ISSUE NO.5 / SPRING 2017

THE MAGAZINE OF THE TUMOUR FOUNDATION OF BC

!NSP!RE

CELEBRATE WITH US:

THE BCNF IS NOW THE TUMOUR FOUNDATION OF BC!

CREW

BRINGING STRENGTH AND HOPE TO OTHERS

JEREMY

ON FINDING A JOB THAT FITS AND NEVER GIVING UP

ALISON

ON UNIVERSITY, COMMUNITY AND IDENTITY

ME TOO

A MOTHER'S CONFESSIONS AND APOLOGIES

EDITOR'S NOTE

TO INSPIRE YOU TO BE THE BEST YOU CAN BE.

It's been a year since our last issue. As I stop in the busyness of preparing for our upcoming events to write to you, I smile as I reflect at how the BCNF, now known as the Tumour Foundation of BC, has transformed.

Last year, we were getting ready to close our doors. A year later, we stand stronger than we have ever been thanks to our volunteers, the NF community, and donors who came together to revitalize our organization.

With a new name, a new look, and a new board of committed professionals (page 27), we have strengthened the foundation of our organization.

We have a new initiative to serve the families living with neurofibromatosis- the NF Support Line (page 4). There are also new events, including the Cocktails for a Cure. Additionally, we are honoured to be partnering with the Children's Tumour Foundation and other international NF organizations, for the Shine a Light on NF campaign in May.

Most exciting is that we are collaborating with a variety of medical professionals right here at home to launch a NF clinic (page 29). After years of pushing forward, the stars have aligned and there is movement on making this dream a reality for the NF community.

We are conditioned to always do more – to stay busy. And while the charity has lots of plans ahead, every now and again you have to stop and take in the view of how far you've come. And from my mountaintop, the view is pretty spectacular!

I invite you to take a few moments today and look back to how far you have come.

Yes, there is always more to do. But taking the time to stop and celebrate how sweet life is despite the challenges is important. It fills you up so you can keep going forward. We have lots of plans ahead to improve the lives of the children and adults living with NF. We would love for you to join us. Get involved to help us end NF.

Desirée Sher
Executive Director
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INSPIRE MAGAZINE
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Together we can make a difference!

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Tumour Foundation of BC

EMPOWERING INDIVIDUALS WITH NF

Follow your bliss and the universe will open doors for you where there were only walls.

JOSEPH CAMPBELL

Image: Matt Politano

New Growth

Meet the Tumour Foundation of BC

Why the New Name?

The Tumour Foundation of BC is the new name for the BC Neurofibromatosis Foundation.

While the BCNF had been actively supporting families for 33 years, the brand wasn't serving us as well anymore. With so many charities vying for attention, volunteers, and donor dollars, we needed a fresh and creative way to share the NF story and raise revenue for our programs and services.

While not everyone may like the new name, to survive we had to try something different. This is our first initiative to create a stronger organization. We have addressed some of the concerns that members have asked.

1. If "NF" isn't in the name, people looking for information on NF won't be able to find us.

Our tagline from our old logo, "Empowering Individuals with NF", carries on. It will be displayed on our website and in our literature.

2. Concern with use of the word "tumour".

If you google 'neurofibromatosis' you will find most sites, including the Mayo Clinic, define neurofibromatosis as a genetic disorder that causes tumours to form on nerve tissue.

Almost every problem with NF is caused by a tumour. Tumours on the optic nerve affects vision; tumours on the spine cause scoliosis; tumours in the brain can cause learning difficulties; tumours on the auditory-vestibular nerve cause hearing loss, etc. "Neurofibroma" is a technical name for a tumour; the difference is everyone knows what a tumour is. Neurofibroma however, requires an explanation.

Using plain language helps people understand NF. For comparison, consider that people with cancer don't say they have "hepatobalstoma" or "mesothelioma", even though those are the correct technical terms. They use the term that people will understand.

3. People will think it's a cancer organization.

People do not describe cancer as "having a tumour"; they call it cancer. They say they have breast cancer, brain cancer, or leukemia, which doesn't involve tumours.

In many ways, NF is worse than cancer. There is nothing to do to prevent NF. There are limited treatments available, and unlike many cancers, which can now be cured, there is no cure for NF.

The New Logo

We are grateful to Laura at Laura Galloway Design for designing our new logo. The logo conveys our new brand direction: connection, education & leadership.

The tree mimics the look of the nervous system. The tree graphic gives the look of branches reaching out to individuals and communities as well as their needs, and the services which the Tumour Foundation provides.

In addition, the tree represents a learning system, and the playful design is friendly and welcoming to all levels of the audience.

Tumour Foundation of BC

Green portrays health, freshness and calm, and the blue-green turquoise adds balance, focus, and stability.

The trunk of the tree shows how the foundation brings a solid base to these separate components of the NF community

EMPOWERING INDIVIDUALS WITH NF

NEW PROGRAM

1-888-342-4175 NF SUPPORT LINE

The NF Support Line is a new program of the Tumour Foundation of BC. We are here to help you navigate living life with neurofibromatosis. If you have a question on an NF topic or a challenge you are facing and need some help please call and talk to our professional staff. We can help. This is a confidential call open to anyone 16 years of age and older.

The phone line operates Wednesdays from 6-8pm. This is a free and confidential call.

TELL YOUR STORY

"Pain shared is pain divided."

We invite you to share your experience of living with NF by telling your story. Story telling is a powerful way to inspire and connect with families newly diagnosed. Share your story and let others with NF know that they are not alone and that the diagnosis does not have to be a barrier to living a great life. Visit the site to submit your journey.

www.tumourfoundation.ca/share-your-story

ON MAY 17, HUNDREDS OF LANDMARKS IN THE U.S., U.K., CANADA, AND AUSTRALIA WILL "SHINE A LIGHT ON NF" TO RAISE AWARENESS

Launched by the Children's Tumor Foundation in 2014 to increase public knowledge of this critical disease, last year the Shine a Light on NF campaign grew to 146 landmarks around the world, lighting up in recognition of the NF cause. Buildings, bridges, monuments, and landmarks across the globe will show their support in the fight against neurofibromatosis (NF) by lighting up in blue and green, the official colors of NF.

"Increasing recognition of NF is essential to driving the critical research that will lead to the development of effective treatments benefiting NF patients and their families," said Annette Bakker, President and Chief Scientific Officer, Children's Tumor Foundation. "It is thrilling to see landmarks and monuments around the world 'Shine a Light on NF' and support this important cause. We're also thankful that NF organizations worldwide are coming together, united in the fight against NF."

The Children's Tumor Foundation has put together toolkit with the resources you may need to request that a landmark in your community light up blue and green as a way to draw awareness to neurofibromatosis on May 17, some other day in May or for the entire month. *At the time pf printing both Vancouver City Hall and Canada Place will ight up blue and green for NF in May.*

Find it on the website at:

WWW.TUMOURFOUNDATION.CA/EVENTS/SHINE-A-LIGHT

LET'S WORK TOGETHER TO SHINE A LIGHT ON NF.

Jeremy

on finding a job that fits and never giving up

Written by Brittany McGillivray

Jeremy De Silveira speaks very highly of his managers at White Spot. “They have done a lot for me.” After finishing college, Jeremy tried to find a job in computer programming. Like many recent-college graduates, he found the attempt to be discouraging: “I had no luck even getting an interview.”

Deciding that it was better to expand his search and find any job until landing one in his field, Jeremy applied to customer service jobs. Eventually he landed one at a small grocery store chain, working part-time, three days a week.

The adjustment was a bit of a struggle – Jeremy’s supervisors were unaware of his living with NF and the ways it affected his daily life. When going through a rough time adjusting to his new workplace, Jeremy decided to open up to his supervisor about NF.

Living with NF can come with a host of hurdles and difficulties, many of which may be ‘invisible’ or hidden to employers or potential employers. Even though NF is more common than Duchenne's muscular dystrophy, cystic fibrosis, and Huntington’s disease combined, it is still clouded under a veil of secrecy – something that the Tumour Foundation has worked to push back against.

In telling his supervisor, Jeremy was bravely taking a step to demystify what it means to live with NF. And while his supervisor at the grocery store was fortunately kind and receptive (Jeremy brought in additional information about NF, which his supervisor was happy to learn from), the store manager was unfortunately unsympathetic. Rather than accommodate the challenges Jeremy was experiencing around NF, his manager decided to find a new employee.

Jeremy recognized that "regardless of the circumstances," his manager's behavior was unacceptable. But luckily, he was resilient: "Having NF all my life and [knowing] the struggles that come with it, the one thing I learned is to never give up."

Jeremy continued to struggle to find work in the service industry that would accommodate his needs. He also demonstrated a strong, candid attitude towards his individual challenges – when asked what his greatest weakness was in a job interview, he told the interviewer about his NF. "But I also told them how I don't let it hold me back."

However, in spite of discouraging reactions from insensitive bosses, Jeremy knew that there was a good fit for him out there. Late in the summer the year after he graduated, Jeremy was walking past a new White Spot on Dunsmuir in Vancouver and asked if they were hiring. He filled out an application on the spot, and moments later, Raymond, the then-manager, interviewed him. "He had a real great attitude" Raymond noticed from the get-go.

In spite of the fact that Jeremy had technically been laid off his last jobs, Raymond, wanted to give him a chance. Jeremy was hired on to the inaugural team as a dishwasher.

Now, Jeremy is a valued member of the team, and brings his own personality, team mentality, and good humor to the kitchen.

"He has a great, great attitude, and is always available to cover sick calls. He's really a team player – he was my go-to guy" Raymond says.

"He's still our go-to guy" the chef, Mike, adds. "He's always there and always dependable."

The praise is unanimous, and speaks to both Jeremy's strong work-ethic and determination, and the need for more businesses like White Spot to consciously hire individuals who may have specific hurdles and different learning abilities. The pay-off, in White Spot's case, has been immense:

"Jeremy has been an absolute asset since the beginning when it comes to teamwork; he's always punctual and diligent about his work area", says Naseer, the current General Manager.

"Having NF all my life and the struggles that come with it, the one thing I learned is to never give up"

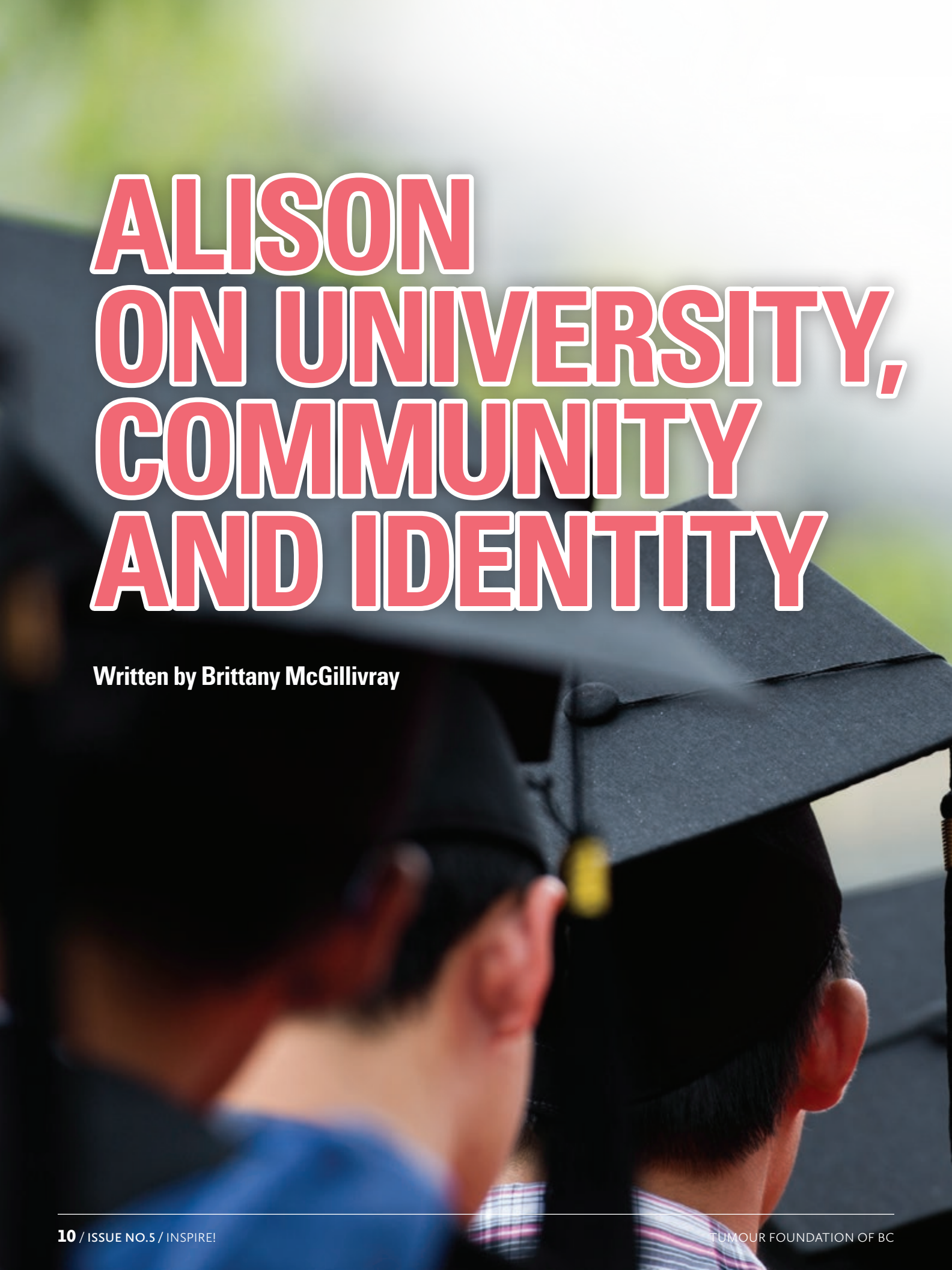
Like any job, working at White Spot has its high and lows: "Sometimes it's a tough job" Jeremy admits. "Especially during the busy nights, but I don't give up. I appreciate everyone here, and when I told my managers about NF they all took it so well. I couldn't have been more relieved. Having flexible hours is a bonus too, so that I can have certain days off to celebrate birthdays or spend time with friends at an anime convention."

The appreciation is mutual. Naseer notes:

"Over the last couple years he has grown from a shy, introverted guy into an outgoing extrovert who likes to share a joke or two with his friend Joe [a server]. He also has a great enthusiasm for Scratch and Win lottos... I have given him my money a couple times to pick up tickets for me, as I do consider him to have that lucky charm."

Whether or not the tickets are success, Naseer notes: "We sure are lucky to have a team player like him on our team."


WhiteSpot
Certificate of
Inspiration & Achievement
WHITE SPOT ON DUNSMUIR



ALISON ON UNIVERSITY, COMMUNITY AND IDENTITY

Written by Brittany McGillivray

Alison is at a crossroads familiar to many twenty-somethings. In her last year at UBC, she is trying to figure out what to do next, and reflecting (mostly) fondly upon her years immersed in academia.

Like many other students, the feeling of accomplishment and assuredness in her final year was hard-won.

"Originally I had the intention of going into social work. I did the first two years at Langara, with the intention of taking requirements to do social work at UBC."

The transition from high school to university was initially hard. "I have quite severe anxiety, and leaving my alternative school where I knew my teachers really well to an environment where I didn't know anyone was a tough adjustment."

During her first semester at Langara, Alison took a Women's Studies course, and was inspired by her enthusiastic professors and the topics.

"The content really captivated me. I took a course in Women and Popular Culture, and noticed how applicable it was to every day life. It really drew me in."

What followed for Alison was a lucky experience of finding topics that related back, helped make sense of, and changed her perspectives of day-to-day life. Inspired, eventually she decided to do a degree in Gender Race Sexuality and Social Justice, an interdisciplinary program at UBC.

Today, Alison is thriving in this environment, having gained wisdom alongside a tight-knit group of equally socially-conscious and engaged students. "I realized I'm really getting good at the whole school thing. I have really found my community within my program, and I've been able to gain more control on my mental health. I have a better understanding of what's expected of me and how much effort I need to put in."

In spite of finding a great community of campus, Alison recognizes where she could interact with and develop connections with more people within the Tumour Foundation community.

Education has allowed a new avenue through which to comprehend what it means to be diagnosed with NF.

"I'm studying disability rights, which is not really a thing in my program – so what I've done this semester is a directed studies class where I've designed my own syllabus and reading list."

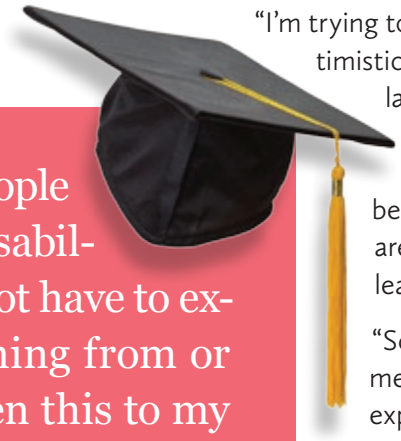
"It's so validating to be able to read about experiences that I can really relate to. For a long time I didn't want to identify as a person who has a disability, and was worried about how it would colour peoples' opinions of me."

Alison is a triplet, and the only one out of the trio to be diagnosed with NF. She has been blind in one eye since her first birthday (a side-effect that she doesn't notice, as it's all she's ever known), deals with chronic pain, and has had a brain tumor that thankfully never required surgery. She is also socially-aware, incredibly smart and articulate, funny, and seems more than equipped to tackle whatever's in store after her final year at school.

> "When I do talk to people with some kind of disability its really nice to not have to explain where I'm coming from or my experience. I liken this to my sexuality, to being queer... the interactions I have with my friends who are straight are very different from friends who are LGBTQ. It's amazing to be with people who get you and get certain aspects about you."

When asked to give advice on how to engage and find connection on campus, Alison offered: "Personally, I joined clubs, and met people through clubs. The idea of going to a really big school can be intimidating. Don't be afraid to say hi to people in class."

"What's really lighting the fire under my belly is volunteering for the Sexual Assault Support Center (SASC) on campus – I'm doing outreach with them. I just started, but what's really struck me so far is that there's a lot of people out there who are willing to learn new things."



"I'm trying to be more optimistic about things lately. I feel like education is such a big thing, and believe that people are really willing to learn."

"School helped me articulate my experience as a lived experience – it gave me more language to articulate the ways I am affected and also to realize my immense privilege in having access to health care and education.

I'm at the stage where I am comfortable talking about NF, and I see it as "living" with a disability rather than having one. If I say "having" it feels like something that is done to me, but to say that I am "living" with a disability it is about how I live my life to the fullest ability that I can. NF is a small piece out of many parts of my life."

NF SYMPOSIUM

Join us in Richmond, BC for our annual day of education, connection and fun. This year's symposium has a great line up of speakers and is an opportunity to meet other families, researchers, clinicians and other health care professionals.

See inside back cover for more details.

ENDING NF: WHAT DOES IT MEAN?

By Connie Sorman

When I stop to think about what it would mean to End NF, the thoughts get tangled as they intertwine in their complexities. Does Ending NF mean that there would no longer be people diagnosed and living with the disorder? Does it simply mean that there would be an array of effective and safe treatments, which would make the many different manifestations of NF manageable? Maybe the meaning would encompass the ability to stop tumors from growing in the first place—genetic modification. Or perhaps, Ending NF would be ending the stigma and the lack of knowledge surrounding the disorder, making NF as known in the public eye as MS or MD or Diabetes and those living with NF would feel valued and validated by society. It would mean that nobody lives with NF in isolation and that there would be many choices for well-informed physicians to treat NF patients and approved treatments to provide to them.

I don't know what End NF means to anyone else, but I'm not very literal in my interpretation. What I have chosen to fight for, as the mother of a child, now grown to be a young man, is to end stigma, increase knowledge, educate others, spread awareness and provide support to those living with the disorder. In addition, I advocate for research funding, I do what I can to raise money on my own and I volunteer. While I hope that one day there will no longer be people living with NF, I am realistic enough to understand that this is unlikely to happen in my son's lifetime. Having said that, it thrills me to know how far the research has come in the 19 years since his diagnosis. The first time I heard the name, Neurofibromatosis, my son was an infant, just 3 months old. At that time, not only were there no treatments, but there were also no clinical trials yet identified for potential treatments. I remember hearing of the very first trial that showed promise in mouse models and I dug up whatever I could find to fuel my hope that learning disabilities, my son's most prevalent manifestation at that time, could actually be reversed. He was too young to participate in the trial at first, but as soon as he was able, he did. Although the research is ongoing for that particular study after 10 years, I still have optimism about it and it holds a special place for us because he was a part of its history.

Today there are many studies for a variety of different symptoms related to the three types of NF. Scientists are working together for the first time in NF history through clinical consortium and Synodos efforts to collaborate on interdisciplinary, multi-institutional, translational research. There are drugs showing significant tumor shrinkage and are very promising to be offered as approved clinical treatments in NF1 in the foreseeable future. There are medicines that are reversing hearing loss in NF2 patients. We have the science, the researchers, consistent funding, passion, enthusiasm and incredible hope among us. We have the ability to End NF and we will. The progress is quite remarkable and for the first time since 1882 when Friederich Daniel Von Recklinghausen recognized NF by describing two cases of multiple neurofibromatosis, we are on the brink of Ending NF in the very real sense that will most directly impact those who are living with it every single day.

What are you doing to End NF? Here are some suggestions:

- Join the NF Registry! Go to www.NFregistry.org and register every member of your family who has been diagnosed with NF.
- Volunteer at a local event, symposium, NF clinic, or create your own fundraising event. Go to www.ctf.org to find resources, ideas and opportunities.
- Spread Awareness! Wear an NF shirt or wrist band, ask your government to recognize May as NF Awareness Month. You can also get buildings, monuments or bridges to "Shine a Light" on NF in May.

Connie Sorman's Bio

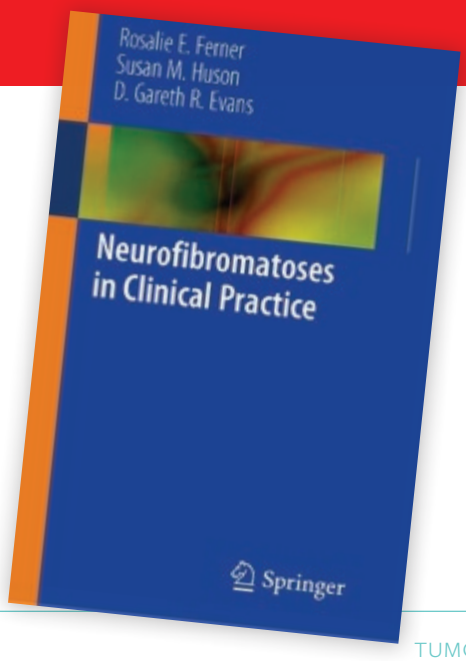
In 1997, my son, Jesse was born healthy at full term, with no complications and six months later he was diagnosed with NF, type 1 He was the fifth child in our combined family of 8 and the first and only to have Neurofibromatosis. Now, 18 years later, I have been involved in the NF cause for quite some time. I have served the Children's Tumor Foundation as a fundraiser, a Chapter Leader in New York and Virginia, a Walk Chair, a Walk committee member, task force volunteer, Facebook group Administrator, as the Vice-Chair of the National Chapter Council and for the past year, as the Chair of the Volunteer Leadership Council.

I live with my husband, Peter and our two youngest children in the Richmond, Virginia area since August of 2013. Prior to that, we lived in Rochester, NY for 26 years, where we raised our six children. I am fortunate to be able to work from home as a volunteer and dedicate as much time as I wish to the pursuit of Ending NF. I have worked in the Fashion industry, Retail Management, Childcare Administration and Education, I ran the front office of Peter's private medical practice for many years, and I now own my own small business in anti-aging. I also write a blog about my experiences of living with NF (nfsaid.blogspot.com). My passion and dedication to the NF cause has been my catalyst over these past 18 years and will continue to push me so long as there is no cure for NF.

RESOURCE AVAILABLE:

The Tumour Foundation's lending library has copies of this book available for loan: **Neurofibromatoses in Clinical Practic**e, authors: Ferner, Rosalie E, Huson, Susan, Evans, D. Gareth R.

Practically focused and accessible it includes clinical photographs illustrating diagnostic features of NF1, NF2 and differential diagnoses and tables showing diagnostic features and protocols for management.



me too

By Connie Sorman

I have a confession and some apologies to make. I confess to feeling more sympathetic to my disabled son's needs, than to my other children's. I know that the reason I have felt this way is because he was given this unjust life sentence of having a progressive tumor disorder. He has had to endure endless specialist visits and procedures, has struggled with learning, has an uncertain future; so this seems perfectly natural, doesn't it?

In retrospect, I have this horrible feeling of guilt (any mother's plague) for behaving this way. I keep seeing my youngest daughter's crumpled face, eyes wide, sometime around the age of three, as she pleaded with me: "Me too."

It was a normal cold winter's day in our home. The older kids were at school and I was getting the younger two ready for their respective preschools. Although she is younger than her brother, I left my daughter to struggle into her snow pants, boots, hat, scarf, mittens and coat by herself. Meanwhile, I attended to my son, who could not even manage his own coat, never mind attempt snow pants and boots! I got him zipped, tucked, bundled, and.. screaming because he couldn't bear to be so confined by clothing. I didn't even notice his sister fumbling with her mittens as I hurried them out the door to get him distracted by a video in the car. She held the mitten up to me and assaulted me with her request, "Me too." In my frazzled state, I was even irritated by her incompetence!

What kind of unrealistic expectations have you placed on your unaffected children?

Here is my list of transgressions:

"YOU SHOULD BE MORE PATIENT WITH HIM BECAUSE IT'S NOT HIS FAULT."

Why is this unrealistic? First of all, ALL brothers and sisters annoy each other. How am I preparing my children, all of them, for the real world if I try to protect them from each other?

In the end, their family is going to be their safety net. If they aren't permitted to feel natural feelings of annoyance and disappointment in one another, they won't

learn how to test that net. My hope would be that they would learn to cope with those feelings within the safety of their own family and take that knowledge with them into life.

Maybe, just maybe, it will teach my unaffected children how to evaluate each person they meet with a broader perspective and it could teach my affected child how to let comments and gestures from others roll off his back with a little more ease.

"YOU NEED TO FIGURE IT OUT ON YOUR OWN."

How many times have I expected my other children to tie their own shoes, attempt their own homework, find their own rides, solve their own problems, because I was "busy" with their brother? Too many times to count.

Although I do feel some guilt about this, I don't think this was entirely a bad thing. I think that often times, we are too quick to solve our children's problems for them. We don't want to see them struggle. I don't know where or when we decided to be this way, it was definitely not from our parents! I don't remember a time that I asked my parents for help with homework. Seemingly, our parents' generation knew that kids needed to struggle in order to develop their brains for critical thinking and to empower them with problem-solving skills. There are whole articles written on this topic.

I do regret not having more patience with them. I was so often overwhelmed by my son's needs that I often felt irritated when my other kids asked me for help.

"I EXPECT MORE FROM YOU."

I saved this one for last because it is the sum and substance of it all. I may have never actually uttered these words to my children, yet there is no doubt in my mind that they know this.

This one is not as much of a regret for them as it is for my son. By expecting more from his siblings, I have actually expected less from him, haven't I? I have always encouraged him to work hard and be his best, yet, I fear for him more often than I do the other kids. I fear that he won't be ready for college when his peers are. I fear that he will not find a job situation that will show him compassion. I fear that the world will be cruel and unkind. I fear he will be alone, in pain, unhappy...I could fill this page with my fears.

Of course, I have the same kinds of fears for all of my children, but the feelings are so much more intense when your child is born at a disadvantage. I know in my heart, that the others are going to be just fine even though they have all had their own struggles in life. I don't have the same confidence for him. This is the most troubling aspect of all.

Connie lives with husband, Peter and their two youngest children in the Richmond, Virginia. She is a Senior Manager for Volunteer Engagement at the Children's Tumour Foundation. Her passion and dedication to the NF cause will continue to push her as long as there is no cure for NF. Read more about Connie's journey at nfsaid.blogspot.com

Now for my apologies:

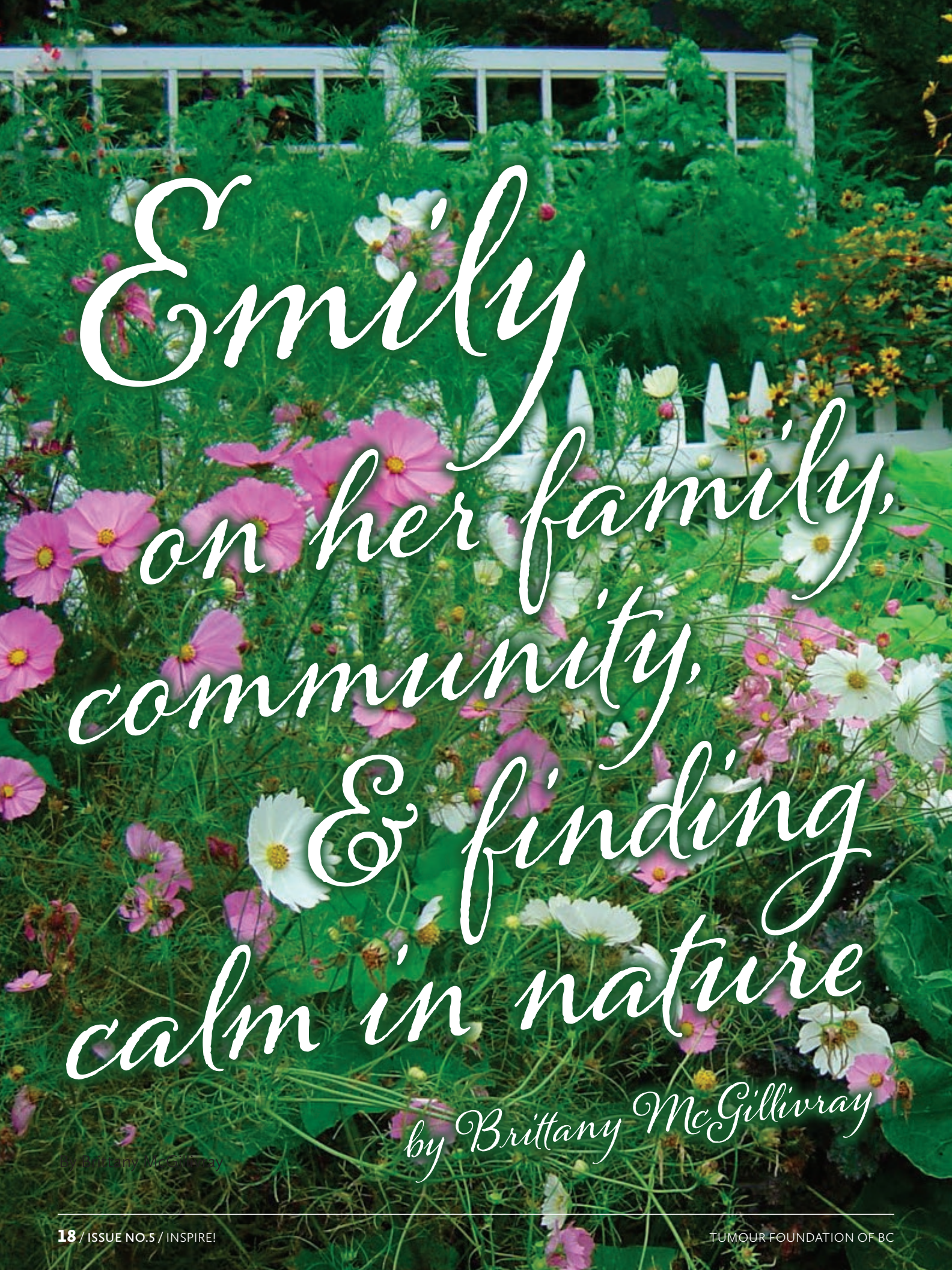
TO MY BIGGEST KIDS

I expected the most from you. You were so much older and in my mind, less needy. I know now that this was not the case. You were just as needy, but your needs were different. I am sorry that I may have made you feel insignificant at times. I am sorry that I made you grow up faster than you should have. I am sorry that I expected you to know certain things, to be more compassionate and to have an understanding beyond your years. Just as your brother didn't ask to have NF, you didn't ask to have a brother with special needs. I love you with every ounce of my being and wish for every happiness in your life. You are strong, you are capable and you are amazing. You are not inconsequential in any way. There are some very important life lessons that you learned by being his sibling. I don't wish to discount that, but you may, at times, have felt less important to me and for that I apologize. I never wanted you to feel that way.

TO THE BABY

You may have been born last, but you were not often given the opportunity to be the baby. Having a "bother," (which you quite aptly misspelled on one his birthday cards) who needed so much attention from me, was often unfair to you. I have expected things from you that were far reaching for your age. I've expected you to take care of him, to watch out for him, to include him and to have more patience than any sister ever could. You have always risen to the occasion and have sacrificed much of your own identity to be a "good" sister. You have traveled countless miles, sat in waiting rooms, entertained your brother during recovery periods and shown compassion beyond my expectations. You have never complained about any of this and you have never expressed any wish to have it be different. I am so sorry that I didn't have more patience when you needed me also. I am sorry if you ever felt left behind. You are a special girl and you have such empathy within you; not many are given that gift. I just want you to know that I love you and respect your kindness more than I can ever express. My hope is that you will never again in your life have to say, "Me too."

My confessions are made and my apologies have been expressed. Do I think that with hindsight, things would have been any different? Absolutely not. We are human beings. We do the best we can in any given situation. Having a child with NF can be very stressful on so many levels. We have to cut ourselves some slack because our expectations of ourselves are often the most unrealistic. We find ways to make all of our children feel valued and loved, but the truth is that circumstances determine who needs the most from us and our other kids find their way. They learn to be stronger and to have more compassion for others. They are better equipped in life than their peers. Perhaps they need special times alone with us to compensate, but what I say to that is: "Me too." It's a win/win situation.



Emily on her family, community, & finding calm in nature

by Brittany McGillivray

By Brittany McGillivray

"I've been blessed with amazing family and friends," says Emily McDonah, of St. Margaret's Bay, Nova Scotia – in her words, a town near "the picturesque Peggy's Cove," less than an hour from Halifax. Emily and her husband, Mike, live in the woods in an off-the-grid home powered by wind and solar power. They live with their two boys, Phinn and Seamus, and their two retrievers and two cats.

Living off the grid has its benefits. "We love to garden – the kids and I grow everything from tomatoes to parsnips to pumpkins and spend as much time outdoors as we can."

In spite of living somewhere remote, Emily is connected with her communities. As founder of the NF Society of Nova Scotia, Emily has involved herself with both her local and extended Nova Scotia community. When asked what motivated her to found the society, she explained:

"I was diagnosed with NF about four years ago and it didn't take long at all to realize that information, support and understanding for neurofibromatosis was sorely lacking in Atlantic Canada. It came at a time that NF Canada was disbanded, so it was all the more lonesome to be diagnosed."

Emily got thinking about NF1 and realizing how difficult it would be for a parent to go through this with their child or teenager without any real understanding or information of the condition.

"Living in rural NS, when someone is down – everyone comes together to help. Even people you don't know. Even in the face of my diagnosis, all that support makes you feel unstoppable."

This realization spurred Emily's desire to create a network of support for those with NF. "It's been a very slow labour of love. It's extremely hard to reach people, to find those with NF that want to be found and embraced, but three years in, we're finally growing a family of NF fighters of all ages, locations and diagnoses."

"We offer a website with relevant, accurate information and resources, the support of meeting each other and keeping in contact, and distribute information to medical professionals. We fundraise to sponsor kids to attend NF Camp in Utah and for a more local camp for younger kids that caters to varying limitations (not NF specific). It's AMAZING to see how this changes their lives and the confidence and optimism it allows them. It makes every ounce of the effort worth it."

Emily herself knows the importance and difficulties of balancing 'everyday life' with NF. Her days are a balance between soccer and hockey games and sports practices for the boys – and appointments, surgeries, and days where living with NF Type 2 can feel more difficult than others.

As someone who understands the potentially isolating side effects of living with NF, when asked what she wishes people knew or understood about it, Emily answered:

"Wow, that's a hard one. I guess I wish doctors and other medical professionals were more familiar with it, so that we'd be diagnosed sooner and treated in a more streamlined way. I feel like patients spend so much time educating doctors...."

"Of course, where NF1 is concerned, when it's more outwardly apparent that folks are affected, I wish people knew that the bumps they see are painful tumors. That there are amazing people under there who aren't gross or contagious, that are very worthy of compassion and acceptance."

Besides founding NFNS, Emily has also demonstrated an entrepreneurial flare as creator of Simply Gorgeous, an all-nature and handmade skin care line. Though currently the business is in a holding pattern – ("It became near impossible to produce my product reliably when only working on my 'good days'" Emily explains) – the line can be seen as a positive outcome of Emily's experience with NF.

"I've always been really environmentally conscious and aware of the staggering number of chemicals we're exposed to 24/7. Not knowing if my tumors were environmentally fuelled [before diagnosis], and determined to protect my kids as much as possible, I went through our home and threw out virtually every cleaning and self care product we owned. Which led to me needing to find an economical way to replace the things we really needed."

In explaining this trajectory, Emily's natural optimism is evident: "I found so much joy in being surrounded by natural ingredients – learning, experiencing and teaching not just my family, but what turned out to be so many folk, that we don't need those chemicals to take care of ourselves and that we can do it without spending a fortune."

Her mix of rational, sensible thinking and genuine positivity is apparent, even if at times it baffles her friends.

"People so often say 'but you look so happy..' or 'how do you do it?' when my health is discussed and my answer is always the same. My kids. They are well aware of my pain and limitations – but I want them to know above all else that we can be HAPPY and follow our dreams no matter what hand we're dealt.

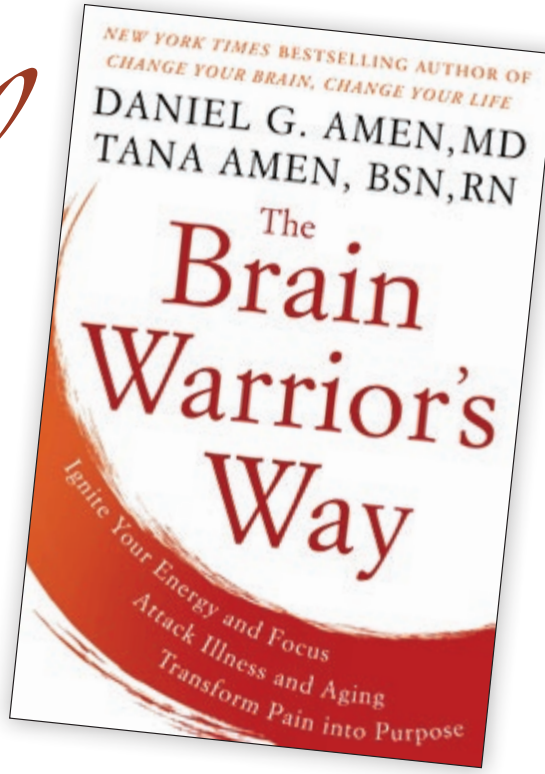
I want them to know that it takes hard work, life takes hard work, but that never makes it bad. So, I smile. I LAUGH. I laugh at my situation, and sometimes that's dark humor, but if I didn't laugh, I'd be lost."

"In a more general way – I'm learning to listen to my body. Rest is part of my day, staying within a moderate level of exertion is also important. I say now that being healthy or striving for healthfulness if my full time job. So if making a healthy breakfast is my morning accomplishment, I feel good about it rather than beating myself up for not doing more (and that is really, really hard for me!)"

Perhaps it is her idyllic location out in the east coast, or consistent interest in the environment, but when all else fails, Emily takes herself outdoors.

"Just fresh air alone soothes me, but having my hands in the dirt, or exploring the woods with my dogs makes me feel more grounded and grateful every time. Since my diagnosis I've become hyper-aware of the little things and being in nature floods my soul with gratitude. It's my best medicine."

Inspirational Read



The Brain Warrior's Way: Ignite Your Energy and Focus, Attack Illness and Aging, Transform Pain Into Purpose

by Daniel G. Amen, Tana Amen

Review by Desiree Sher

When trying to live a healthy lifestyle, every day can feel like an uphill battle. Add NF, or another health condition into the mix and life at times can feel insurmountable. With thousands of books and websites available on getting fit and healthy, it is hard to know where to start. I offer you *The Brain Warrior's Way* as a good place to begin.

This book advocates living a full and healthy life by starting with your brain. Your brain runs your life. When it works right, your body works right, and your decisions tend to be thoughtful and goal directed. Bad choices, however, can lead to a myriad of problems in your body.

I was inspired while reading this book to make a variety of small changes to my daily life. Backed by scientific studies, the book outlines very clearly how small changes to our habits can improve our health.

Based on a scientifically-designed program created by the authors, I dove all in. With just a few small changes I experienced increased energy, improved focus, and a deeper sense of inner peace. My changes included getting consistent sleep, reducing caffeine, adding daily exercise, taking a new supplement, releasing toxic relationships, and reducing my intake of news and time spent on social media.

I have read dozens of books about improving my health since my stroke in 2014 but I found the changes most experts advocated just weren't sustainable in my busy life, (such as that all raw food diet that I tried and quit). I'll admit, the book's powerful images of what a brain that has been abused by poor habits looks like, that kicked me into high gear to live a healthier life.

Despite what challenges you are experiencing you have the power to live your life to the fullest and to feel your best. The key to success starts between your ears. The book is available at your favourite bookseller and on Amazon.

THIS IS MY SON CREW AND NF HAS GREATLY IMPACTED HIS LIFE.

By Hilary Berens
Hilary and her family live in Michigan

At two and half years old, Crew has had at least five MRIs under sedation, had eight different doctors or specialists, and too many medical appointments to count. He has tumors in his mouth, cheek, near his brain stem and neck. The tumors have caused his tongue to be asymmetrical to the extent of the center of his tongue being on the left side. His speech is being greatly affected and has started speech therapy. He often accidentally bites his tongue and gets frustrated when others can not understand him. The tumors have caused his parotid gland in his cheek to be blocked and will be needing Botox injections under sedation. Due to the tumor on the trigeminal nerve, every time he chews food, red flushing occurs on his right cheek that sometimes goes into his ear, eyelid and hairline. Sometimes when his skin flushes his right eye will water. Crew has been taking a chemotherapy medication since November 2016. Sometimes the meds make his stomach feel upset or give him headaches. Crew has been to the doctor so often that even as a toddler he often tells the professionals what to do and when: "Check this ear, that ear, eyes." He pulls up his shirt for them to hear his heart and back.

We have an amazing support group that has banded together to put together and support fundraising for a lifelong medical fund for Crew. This includes hosting fundraisers and awareness basketball games at local high schools, Facebook fundraising, selling homemade holiday arrangements plus more. Our family was also just interviewed with Fox 17 News. They featured Crew, his journey with NF1 and his fundraisers.

We hope to bring awareness to this disorder, and help provide strength and hope to others on similar paths.

For more information on Crew and his journey please follow his Facebook page:
www.facebook.com/HisBattleIsOurBattle

And to view the Fox video visit
www.bit.ly/2jULBYP

EARLY-PHASE TRIAL DEMONSTRATES SHRINKAGE IN PEDIATRIC NEURAL TUMORS

In an early-phase clinical trial of a new oral drug, selumetinib, children with the common genetic disorder neurofibromatosis type 1 (NF1) and plexiform neurofibromas, tumors of the peripheral nerves, tolerated selumetinib and, in most cases, responded to it with tumor shrinkage. NF1 affects 1 in 3,000 people. The study results appeared Dec. 29, 2016, in the New England Journal of Medicine.

The multicenter phase I clinical trial, which included 24 patients, was led by Brigitte C. Widemann, M.D., acting chief of the National Cancer Institute's (NCI) Pediatric Oncology Branch, and was sponsored by NCI's Cancer Therapy Evaluation Program. The study, conducted at the NIH Clinical Center and three participating sites, took advantage of techniques developed by Dr. Widemann's team that enabled very precise measurement of the plexiform neurofibromas. Experiments in mice that developed neurofibromas due to genetic modifications were performed at Cincinnati Children's Hospital in the laboratory of Nancy Ratner, Ph.D. NCI is part of the National Institutes of Health.

Plexiform neurofibromas develop in up to 50 percent of people with NF1. The majority of these tumors, which can cause significant pain, disability, and disfigurement, are diagnosed in early childhood and grow most rapidly prior to adolescence. Complete surgical removal of the tumors is rarely feasible, and incompletely resected tumors tend to grow back.

The primary aim of this clinical trial was to evaluate the toxicity and safety of selumetinib in patients with NF1 and inoperable plexiform neurofibromas, and, encouragingly, most of the selumetinib-related toxic effects were mild. At present, no therapies are considered effective for NF1-related large plexiform neurofibromas, but, in this trial, partial responses, meaning 20 percent or more reduction in tumor volume, were observed in over 70 percent of the patients.

Responses were observed in tumors that were previously growing at a rate of greater than 20 percent per year, as well as in non-progressing lesions. Tumor shrinkage was maintained long term, for approximately two years, and, as of early 2016, no disease progression had been observed in any trial participant. Additionally, anecdotal evidence of clinical improvement, such as a decrease in tumor-related pain, improvement in motor function, and decreased disfigurement, was reported.

The disease-causing gene for NF1 was first identified in 1990 by two independent teams, one of them led by NIH Director Francis S. Collins, Ph.D., M.D., who at the time was chief of Medical Genetics at the University of

Michigan. The other team was led by Ray White at the University of Utah. Research to understand the gene's function revealed that deregulation of the RAS signaling pathway was the most likely cause of tumor development. Numerous drugs that target RAS-related signaling pathways have been tested in patients with NF1 in phase I and phase II clinical trials, with disappointing results, hence the interest in selumetinib.

Selumetinib, provided for the study by AstraZeneca, is a selective inhibitor of the MEK protein, a part of the complex network of RAS signaling pathways. The drug has demonstrated activity in some advanced cancers, but it is not yet approved by the U.S. Food and Drug Administration for use in the United States. It is manufactured in capsule form to be taken orally.

Trial enrollment began in September 2011 and 24 children (11 girls, 13 boys) participated. Twice daily doses of the medicine were taken continuously, over a median of 30 month-long treatment cycles. The majority of patients are still continuing with therapy, some for as long as five years, and the long-term treatment has had no observed adverse effect on their development or overall health.

Experiments in mice with similar neurofibromas confirmed the inhibition of the MEK protein function in the tumors. Inhibition of the MEK protein diminished as early as two hours after drug administration. In addition, the animals received treatment with regular interruptions and still demonstrated tumor responses. This indicates that even limited MEK inhibition could cause tumor shrinkage in this disease.

"Some may say that a 20 percent volume reduction is too small to be meaningful, but to me, just stopping the growth of these devastating tumors is an important achievement,"

Dr. Widemann.

"In the future, we may wish to look at intermittent dosing in patients to minimize toxicity and retain maximal outcomes," said Dr. Widemann.

In some patients, a loss of response to selumetinib with slow regrowth of tumors was observed, particularly after dose reductions. The researchers believe that additional studies are warranted to characterize tumors that no longer respond to selumetinib. NCI is currently sponsoring an ongoing phase II trial of the drug for adults with NF1, in which serial tissue samples are being obtained. This study should provide information about possible mechanisms of resistance to selumetinib.

In addition, a larger phase II pediatric trial is enrolling patients and should help establish the efficacy of selumetinib treatment in children. In this trial, in addition to tumor volume measurements, evaluations are being performed to assess the effect of selumetinib on plexiform neurofibroma related disfigurement, pain, quality of life, and function.

This research was supported by NCI's Center for Cancer Research and the Cancer Therapy Evaluation Program; by the Children's Tumor Foundation to Michael Fisher to support participating sites other than the NCI; by AstraZeneca providing selumetinib and funding for the pharmacokinetic analysis; and by grants from the Children's Tumor Foundation and the Neurofibromatosis Therapeutic Acceleration Program (to Dr. Ratner for the mouse preclinical trials).

Source: National Cancer Institute (NCI) cancer.gov

Q

with the new President: Steve Billington

& A

Q: What inspires you?

A: People with passion for a cause. I've always admired the 'greats' of history – from Caesar to Ghandi to Obama – who had a vision, whatever it may have been, and were driven to accomplish it.

Q: What are you most proud of?

A: I have followed my heart in most things in life and I'm proud that I've been true to myself.

Q: What do you think about when you're alone in your car?

A: Sometimes the places I've seen (we were able to backpack-travel a lot in the 90s) and often my son's future. He lives with NF and because of the uncertainties of this disease we don't know what his future holds. We never do with anyone but NF adds extra difficulties to life.

Q: What's your favourite tune to rock out to?

A: 'Ahead By A Century' by the Tragically Hip. I love that band and I've always liked the song but recently learned it's about our connection to our children. My favorite line and one I find to be very true is "No dress rehearsal, this is our life". My son and I were given a gift by my wife of two tickets to the Tragically Hip final tour show in Vancouver last summer. That was an amazing experience to share and the Hip played Ahead By A Century – just for us. At least that's how it felt.

Q: What is your biggest hope?

A: That a cure for NF will be found in my son's lifetime. Seeing the inventions and advances that have happened in my fifty years of life, I think that is entirely possible.

Q: Where do you go when you want to escape?

A: I love camping and find being in the wilderness a great stress-reliever. I wish I could say I'm a great fisher but I can say that I can sit by a campfire like few others!

Q: What is the luckiest moment of your life?

A: That back in the 80s my wife put off science as long as possible in her senior years but found she needed a science credit for graduation and so took Physics 11-- where she met me. We met in high school and have been together for the 33 years since.

Q: What book are you are reading now?

A: Several. The History of the World in 100 Objects by just-retired British Museum head Neil MacGregor, The Wyrd Sisters by Terry Pratchett, and Ancillary Justice by Ann Leckie.

Q: What's the last thing you watched on TV?

A: Dirk Gentley's Holistic Detective Agency. Much darker than the novel and not recommended for under-14's.

Q: What is the funniest thing that has happened to you recently?

A: Dinner parties with a close group of friends always end in silly stories, games, and laughter.

Q: What do you do in your free time?

A: I enjoy science fiction and computer games.

Q: Who would win in a fight between Batman or Spiderman?

A: Batman. Fewer scruples.

Q: What is your super power as President?

A: I can see strengths in others that they may not see themselves and I can help motivate them to use their powers for good!

NF FACTS & STATISTICS

Neurofibromatosis is an umbrella terms for three distinct disorders: NF1, NF2 and schwannomatosis. They are caused by different genes, that are located on different chromosomes.

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

NF2 is a rarer type, occurring in 1:25,000 people worldwide.

While today there is no consensus, studies indicate that schwannomatosis occurs in 1:40,000 people.

All forms of NF can be inherited from a parent who has NF or may be the result of a new or "spontaneous mutation"

NF is more prevalent than cystic fibrosis, Duchenne muscular dystrophy, and Huntington's Disease combined, affecting more than 2 million people worldwide.

Each child of an affected parent has a 50% chance of inheriting the gene and developing NF. The type of NF inherited by the child is always the same as that of the affected parent, although the severity of the manifestations may differ from person to person within a family.

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

NF2 can also cause severe vision problems, including cataracts, retinal abnormalities and orbital tumors.

NF research may benefit millions worldwide living with caner and learning disabilities.

The distinguishing feature of NF2 is tumors that grow on the eighth cranial nerve in both ears, commonly causing deafness and severe balance problems.

NF2 brings on increased risk of other types of nervous system tumors as well.

Although most cases of NF1 are mild to moderate, NF1 can lead to disfigurement; blindness; skeletal abnormalities; dermal, brain, and spinal tumors; loss of limbs; malignancies; and learning disabilities.

MAKE A DIFFERENCE BY DONATING TODAY!

THE NF CLINIC

AN UPDATE

In our first issue of the INSPIRE magazine we dared to dream about having a dedicated clinic for the NF community in British Columbia. Four years later we are closer to that dream than ever before.

With the generous contributions of our supporters, we have raised almost $100,000 to launch the clinic. We are now working with physicians at Children's Hospital, Women's Hospital, and UBC to create a sustainable clinic model and NF care protocols.

WE ARE ON OUR WAY!

> *"The time is right. There are research and clinical trials and new therapies that are happening, and our patients in BC can't access them because there is no clinic."*
>
> – Dr. Jan Friedman, Professor of Medical Genetics, University of British Columbia

However, creating a clinic takes time. There are lots of layers to work through but we are making progress as we work to bring the clinic dream to life. Sign up on website to make sure you don't miss an update on the clinic or you can connect with us via our Facebook page at facebook/tumourbc.

It is not too late to donate to the clinic project. Every dollar makes a difference to the families we serve.

TUMOURFOUNDATION.CA/DONATE

10 Simple Ways to Infuse More Happiness into Your Life

"Each morning when I open my eyes I say to myself: I, not events have the power to make me happy or unhappy today. I can choose which it shall be."

~ Groucho Marx

I have tried many different ways to increase my happiness.

I believed when I had more money in the bank, a bigger house, a fitter body, then I would be happy. This mindset, that happiness was only achieved by external achievement, drove me to spend countless hours working and working out, attending courses and workshops and competing in triathlons and marathons. I was always looking for the next thing that would make me feel happy. Yet, as I went up the ladder of success, the more empty, depressed and emotionally flat I felt.

It took many storms, including a divorce, loss of loved ones, a stroke, and a car accident, to learn that being happy was actually very simple – it's a choice.

A choice we can make in any moment, despite the circumstances that we find ourselves in.

I know is easy to say, but "Choose Happiness".

And yes, it can be a lot harder to make that choice when you are grieving the loss of a job, the end of a relationship, or the NF diagnosis. When we feel overwhelmed, fearful or confused we forget that being happy is a simple shift and we return to old mindsets and patterns that keep us stuck in misery.

But you don't have to stay feeling discouraged, hopeless or passionless.

There are simple ways you can bring happiness back into your life just by putting your attention on one of these new habits.

1. Connect to Your Breath

When things are just 'too much' try slowing down and concentrating on breathing deep into your belly. Stay here for a few moments. Connecting to your breath will relax you, reduce anxiety and bring you back into the present moment.

2. Shift Your Perspective

Try looking at your situation through a different lens. No matter how bad things are remember that they could be worse and be grateful for all the good things that are in your life, even when it feels like that there is more bad than good. Take a minute to think of three things you are grateful for and write them down. (Science has proven that doing this every night for 21 days will make you happier.)

3. Perform an Act of Kindness

Go do something nice for someone else. Doing something nice for someone you care about gets you out of your head and the cycle of negative thoughts. You will feel good doing something nice and you will definitely make that someone feel happier. Go give someone a hug, buy a coffee for a friend, take your neighbour's dog out for a walk.

4. Move the Negative Energy

Fifteen minutes of cardio exercise has the same benefit as an anti-depressant and the effects last longer. Working out moves the energy through your body and releases chemicals that give you a mood lift. Take a jog, play tennis, or just walk around the block to increase your happiness.

5. Meditate

The benefits of meditation are many and one of them can be encouraging positive thinking. By clearing your mind and relaxing you can let go of some of the challenges that are troubling you. You don't need flowing robes and incense. Just sit silently for a few moments in your day and focus on the air move in and out of your nose.

6. Smile

Sometimes all it takes to feel good is to put a smile on your face. Try putting on a happy face even when you don't feel like smiling. You will instantly feel better.

7. Understand the Why of Obstacles

Along your path to your dreams you are going to encounter some roadblocks. These don't have to stop you. Obstacles just help ensure that you truly want what you are working for. Keep going!

8. Get into Nature

Research shows that being in nature has a profound effect on our mood and our happiness. It reduces anxiety, increases feelings of connectedness, creativity and makes you feel more alive. Find some space in your day to go outside even just for a minute to two to feel the sun, wind or rain on your face.

9. Let the Love Flow

Tell someone in your life how important they are to you. It could be a child, parent, your partner, a co-worker. Sharing your love and appreciation will increase the happiness and the love in your life. You can call, send an email or mail a card.

10. Take a Small Imperfect Step Towards Your Dream

Huge goal can be overwhelming and sometimes discouraging that we don't take any action. Break your goal down to a bunch of micro-steps and you will get to the same destination as big leaps. It doesn't have to be the perfect move. Ask yourself what you can do right now, that won't take more than five minutes, but will move you towards your goal. Go do that now! You will feel happier after you take action as you are taking control of your future.

Desiree Sher is the Executive Director of the Tumour Foundation of BC. She is also a speaker and life coach and enjoys presenting to audiences across North America on expanding happiness. You can find her online at desireesher.com

NF SYMPOSIUM

MAY 6TH

Join us in Richmond, BC for our annual day of education, connection and fun. This year's symposium has a great line up of speakers and is an opportunity to meet other families, researchers, clinicians and other health care professionals.

Speakers this year include Dr. Jan Friedman, Dr. Saber Ghadakzadeh from Montreal Shriner's Hospital, Ben Lipson from Sunnybrook Health Centre plus many other special guests. Topics include an update in NF1 research, bones and NF, clinical trials with plexiform tumours, courageous living and more. You don't want to miss this event. Limited tickets are still available. Visit us online to secure your spot today!

GET YOUR TICKETS TODAY!

www.tumourfoundation.ca/events/annual-nf-symposium/

SEE YOU THERE!

INSPIRE OTHERS TO MAKE A DIFFERENCE

RUN, JOG OR WALK WITH US AT THE 2017 SCOTIABANK HALF MARATHON AND 5KM CHARITY CHALLENGE

SUNDAY, JUNE 25TH

WHEN AND WHERE

7:30am
Half-Marathon Start at UBC Thunderbird Arena

9:30am
5k Fun Run/Walk Start at Stanley Park Fish House

WHY

- *Help raise funds, which will support research and education*
- *Join our team for fun, prizes and a crazy pasta dinner the night before the race*
- *Enjoy a day with our family and friends in a stunning location*
- *After the event run join us at the tent for a celebration of cake and surprises!*

HOW

To register go to: vancouverhalf.com

COMMIT TO RAISING A MINIMUM OF $200 AND WE WILL PAY YOUR REGISTRATION FEE. *That means no cost to you to participate in this fun event and you get two free t-shirts!*