health care system. Balancing appointments, tests, follow up visits, lab work, procedures, even just learning medical terminology is a daunting task. Who orders your lab work? Which specialist refills your prescriptions? It can all seem so overwhelming if you're new to, or unfamiliar with the ins and outs of health care and there is no expert or clinic to turn to.

Let me just preface by saying this: I have received excellent medical care since my diagnosis of neurofibromatosis, and I am grateful for all of the kind hearted, talented and resourceful physicians I have had the chance to work with. However, I have faced my fair share of frustrations and struggles over the years that I think could have been prevented if a specialized team had been in place.

A neurofibromatosis clinic would provide competent and comprehensive medical care to NF patients such as myself. There have been countless times that I have had to explain my condition to physicians, which is frustrating and completely time consuming. It adds another layer of challenges to living with a complex health condition when doctors look to the patient for expertise and guidance. Could you imagine taking your loved one to a medical appointment and having the doctor ask you what to do? That is what it's like for every patient with NF living without a clinic. While NF is common, it is not common enough for most family doctors to be knowledgeable in providing specific care.

About a year ago while I was at work, I asked one of our medical residents if they happened to know what Neurofibromatosis was. She looked at me, paused and said, "I know what it is, but only at a very basic level. We only got a half hour lecture on it in school." I was shocked. Half an hour for a condition that has taken me over 20 years to begin to understand?! It's really not that surprising that I have been met with such unease and uncertainty in the past. Again, I feel like an NF specialty clinic would help amend those feelings.

At a recent doctor's appointment, I went in with some concerns about new symptoms I felt were attributed to one of the new medications I was

on. I was told that I actually was not reacting to the medication I was on, but I had an entirely new condition that I apparently was not aware of. This was all based off of me being in the office for less than five minutes, and me having one symptom of this alleged condition. I was prescribed a medication (one that can have some serious, life altering side effects) to take three times a day, and was sent on my way. Most patients would have blindly accepted this as the truth, and carried on following doctor's orders. However, I knew that this was not what was going on with me, and that something needed to change with my current medication regimen.

After I had a discussion with another specialist about the symptoms I was experiencing, he agreed that it was a side effect of my medication and promptly switched me to something different. In less than 24 hours, I was feeling the best I had in months. I feel like this was an oversight in my care and if there had been a clinic in place that was familiar with my case and my condition, I wouldn't have had to endure this incredibly frustrating experience.

People living with complicated medical conditions often spend hours researching, learning, and relentlessly advocating for themselves so they can receive the best medical care. A neurofibromatosis clinic would change this. It would give people a place to go to get their questions answered and their concerns clarified. A clinic would provide a sense of community for people dealing with this condition. Most importantly though, patients utilizing this clinic would not be met with apprehension or uncertainty regarding their diagnosis. They would be empowered with knowledge, and the anxiety that permeates each day would be alleviated with the understanding that a team of knowledgeable medical specialists are looking after them.

MOST PATIENTS WOULD HAVE BLINDLY CARRIED ON FOLLOWING DOCTOR'S ORDERS. HOWEVER, I JUST KNEW THAT ... SOMETHING NEEDED TO CHANGE WITH MY CURRENT MEDICATION REGIMEN.

Courtney was diagnosed with Neurofibromatosis Type 1 at the age of 3. She currently lives in Red Deer, Alberta and work as a Registered Nurse in labour and delivery. In her spare time, she loves to explore the mountains, garden and blog! She also sits on the board of directors for the Alberta Tumour Foundation and loves raising awareness for neurofibromatosis.

Visit Courtney's Blog:
courtneys-column.blogspot.com
abtf.ca

ONE CHILD SHAPING THE FUTURE THROUGH CLINICAL TRIALS

KELLY CARPENTER

I still remember sitting in a presentation on clinical trials for neurofibromatosis Type 1 (NF1) and thinking there is no way I could enroll my child in a clinical trial. Fast forward 3 months and due to significant tumour growth, I was enrolling my 3 year old son in his first clinical trial. The ironic part being that it was with the same doctor who gave the clinical trial presentation. My son Travis (now 11) is currently enrolled in his third clinical trial.

WE WORK AS A TEAM WITH HIS MEDICAL STAFF AND HAVE NEVER FELT LIKE GUINEA PIGS.

NF1 causes tumours to form on nerves anywhere throughout the body. Travis' tumour extends over half of his body length and doctors classified his tumour as inoperable, making a clinical trial the only option. My husband and I felt compelled to look beyond the typical "wait-and-see" option given to NF1 families. For us, seeking a second opinion for Travis created the path towards clinical trials.

Before each of Travis' three clinical trials, we obtained a copy of the protocol information, a multi-page document listing what is involved with each clinical trial and the contact information for the Principal Investigator (PI) or lead doctor. The protocol includes important information such as: clinical trial phase, how and when the medication is taken and stored, additional medications to take, medications or foods to avoid, required exams, follow-up frequency, how the team will determine if the medication is effective, and potential side effects. This information can be provided by the clinical trial PI without obligation to enroll. We reviewed this document with the team and our local doctors to discuss our questions.

After weighing the risks and benefits for each clinical trial, we determined the right answer for our family at that time.

Each of the clinical trials brought travel and logistical considerations. The first clinical trial meant traveling 1,000 miles by car, and the second two trials involved flying to the East Coast. In addition to travel expenses, hotels, and testing, we also factored in the time away from family, school, and work. Many great organizations like Miracle Flights, Ronald McDonald House, and the Children's Inn helped us with travel logistics. Some clinical trials even include assistance to help cover travel costs. We reached out to a social worker at each hospital to help connect us with options for travel resources.

All potential clinical trial participants must complete testing to determine eligibility for the trial before the first dose of medication. Travis' testing lasted from a day to a week,

depending on the clinical trial. The results of these exams ultimately determined his enrollment in the trial. The strain of completing the testing with no guarantee of enrollment brings a complex series of emotions as you want to see your child healthy balanced with the hope for enrollment, i.e. "sick enough" for treatment.

Every clinical trial provides us with journals to document the timing of the trial medication, side effects, illnesses, and other findings. We submit these journals to the clinical trial team on a routine basis. These journals provide the necessary documentation for review by the team, other investigators, the drug manufacturers, and others involved in the clinical trial. We also receive calendars for follow-up appointments and cards with emergency contact information of the study doctors.

The clinical trial team constantly monitors all participants for side effects. These are listed in the documentation and are common to rare in frequency, and mild to severe. However, not all side effects cause harm. In his current clinical trial, Travis' hair changed from brown to platinum blonde and he LOVES this color change.

During the follow-up appointments, we discuss Travis' results with his medical team. Each clinical trial brought a different set of results. Travis' tumor grew too much on the first clinical trial resulting in his removal from the trial and no words describe the devastating feeling when we learned of his removal. The second clinical trial showed slowed tumor growth. At his 3.5 year appointment on his current clinical trial, Travis' tumor shrank 38%! We are thrilled with this result, and with minimal side effects.

We build in time for fun activities and meeting up with friends while we travel for the clinical trial appointments. The timing of one trip worked out for Travis' dad and 2 older brothers to join us and we enjoyed exploring Washington D.C. as a family. Another trip brought an opportunity for Travis to attend a NASCAR race and meet drivers and crew members of his favorite teams.

One thing remains consistent throughout all the appointments, discussions, phone calls, and emails, we work as a team with his medical staff and have never felt like guinea pigs. For Travis, participating in clinical trials helps the doctors learn more about his condition as he hopes "no one else has to go through this". His current clinical trial may lead to the first medication to be approved for the treatment of plexiform neurofibromas in NF1 patients.

For more information about clinical trials, go to *clinicaltrials.gov*.

Kelly Carpenter, her husband Scott, and their 3 sons (Nolan, Barrett, and Travis) moved to Salt Lake City 8 years ago to be closer to Travis' medical teams for his NF1 care. Kelly champions the efforts to #EndNF through volunteering with the Children's Tumor Foundation; weekly at the NF Clinic in Utah and helps coordinate Utah NF Symposium. Kelly and family are actively involved in sports, especially racing and hockey in addition to managing Travis' medical appointments and care. Kelly earned her Meteorology degree at Texas A&M University and proceeded to earn a Masters Degree in Atmospheric Science at Colorado State University with an emphasis in tropical meteorology and satellite imagery. Kelly currently works at the Children and Young Family Ministries Coordinator at Christ United Methodist Church in Salt Lake City, UT.

MAKING PEACE WITH PAIN

DESIREE SHER

Pain, especially when it is chronic, can claim the joy from your life. Chronic pain can cause emotional turbulence as you cope with physical discomfort, frustration, and loneliness. It can also create overwhelm with doctor appointments, juggling medications and treatments, and constant searching for a cure.

Chronic pain is pain that lasts three months and longer, and affects the quality of your life. It's more common than you think: one in five people in British Columbia live with chronic pain.

Chronic pain has been my companion since an accident almost four years ago. In the beginning, I fought with a warrior heart to find treatments that would heal me. I left no stone unturned in my quest to rid my body of any, and all, daily pain. I participated in physiotherapy and active rehabilitation. I received corticosteroid injections, cold laser therapy, craniosacral therapy, trigger point injections, and acupuncture treatments. For years, I mounted a daily war to heal myself. Then one day I got tired of the fight. I needed to find another way to live.

I learned that making peace with pain when pain has you in its relentless grip may seem contradictory. However, when we make peace with pain, we make room to calm our hearts and expand our happiness.

If this resonates with you, I offer you another way to exist with pain. On this journey, you give up the fight, accept the pain, and live a happier life.

Here are five tools to help you make the shift to peace:

ACCEPTANCE

To accept your pain is to allow it. I am not suggesting you stop looking for treatments or a cure; of course we have to keep looking. (I am always searching for a new pathway to heal.) It is also not about giving up hope that you will one day be pain-free. Acceptance is about shifting your mindset from the battle and the belief that life can only be good or you can only be happy when you rid yourself of the pain. It is about allowing whatever is happening in the present moment to happen. When we stop resisting and denying the pain, we ease our emotional suffering of anger, frustration, despair

1

SITTING OR LYING IN A COMFORTABLE, RELAXED POSITION, CLOSE YOUR EYES.

2

TAKE A FEW SLOW DEEP BREATHS IN AND FEEL YOURSELF RELAX.

3

NOTICE YOUR BREATH FOR A FEW MOMENTS, THEN BRING YOUR ATTENTION TO THE PAIN.

IT CAN BE SCARY AT FIRST, BUT AS YOU BREATHE IN, LET THE PAIN EXPAND.
ALLOW IT ALL THE SPACE IT NEEDS WITHIN YOU.

4

AS YOU BREATHE OUT, ALLOW YOUR RESISTANCE TO THE PAIN TO SOFTEN AND FLOW OUT WITH YOUR BREATH.

BREATH IN: LET THE PAIN EXPAND ... BREATH OUT: RELEASE THE RESISTANCE.

5

REPEAT THIS PRACTICE ANYTIME YOU FEEL YOUR PAIN AND RESISTANCE RISING.

and fear – emotional states that bring our focus back to the pain again and again. In this act we take back control of our lives.

Try this breathing exercise to move you onto a path of acceptance.

When I began to accept my pain instead of fighting it, I became aware of two things. One, my pain level decreased as my mental anguish softened. Secondly, I had more energy. All that precious and limited energy that had previously been spent fighting the pain was now available to do other things. I started writing again.

When we stop fighting and resisting the pain we find there is a deep well of joy available to us, exactly where we are today. What would you do if you had more energy?

CHANGE YOUR STORY

The stories that we tell ourselves about our present and future can be sneaky thieves, stealing away our happiness. While we crave a future where we are pain free, we don't know what the future holds. No one does. Yet, we spend hours spiralling in the stress-filled stories of our mind worrying about our future health, relationships, and finances. These stories can leave you feeling discouraged, defeated, and incredibly unhappy. While I continue to have faith that there is a doctor or a treatment that will help heal my pain, I also accept that I might have this pain forever. Instead of worrying about the future, I stay in the present and trust that all will be okay.

STOP THE COMPLAINTS

When you live with chronic pain, you can feel justified in complaining about it. Symptoms hurt and interfere with life, there are doctor appointments with long waits, and medications that have side effects. But when we continue to repeat statements like "I am in pain", "I am struggling", or "I am tired", we are exacerbating our pain by adding mental distress to the mix. Not long ago, I became aware that I was complaining a lot to my family and friends. In fact, I even got tired of hearing myself gripe about my symptoms. So I decided to challenge myself and not complain to anyone for twenty-four hours. Complaining wasn't making a difference to the pain, anyway!

Not talking about the pain actually came easy when I set the intention to focus on the positive. What shocked me was the hundreds of negative thoughts I didn't say out loud but that were playing on repeat in my mind. When I started replacing the negative thoughts with more positive perceptions, by the end of the day I felt energized, the pain had softened, and I definitely felt happier!

REDISCOVER YOUR PASSIONS

When you are focused on the pain it is easy to hone in on your physical limitations and forget about the things, activities, and people that once filled you with joy. Perhaps you can't go skiing or spend hours gardening, but what can you do that would make you happy again? I invite you to make a list of what makes you happy right now. Then take one item from your list and see how you can turn it into a daily practice for happiness.

SOCIAL CONNECTION

People who live with chronic pain tend to withdraw. This isolation adds another layer of suffering. While at times it is easier to be alone than to navigate the energetic and emotional demands of an outing, research has shown that social connection is one of our greatest natural medicines! When you widen your circle of support beyond family and immediate friends, you also have an opportunity to build community with people who understand the same challenges you're going through. Look for support groups in your community. Pain BC (painbc.ca) has groups and a support line that I recommend as you navigate your own journey.

Making peace with my pain allowed me to reclaim joy in my life. Now's the time to reclaim your joy! Choosing to be happy today, regardless of your pain or other life circumstances, puts you back in the driver's seat of living your best life possible.

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Desirée Sher is the editor of *Inspire* magazine and author of the book, *Refuse to Sink*. When she's not busy at the Foundation she works as a mindset coach and motivational speaker helping people reclaim a passionate and joyful life. She shares her passion of turning tragedies into potential at workshops, conferences and online through her podcast and blog. For daily inspiration and resources visit her at ***DesireeSher.com***

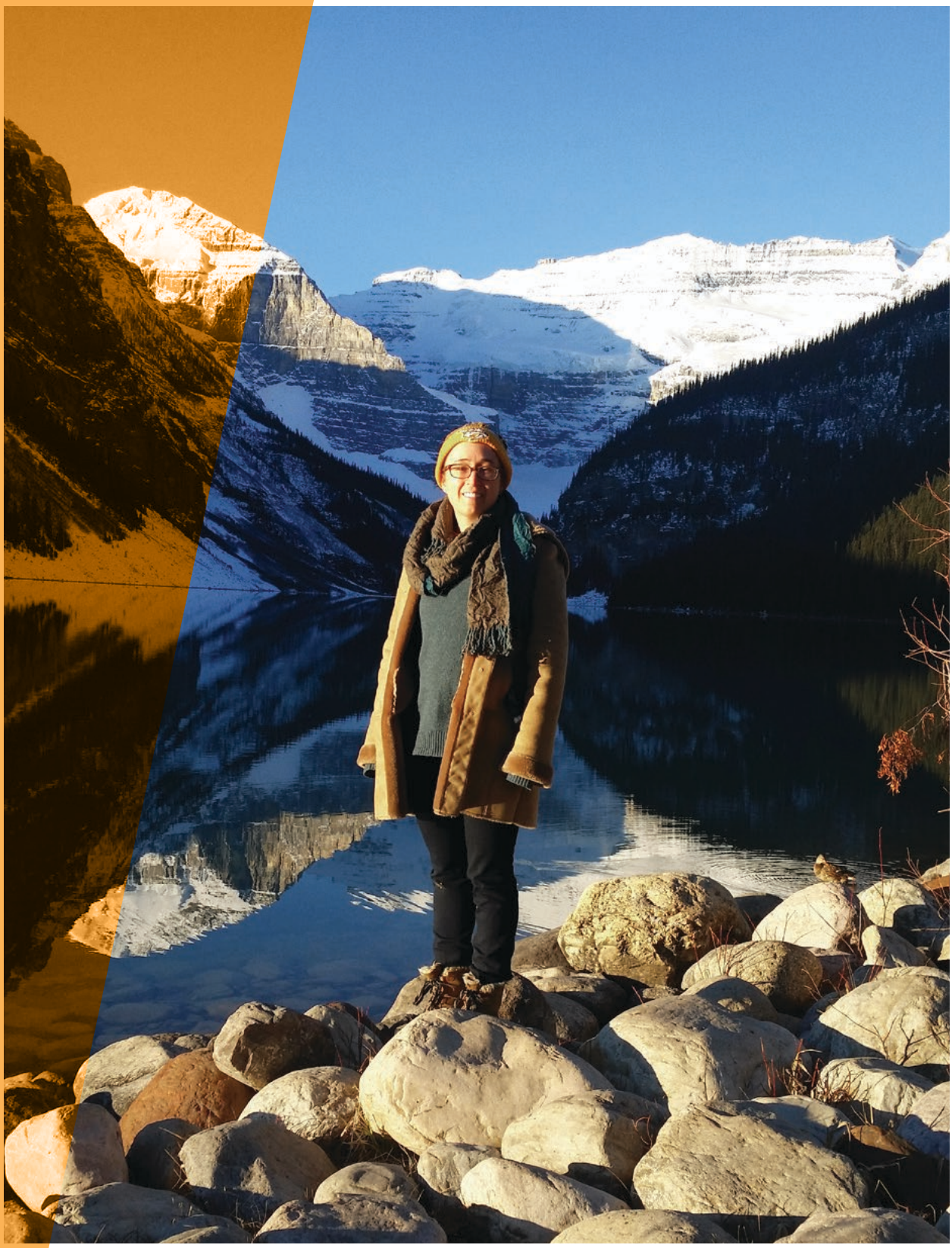
MORE THAN JUST TUMOURS

AN INTERVIEW WITH HANNAH

Hannah lives with NF 1 in Alberta, Canada. Originally from Tennessee, she struggled to build community when she moved to Alberta to pursue a Master's degree. She shares her insights on navigating life with NF in the following interview with Desirée Sher.

WHEN WERE YOU DIAGNOSED WITH NF?

I'm 32, and I was diagnosed much later then most children are now (I was 8 or 9). I was seeing a neurologist for many years, on the assumption that I had epilepsy. One day, he



brought a student-doctor to my appointment to practice a physical exam. While the student was doing the physical, she noticed that I had café au lait spots and freckling in the armpits. She brought my neurologist back in and observed to us that I may have NF. My neurologist ordered an MRI and that's when we discovered an optic glioma. I remember when the neurologist told us, he was just as shocked as we were to discover I had NF.

WHAT WAS THE EXPERIENCE OF GOING TO A MULTI-DISCIPLINARY NF CLINIC?

It was really great to have the NF clinic in Nashville. There was one core doctor who is there one day a week for the clinic. He and his secretary help to coordinate all the meetings that you need with other specialists who are connected to the NF field. I never had to wait very long for those appointments, either. An MRI would sometimes just take a day, and I never waited for an appointment for more then a month. With the advent of the clinic, you no longer had to tell your whole story of NF to every doctor you saw, or wonder if your doctor even knew what NF is.

When I was living in Seattle, I went to a regular family doctor about a neurofibroma located next to my spine and he said he could take it off right then, in the small room we were in. I remember looking at him and thinking that he does not know these neurofibromas can bleed and are below the fatty layer of skin. It's impossible to remove them in just a standard examination room!

It was hard to go from Nashville where I had the clinic as a central hub for all of my NF concerns, and then move to a city where you have to start all over. And it was a bit like that when I moved to Edmonton too. My doctor here is an MS doctor, and he's willing to work with me, but still isn't immersed in NF.

HOW DID YOU MAKE THE TRANSITION FROM HAVING A CLINIC OF EXPERTS MANAGING YOUR CARE TO HAVING TO BECOME YOUR OWN EXPERT?

I have a package now for when I see doctors. I have all my medical history, timelines, and a condensed summary so I have everything prepared. Then if a doctor says something to me that I know is wrong, I'm able to refute it. They don't always like that (some of them get a bit miffed), but it's my health. There's only so much that I'm just going to accept. Whenever I have a bad experience with a doctor, I have no problem standing up to them or looking for another doctor. I think that's more common of an attitude in America than in Canada.

But it would be nice if there were more NF clinics in Canada. In Alberta, there are many people with NF but we still have no clinic. It would make sense to have one here.

WHAT HAS BEEN YOUR HARDEST CHALLENGE OF LIVING WITH NF?

The hardest challenge for me was probably seizures and then an optic glioma. But I'm very lucky that those have both stabilized.

My current challenge is that I have plexiforms on both of my outer ankles. The one on my right was removed, and the one on the left was small enough that it didn't need to be removed. The issue with my right leg is that the plexiform has invaded a lot of my muscles so even though it was removed years ago, I've now developed a lot of balance issues and pain associated with the plexiform. Some days I can't walk straight which causes pain in my knee. I have begun to develop osteoarthritis as a result.

As I've gotten older, I've realized that removing a tumour doesn't mean that the problem is gone. It's been ten years now since the plexiform tumour on my ankle has been removed, and it only gets harder every year. I have other neurofibromas along my stomach and spine, so I can't do some things like sit in some chairs, or carry certain backpacks. Overall, I would say I'm fairly lucky as all of my tumours are subdermal. I've never had to face teasing or being ostracized. So I count myself lucky.

HOW DO YOU COPE WITH THE PAIN?

I made a decision to only rely on opioids if absolutely necessary. I actually use a form of meditation and mindfulness to try to separate my brain from the symptoms. I'm not a professional, but I learned through videos and a mindfulness program. When my pain was at its worst, I did microdose with cannabis at night to help sleep.

HOW DO YOU MAINTAIN A POSITIVE ATTITUDE?

I'm a very stubborn person. I think I was just born with tenacity and the ability to speak up. Some people do struggle with their NF and it overwhelms them, but that's not me. I remember as a kid, my teachers didn't want me to take any advanced math courses. So I forged my parents' signature and forced my teachers to allow me to take those courses. I've never let NF define or stop me.

WHAT ADVICE WOULD YOU GIVE TO SOMEONE WHO IS STRUGGLING WITH AN NF DIAGNOSIS?

What has always helped me is that I've had external passions and developed an identity outside of my NF. You can't create your own identity; you have to discover it. For example, I love cycling and traveling. Those are my passions that pull me forward.

ANY LAST WORDS?

Through all of these things, I've never let my NF stop me. I will say that people do underestimate how many people with NF struggle with learning disabilities and social interaction. There's much more to NF than just tumours.

The facts about NF

1

Neurofibromatosis or NF, as it is commonly known, is a genetic disorder that causes tumours to grow on the nerves throughout the body.

2

NF has been classified into three distinct types: NF1, NF2, and schwannomatosis.

3

NF1 is the most common neurological disorder caused by a single gene, occurring in one in very 3,000 children born.

4

NF is more common than cystic fibrosis, Duchenne muscular dystrophy, and Huntington's disease combined.

5

NF affects both sexes equally and has no particular racial, geographic or ethnic distribution. Therefore, NF can appear in any family.

6

NF is NOT the "Elephant's Man" Disease, although at one time it was believed to be. Scientists now believe John Merrick, the so-called "Elephant Man" had Proteus Syndrome, an entirely different disorder.

7

Although most cases of NF1 are mild to moderate, NF1 can lead to disfigurement; dermal, brain and spinal tumours; skeletal abnormalities; disabling pain, and cancer.

8

NF1 also has a connection to developmental problems, especially learning disabilities, which are five times more common in the NF1 population than the general population.

9

Half of the people who develop NF1 and NF2 inherit it from a parent. The other half, develop it as a result of a spontaneous mutation.

10

Every person with NF1 and NF2 has a 50% chance of passing the condition on to their offspring.

11

NF2 occurs in one in 25,000 people. The hallmark of NF2 is tumours that grow on the eight cranial nerve in both ears, commonly causing deafness and balance issues. NF2 can also cause severe vision problems.

12

Schwannomatosis is the most rare form of NF, affecting one in 40,000 people worldwide.

13

Most individuals with schwannomatosis have severe pain that can be disabling.

14

There are few treatments and there is no cure.

15

In BC, there is no clinic for people living with NF.

Share your story

MAKE OUR VOICES HEARD

In each issue of ***Inspire***, we bring you stories of people just like you – stories of courage, of struggle, triumph and hope. Living with NF is hard, but we aren't alone and there is strength in facing the challenges together.

We need your story, too.

Readers just like you are eager to hear about your experiences and your journey. Please be a part of our next issue.

Visit **tumourfoundation.ca** to find out how you can take part.

WE'RE IN THIS TOGETHER

Tumour Foundation of BC

EMPOWERING INDIVIDUALS WITH NF