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ANNIVERSARY EDITION

MORE THAN
JUST TUMOURS

Long Distance
Love

BRAVELY
FORWARD

COMING
OUT OF THE
SHADOW

Faces of
Courage

FINDING
RAINBOWS

The magazine of the
Tumour Foundation of BC
Issue No. 9
Fall 2022

inspire

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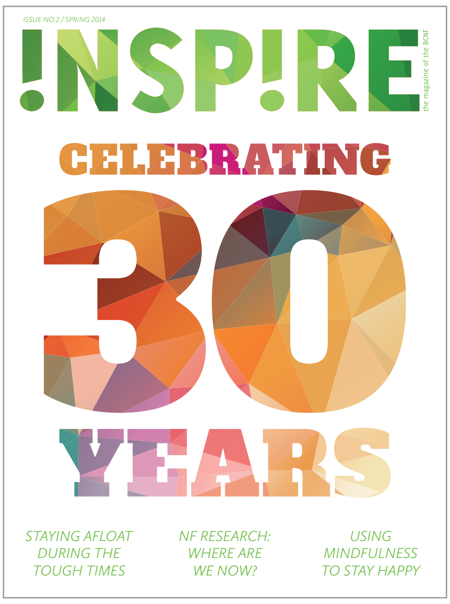
Tumour Foundation of BC



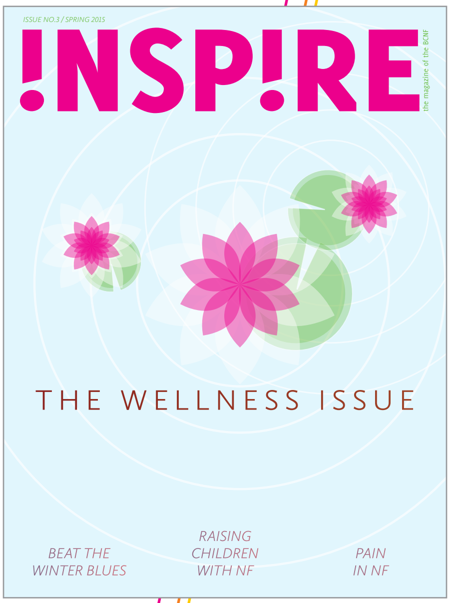


Foto Sukanen

From Issue #1, Spring 2013

THE FACE OF NF

SHINING A LIGHT ON
MEMBERS OF THE
NF COMMUNITY

Until Foto Sukanen became involved with BCNF (now TFBC), she had never met anyone else with NF. As one of the founding members of BCNF, back in 1984, Foto has recently re-joined the BCNF Board of Directors. Foto recalls that in 1984 she heard that there was a group forming for those with NF and their family members. "I had gone to genetic counselling in regard to family planning, and called one of the contacts and got involved." Foto is getting close to retirement, so in September of 2012 she decided to re-join the BCNF board. She now has some free time and energy to devote to NF. Foto has always been a silent supporter of BCNF, but looks forward to getting actively involved once again in fundraising and wherever else she can be of assistance.

Foto was diagnosed with NF1 in 1962 when she was six years old. Prior to her diagnosis, her mother took her to the cancer clinic in Saskatoon, Saskatchewan to keep an eye on a tumour on the left side of her nose. The doctor referred her to a plastic surgeon for removal of the tumour. When asked how NF has affected her life, Foto says that it had a major impact on her decision to not have children. Aside from two surgeries to remove the tumour from her nose and several reconstructive surgeries, her NF has not been a major concern. Foto has several signs of NF1, but none are severe. "I have high blood pressure, slight scoliosis, café-au-lait spots, liche nodules in my right eye, a slightly larger head, and short stature," tells Foto. Foto is concerned about how her NF might be affected by aging. "I have noticed that the nodules on my midriff are increasing in number," says Foto.

Aside from NF, Foto has been with her soul mate, John for 34 years. "After 34 years, we can still sit and talk for hours," tells Foto. "Our piece of paradise is Long Beach on Vancouver Island. We try to get there every couple of years." Foto enjoys cooking/baking, beading, and crafting. She hopes to get back into sewing once she is retired. Foto also has a deep love for animals. "I have always had my furry kids. The current count is four cats and no dogs," says Foto. "Our young grey tabby is called Yogi. Yes he does yoga poses," Foto humorously says. Foto also has a white and tabby male called Woody and a black elderly girl called Spike. "I look forward to adopting a rescue puppy once I have retired," shares Foto. •

WORDS BY **SARAH GORDEN** / PHOTOGRAPH BY **CARA GRIMSHAW**

Foto Sukanen *in 2022*

What have you missed the most through the pandemic?

Lunch with friends. In person symposiums and other events. My TOPS meetings.

What makes you feel successful in dealing with NF and life?

I take each day as it comes. There is no point in worrying about something I can't control.

What or who are you enjoying connecting with the most now?

My TOPS meetings and lunch with friends.

Robert McNaughton

From Issue #1, Spring 2013

THE FACE OF NF

SHINING A LIGHT ON
MEMBERS OF THE
NF COMMUNITY

ONE FOOT IN FRONT OF THE OTHER

Fifteen year old Robert McNaughton has a passion for running. Much like his love for running, he lives life putting one foot in front of the other and never gives up until he's crossed the finish line.

Robert was diagnosed with NF1 when he was only a year old. In elementary school, Robert participated in cross country running. Despite weakness in his left leg, he gave it his all and never gave up, even if it meant coming in last place. "He never quit running until he crossed the finish line," recalls his father Dave. Robert is now fifteen years old and continues to have a passion for running. "He practiced very hard on his own time and now in his grade ten year he is consistently in the top three in his class," says Dave. Robert also enjoys taekwondo, and despite being held back a year, he persevered and is gradually moving up in his belt class.

Robert has had fourteen major surgeries due to his NF1. "They have caused much discomfort and time away from school due to recovery," says Dave. When Robert was younger he had trouble with physical activity which limited him in playing certain sports. "His symptoms include a nodule under the skin below his right eye, numerous café-au-lait spots all over his body, and the right side of his face is slightly bigger." Robert also has weak vision in his left eye and dental problems related to NF1.

Robert has a wonderful support system in his parents and grandparents, who are there for every surgery and are also very involved with BCNF. "Through this organization we were able to obtain much information, guidance and comfort when Robert was diagnosed with NF1." Robert and his family raised over $4,000 in just two weeks for the BCNF Scotiabank Charity Challenge where Robert ran the 5 km event. "Robert wrote a personal letter explaining a little bit about his illness with a picture of himself attached asking for donations towards research in finding a cure." Dave circulated the posters at his workplace, CN Rail. "The response and generosity of my fellow employees was overwhelming," recalls Dave. Over $2,500 was donated by employees at CN Rail. The McNaughton family also circulated the posters to friends, neighbours, and at Robert's school where generous donations continued to pour in.

In addition to running and taekwondo, Robert enjoys travelling to Pokemon tournaments across North America, playing video games, cooking, the scouting program, attending his church's young adults group, and graphic design. "Even though I have had many surgeries since I was a young child, I never let the recovery time discourage me," says Robert. "When I am fully recovered, I continue doing the things I enjoy." •

"HE NEVER QUIT RUNNING UNTIL HE CROSSED THE FINISH LINE"

Karen Thornton

From Issue #1, Spring 2013

THE FACE OF NF

SHINING A LIGHT ON
MEMBERS OF THE
NF COMMUNITY

FREQUENT FLYER

Karen Thornton loves to fly. For her fiftieth birthday while on vacation in Lumby, B.C., Karen's husband, Ken bought her a glider flight. "What a trip that was!" explains Karen. "When we landed, I couldn't feel my feet on the ground I was so high!"

But that was only the beginning. Five years later, she was taken up in a motorized hang glider in Hope, B.C. Then, for her sixtieth birthday, her daughter gave her a flight in a hang glider. "The feeling of total freedom I get is indescribable!" exclaims Karen. Next on her list of things to try is paragliding.

Things have not always been carefree for Karen. When she was 18 years old and pregnant, doctors diagnosed Karen with Neurofibromatosis Type One (NF1). Unfortunately, Karen's daughter, Kim, was also born with NF1 and had to have a tumour removed from her mouth shortly after birth. Karen also has a son, Dan, who did not inherit NF1.

Karen enjoys spending time with Dan's two daughters, who are five and two. Karen is a spontaneous mutation, as her parents and siblings do not have NF1. Karen has lived with tumours on various parts of her body since childhood, but the pregnancy made the tumours grow and new ones to appear on her face and neck. "The biggest challenge for me was the fear of meeting people and not being accepted due to the visible tumours," says Karen. "My interest in motorcycles and motorcycle riding (as a passenger only) is what enabled me to overcome my self-image hang-up."

Karen and her husband bought their Honda Gold Wing motorcycle in 1990 and rode for a couple of years before they joined the Gold Wing Road Riders Association (GWRRA). "I was accepted for who I was," says Karen. They became provincial directors in the organization and met hundreds of people. According to Karen, "I had never had so many people wanting to hug me!" To many people, owning a Gold Wing means buying chrome, lights, and accessories for their bikes. After becoming friends with the owner of a bike shop in Bremerton, Washington, Karen decided she would like to start her own business. She now runs a small, home-based business selling motorcycle accessories called Karen's Krome. •

WORDS BY **SARAH GORDEN** /
PHOTOGRAPH BY **CARA GRIMSHAW**

Sarah Gorden

From Issue #1, Spring 2013

THE FACE OF NF

SHINING A LIGHT ON
MEMBERS OF THE
NF COMMUNITY

HOW SWEET THE SOUND

To Sarah Gorden, being able to hear her husband say “I love you” is a miracle.

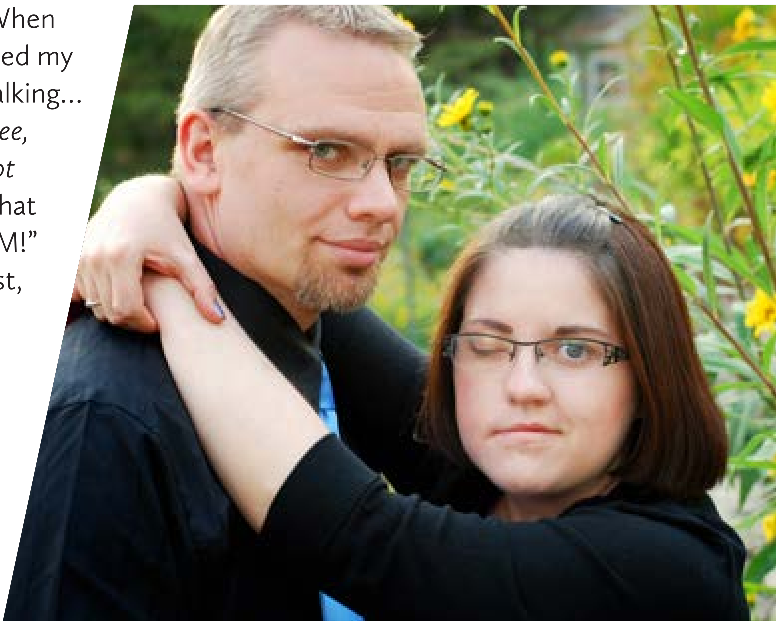
Four years ago, Sarah had to undergo a surgery which took her hearing. Living with Neurofibromatosis Type Two (NF2), she had tumours on both sides of her brain, affecting both her hearing and balance. When the larger of these two tumours had to be removed, she had to sacrifice her only remaining hearing. Stepping into a now silent world was difficult, but there was hope.

“I connected with other NF2 patients through an online support group called the NF2 Crew,” Sarah explains. “It was through this group that I learned of the House Research Institute (HRI) in Los Angeles, California.” The House Research Institute specializes in disorders affecting the ears and hearing. They are one of very few centers in the world that specialize in NF2. At HRI, they have developed a specialized hearing implant called an Auditory Brainstem Implant (ABI). The implant is specifically for people with damaged auditory nerves. When the NF2 tumours are removed, the auditory nerve is destroyed. Devices like hearing aids or cochlear implants are no longer an option. The ABI bypasses the auditory nerve and stimulates the brainstem to restore some sense of sound.

The ABI was placed at the same time as the tumour was removed. Two months after her surgery, Sarah returned to Los Angeles to have the device activated. “When the audiologist flipped my ABI on and began talking... ‘*Testing one, two, three, popcorn, baseball, hot dog*’ I was amazed that I COULD HEAR HIM!” Sarah recalls. “At first, the sounds were artificial sounding and peoples’ voices sounded like they had been inhaling helium. With time, this got better and everything started to sound more natural.” With a lot of practice, Sarah now does very well with her ABI. “Although it did not restore my hearing, I am able to hear things that I never thought I would get back. I am especially grateful to be able to hear my husband’s voice and am relearning how to hear some music.”

Unfortunately, during the surgery, Sarah’s right facial nerve was traumatized, leaving her unable to move half of her face and to smile. Having her ability to smile and show emotion taken away has been very difficult for her to cope with. “Despite it all, I try my best to face each day thankful for what I still have.”

Since 2008, Sarah has been participating in an NF2 natural history study at the National Institutes of Health (NIH) in Bethesda, Maryland, USA. The purpose of this study is for the researchers to learn more about NF2 in hopes of finding better treatment options.



WORDS & PHOTOGRAPH BY **SARAH GORDEN**

Sarah has many other tumours throughout her brain, spine, and peripheral nerves and has undergone numerous surgeries.

Sarah has a love for animals, especially her beloved dog, Bailey and her two cats, Oliver and Maddie. “They bring me a lot of joy and help me cope on the rough days.” She enjoys graphic design, photography, the outdoors, exercising and spending time with her husband, Hans, family and friends. She volunteers her time as the graphic designer for AdvocureNF2, a non-profit organization advocating for the NF2 community. Sarah tries to live life to the fullest, one day at a time and her motto is “Never give up hope!” •

Jessica & Elissa

From Issue #1, Spring 2013

THE FACE OF NF

SHINING A LIGHT ON
MEMBERS OF THE
NF COMMUNITY

NEVER GIVE UP

It's the motto that many patients with NF2 live life by. This certainly holds true for the Viitanen family. Twenty-four year old Jessica and 20 year old Elissa of Delta, B.C., both have NF2 which they inherited from their mother Kaarina.

Since they had a known family history, the doctors knew to check the girls with MRIs, and sadly they were both diagnosed as children. "Some people have assumed my sister having NF2 made it easier to deal with because we could relate to each other's experiences and we wouldn't have to deal with it alone," tells Jessica. Jessica explains that it is very difficult knowing her baby sister has tumours and will end up deaf one day. "I'd do anything to bear that burden for her."

Jessica and Elissa's mother, Kaarina, also lived with NF2. She passed away when Jessica and Elissa were small children, ten days after celebrating her thirtieth birthday. "She had dozens of tumours all over her spine and a big one in her brain that eventually killed her," tells Jessica. She didn't let that stop her from living her life though. Despite being fully deaf, Kaarina still played the organ at church. She had a friend type the sermons on a laptop so she could follow along with the church service. The same person still types for Jessica and Elissa at church. Kaarina exchanged long letters with a close friend from the United States for many years. After she passed away, the letters were published into a short book which the girls can now look back on in memory of their mother. "One thing I noticed in the book was that she never mentioned NF2 and didn't worry or complain about her situation," tells Jessica. "Instead she wrote about all the good things in her life and the things that brought her joy, like Elissa and I." She lived her life as a person who had NF2 but did not let the condition define how she lived her life.

Jessica, who recently finished schooling for applied business technology, explains the challenges of living with a hearing impairment. "It's put up a barrier between me and the rest of the world," tells Jessica. "The last job interview I had lasted less than two minutes. After the employer learned that I couldn't hear, he refused to write down what he wanted to say and wasn't willing to speak a little louder," tells Jessica. She explains how difficult it is to have self-confidence in moving ahead in life and gaining employment when so many people are not willing to put in the effort or be accepting of differences.

Since NF2 patients tend to lose their hearing gradually, the change from the hearing world to the deaf world happens slowly. "For me, this means I still think like a hearing person, when in most situations I might as well be deaf because I can never understand anything," tells Jessica. Jessica, who is severely hard-of-hearing, explains that it would almost be easier to be completely deaf. "Of course I'd miss the sounds of rain falling on the roof, snow crunching under my feet, and birds tweeting in the spring."

Jessica loves to renovate and build things. "I'd love to go to Mexico with a group one day to help build small houses or classrooms for less fortunate communities," says Jessica. Elissa recently finished culinary school and is working as a baker in Vancouver. Jessica and Elissa are carrying on their mother's legacy and will never give up! •

WORDS BY **SARAH GORDEN**

THE FACE OF NF

SHINING A LIGHT ON
MEMBERS OF THE
NF COMMUNITY

in Issue #1, Spring 2013

Long Distance Love

GAIL AND TIM HAVE SO MUCH IN COMMON, but it was fate that brought them together. "NF1 helped me find my soul mate and one true love," explains Tim. On August 11, 2010, Tim Golumbia, who is a Social Worker, was asked to assist with a task at work that he doesn't normally do. This task involved a phone call to an Edmonton office. In the conversation with the worker in Edmonton, the topic of NF1 came up and the worker shared with Tim that she had a co-worker with the same condition. "She asked me if I was single and told me she was cupid," Tim recalls. Tim explains that this worker has a history of trying to find a man for Gail. Gail called Tim and left a message, and when they finally managed to connect, it was at the end of the day on Friday, August 13th. "We only talked for a few minutes, as she was meeting friends for dinner," says Tim. "She called me again on Sunday and we talked for around an hour and a half. It was like WOW, she is amazing and we have so much in common," Tim explains.

Tim and Gail both have Neurofibromatosis Type One (NF1). Tim was diagnosed when he was around ten years old. "I did not have a lot of bumps until I was older, but I did have other signs," says Tim. Tim went through puberty earlier than most and therefore was much taller than his classmates. He also had two growths removed from his left arm and one from his abdomen which led to a confirmation of a diagnosis of NF1. Tim explains that he was teased a lot in school, especially when changing for swimming or gym class. "Going shirtless was difficult for me because I was very self-conscious about my body." Tim also has a learning disability due to NF1 and it made school more difficult for him. "I am actually quite bright, and looking back I feel it was just a matter of learning how I learn," explains Tim. "As a kid it was so difficult to get my thoughts onto paper, as my mind runs so much faster than I can produce hand written documents." Computers helped change this for Tim as he could properly organize his thoughts and use spell check. Dealing with peers was difficult for Tim and he was treated quite badly. "I never had a lot of friends, but the friends I had were close," Tim explains. "Despite being treated badly by my peers, I was a very giving person. I did volunteer work in nursing homes and had a number of friends with physical disabilities. I learned so much from these experiences," Tim recalls. After high school, Tim had great difficulty finding his spot in life. He tried many different careers before returning to University for a degree in Social Work. "My decision to return to University was prompted by a friend who had been through a very abusive childhood but was moving ahead with her life," explains Tim. "I decided that it made sense for me to try again." Today, Tim uses his NF1 and bumps as a tool to "break the ice" when talking to the kids he works with. "They always look and ask questions, so I use that as an opportunity," explains Tim. It was because of this that he ultimately met Gail.

Gail Appelgren has a similar story to tell of the difficulties growing up with NF1. "I was born with an NF tumour on the left side of my chest, where my breast should have been," explains Gail. "This tumour grew as I aged. I was teased as a child and called names such as lopsided." Gail was under the care of doctors in Moose Jaw, Saskatchewan. "The doctors *in Moose Jaw in the 1960's didn't know what it was and since it didn't seem to affect my health, my aunt, who was raising me, didn't feel the need to seek out other professional opinions," says Gail. "When I was about twelve years old, I saw a new doctor who knew immediately what it was. He told me what I could expect from having Neurofibromatosis and talked to me about seeing a plastic surgeon when I was an adult." Gail explains how difficult it was growing up with NF1. "As a teenager it was difficult to have a relationship with a boy as they just wanted to try and see what was under my shirt. When I hit puberty, my body started to develop more. I developed many smaller tumours all over my body," Gail shares. "People who didn't know me were afraid of me. They didn't want to sit beside me on a bus. I was asked to leave a swimming pool and not to touch the tomatoes at the grocery store," Gail recalls. Although she was often saddened by people's reactions to her, Gail just wanted people to know she was just like them. "I just happened to look a little different or special," explains Gail. "I would just try and talk to them and give them one of my big smiles," says Gail. Gail feels that living with NF has made her more accepting of others who are different. "It has made me more caring, forgiving and tolerant. I am always looking at the positives in every situation, always having hope and always making the best out of whatever I am faced with," Gail explains. Gail deals with a lot of ignorant people who assume she is unable to care for herself. "They are often surprised to hear that I have two University degrees and I live on my own," says Gail. "I always see this as an opportunity to educate individuals on Neurofibromatosis."*

Tim and Gail met in person for the first time in November of 2010 and it was confirmed, "We had a relationship starting," Tim says. When asked to describe their relationship, Tim says, "It is amazing. I have been in relationships before but have never felt such a connection with the other person." Tim explains that being with another person with NF helps in that they both understand how the disorder affects each other. "Gail is a warm, caring, thoughtful, loving, and polite person," Tim says. He loves her eyes, smile, and hearing her laugh. "Being in a relationship with Gail means having a relationship with three dogs as they are like her children," Tim says. "I love spending time with her 'kids' when I am in Edmonton."

Tim and Gail are now engaged to be married. When asked to share their proposal story, Tim shares "In April of 2012, Gail was arriving at the airport in Comox and I went to pick her up. I had told her to make sure she wore good shoes as we would be going for a walk at Cathedral Grove on our way back to Nanaimo. The massive old growth forest is amazing and we had been there before. It was a cool but sunny day.... quite nice. Gail went off the beaten path at one point and I followed. I tried to get her to turn around at one point and she walked further into the clearing. I walked up to her and she turned, I said "Gail..." and she looked at me and said, "Are you sure you want to do this?" I started to say the first verse of John Denver's "Annie's Song." She loves John Denver's music. Between the first and second verse I asked the question and gave her the ring. While she was on the phone with our matchmaker in Edmonton, I noticed another couple had walked into the area where we were standing... so I asked if they could take our picture. We continued our walk through the trees, hand in hand."

Tim, who currently lives in BC, plans to move to Edmonton to be with Gail. He is currently in the process of finalizing employment in Edmonton. They will make wedding plans once Tim is in Edmonton. Tim and Gail's story proves that everything happens for a reason. Although they have both had their fair share of struggles with NF1, it is ultimately what brought them together. Tim is currently the president of BCNF. "I will miss BCNF when I leave the province but I will maintain contact and continue to support them financially," Tim says. •

Ross Phillips

From Issue #2, Spring 2014

THE FACE OF NF

SHINING A LIGHT ON
MEMBERS OF THE
NF COMMUNITY

Ross Phillips is a 66 year old from Delta, BC, living with Neurofibromatosis Type One (NF1). NF1 has been in Ross' family for five generations. His mother also had NF1, which was called Von Recklinghausen Disease at that time. Two out of four of Ross' siblings inherited NF1, including Ross. Fortunately, Ross has a fairly mild form of the disorder and does not have any internal tumours. He has had a few elective surgeries to remove surface tumours from his skin. When asked how NF has affected his life, Ross proudly states, "I think it has made me stubborn. If someone says I can't do something, I like to prove them wrong." Ross has two children and two grandchildren, who fortunately do not have NF.

Eight years ago, Ross suffered a sudden stroke in his home while having a bath. He called to his wife who worked at Vancouver General Hospital (VGH), who knew his symptoms were that of a stroke. She called 9-1-1 immediately. Thankfully, Ross has almost fully recovered from the stroke, but he still cannot drive. Ross suffered brain damage and his brain does not receive messages from his eyes. His balance is also affected.

Ross is now retired, but he worked in the software industry for ten years. Before that, he worked for the Hudson Bay Company, managing all of the restaurants in British Columbia. In his free time, Ross loves painting and sketching. He also enjoys working with stained glass. He used to enjoy pottery, but hasn't done much of that lately. Ross used to be a long distance runner and has always had a passion for running. Even after all of the challenges Ross has faced due to his stroke, he still walks/runs three miles a day. Despite a few falls due to his poor balance, he puts one foot in front of the other and never gives up!

WORDS BY **SARAH GORDEN** / PHOTO BY **SAM CHUA**

Ross Phillips in 2022

What have you missed the most through the pandemic?

I missed seeing friends the most. I haven't driven since 17 years ago when I had the stroke so I didn't miss that. And we were fortunate our kids were close during the pandemic.

What makes you feel successful in dealing with NF and life?

I've always been successful in work. NF never held me back – in fact it made me more competitive. I've never really considered NF to be a disability.

What or who are you enjoying connecting with the most now?

I walk 5km walk every day with our big dog a Newfoundland/Standard poodle cross. We also recently brought a puppy home who is a Border Collie and Australian Shepard cross. I love watching them play together.

Courtney Willoughby

From Issue #2, Spring 2014

THE FACE OF NF

SHINING A LIGHT ON
MEMBERS OF THE
NF COMMUNITY

Nineteen-year-old Courtney Willoughby has chosen to embrace her uniqueness rather than be ashamed of it.

When Courtney was just three years old, she was diagnosed with Neurofibromatosis Type One (NF1). She was diagnosed by a dermatologist who noticed café-au-lait spots and "birthmarks" on her body when treating her for shingles. Thankfully, NF1 did not impact Courtney until she was thirteen years old when she had a plexiform neurofibroma removed from her back. "The surgery went well, and I had no complications. However, my doctor suggested that I have an MRI as a baseline since I had never had one before."

Courtney waited anxiously for the results to come back, and when they did it was revealed that she had a tumour in her brain. Thankfully, her brain tumour has not grown over the years and has miraculously shrunk with no medical intervention. Courtney also suffers from scoliosis, headaches, and multiple tumours elsewhere on her body. Despite her medical challenges, Courtney is determined to not let her condition define her life.

Life has not always been carefree. Growing up, Courtney struggled to accept her differences. She didn't tell her peers or teachers about her NF as she felt people would treat her differently and she just wanted to fit in.

"Eventually the diagnoses began to pile up, and my anger and frustration piled up alongside it," Courtney recalls. She developed depression and an eating disorder as a way to cope with her struggles. "I could not control what was going on with me medically and I was in a really dark place." Just when she needed it most, Courtney was able to attend an NF symposium and meet a fellow NF1 patient, Reggie Bibbs. "He truly made me realize that I need to accept me for me," explains Courtney.

Ever since she was a child, Courtney dreamed of working in the healthcare profession. She completed the first year of her Bachelor of Science in Nursing at Red Deer College in the spring of this year. "It wasn't until I started dealing with nurses that I realized that was what I was destined to do," says Courtney.

Courtney decided to hold a fundraiser in 2012, not only to raise awareness for NF but also to teach people to embrace their differences. She decided to donate the funds raised to the Friedman Lab in Vancouver, BC. "I feel really passionate about research, as one day there could be that potential cure to help all of those impacted by NF," Courtney shares. For her fundraiser, she sold 5,000 green silicone bracelets that said "Solve the puzzle – CURE NF." She also held a music night at the restaurant where she is employed.

"My main event was a silent auction which brought in many different people from Red Deer and surrounding cities," tells Courtney. Her original goal was to raise $5,000 but she far exceeded that and raised a total of $17,500 for the Friedman Lab. "I was so excited and so thrilled by the generosity of my friends and family, and even of those people whom I did not know," Courtney recalls.

When she is not in school or working, Courtney enjoys spending time with her family, friends, and her dog. She also enjoys scrapbooking and has spent several years volunteering at the local hospital which contributed to her desire to become a nurse.

"No matter how hard I try to forget it, NF will always be a part of me," Courtney shares. Courtney's accomplishments show that she has risen above her struggles and the diagnosis of NF1 and continues to live her life to the fullest. •

In October 2013, Courtney was awarded with a volunteer award from the Just Ask Foundation for her outstanding contributions to NF.

Andrea Meadows

From Issue #2, Spring 2014

THE FACE OF NF

SHINING A LIGHT ON
MEMBERS OF THE
NF COMMUNITY

Andrea Meadows lives with NF1, but she has never let the disorder define her life or stop her from achieving her goals.

Andrea received an Educational Scholarship from the BCNF in 2006. She used the scholarship to begin her schooling for her Early Learning and Childcare (ECE) Diploma, which was a two year program at Keyano College in Fort McMurray, Alberta. She has spent the last three years at Vancouver Island University in Nanaimo, BC, and recently graduated with a Bachelor of Arts in Child and Youth Care. She still plans on doing either a Master's program or a business program in the future.

"I worked part time in after school programs and residential homes while in school," says Andrea. She is currently working full time at a daycare and hopes to find a full time position in the Child and Youth Care field. "I also do gardening and odd jobs for people in my neighbourhood on weekends and evenings."

> ***"I HAVE ALWAYS BEEN VERY OPEN AND HONEST WITH PEOPLE AND NOT AFRAID TO TALK TO THEM ABOUT NF."***

When Andrea was six months old, her mother, who also suffers from NF1, noticed birthmarks on her daughter and suspected that she may have the disorder. She saw a doctor at that time who said it was likely that she had NF1. When she was a teenager, she was sent to a genetic specialist due to sore knees and a sore hip. It was then, at fifteen years old, that the diagnosis of NF1 was confirmed. "NF has never really affected me too much," tells Andrea.

Andrea shares that the children she works with are often curious about the marks on her body. "I explain to them that I have had them since I was born, just like some people are born with brown eyes and some people with blue eyes," tells Andrea. She says the kids think it is neat because they see shapes in some of her birthmarks such as a butterfly on her shoulder.

Although she is not sure if her current boss knows about her NF, Andrea shares that she is very open and honest about her condition. "I am not afraid of ever being fired or judged due to my NF," says Andrea. "I work in a field that is supposed to be very inclusive of all people no matter their culture or disability." Andrea shares that if anyone in the workplace ever judged her or viewed her differently because of NF (which does not affect her work performance); it is not somewhere she would want to work.

"I was teased about the birthmarks on my neck in school," Andrea shares. She did not know much about NF when she was a child other than the fact that she had it. "I mostly ignored the teasing, but at some points in my life I became very withdrawn with the kids my age," says Andrea. "I spent all of my recesses and lunch breaks being a crossing guard or monitor for the younger kids." When she got older and learned more about NF, she was able to explain to her peers why she had the birthmarks and what they were. "I was then able to laugh off the comments and teasing," shares Andrea. "I have always been very open and honest with people and not afraid to talk to them about NF."

Since Andrea works with young children, she has at times noticed suspicious, numerous birthmarks on some of her students. She hesitates to mention NF to the parents. "Approaching parents about something that may be 'wrong' with their child is a very difficult thing to do. I have had good experiences and very bad experiences in the past when talking about behaviours or delays the children I work with may be experiencing," Andrea shares. "I have mostly just seen a few birthmarks on the kids. If I was really concerned, I would definitely approach the parents." Andrea also worries about future children of her own. "I am nervous about how badly my future children could be affected," says Andrea.

When she is not working, Andrea loves kayaking, gardening, walking, and camping. "Now that I am finished this part of my schooling I hope to have the time to spend on my hobbies." •

Andrea Meadows in 2022

What's new with you since the last time you were featured in our magazine (anything you want to brag about)?

Many things have changed in my life! I am married, bought a house and have an amazing 7 year old daughter, a dog, a cat and a bearded dragon.

After finishing university I decided I wanted to continue working with children aged 3-5 and am currently working at a local private school in the Early Learning Center.

How has your relationship with NF changed since our last conversation?

My NF still doesn't affect me too much. Through my pregnancy, and as I am getting older i notice more bumps appearing but, other than being itchy all the time, they do not bother me. I had surgery to remove some bumps from the back of my neck and am considering having more removed from my face/hair.

My daughter was tested and does NOT have NF. I have a niece who has not been tested yet, but since birth has shown many signs of NF such as infantile spasms, cafe o lait spots and pseudarthrosis.

I am still very open with people about my NF and often stop people in stores (Who appear to have NF)

What are you most excited about for the near future (any goals)?

I am excited to watch my daughter grow and hopefully to do some travelling in the near future. Maui and Ireland are our goals for travel.

Ingrid Nagy

From Issue #3, Spring 2015

THE FACE OF NF

SHINING A LIGHT ON
MEMBERS OF THE
NF COMMUNITY

BRAVELY FORWARD

Ingrid Nagy on Raising Children with NF

WORDS: BRITTANY MCGILLIVRAY / PHOTO THIS PAGE: SAM CHUA

Ingrid Nagy's twin daughters, Anina and Alexa Nagy, are very lucky – they are two of few people who look forward to going to work every day. At the Mediated Learning Academy, where the girls both went to school, Anina and Alexa now work with younger children, helping to teach math and arts & crafts. The school's students naturally gravitate to them, thanks to the twins' playful and kind demeanors. Outside of work, Anina and Alexa love to hike with their parents, socialize, travel, and go for bike rides. At age 27, they live happy lives, and with the help and support of their parents, guide others to embrace the same positivity.

But 25 years ago, Ingrid wasn't sure how to take the news when her two-year-old twins were diagnosed with neurofibromatosis. She had never heard of the genetic disorder before. When the girls were first diagnosed, Ingrid cried for days. But in some ways it was also a relief – the family had been concerned about the girls' delayed speech development, and with a diagnosis they could begin to properly address any learning and health difficulties.

"It was a mixed bag," Ingrid admits. "In some ways, I was happy I got those carefree years before the diagnosis. But learning what the girls had helped me to finally focus on making things better for them."

In many ways, Ingrid felt isolated at first – after all, 25 years ago, NF was talked about much less than it is today. Even many doctors and health specialists, Ingrid found, weren't always familiar with the disorder. Luckily, with the help of BCNF, Ingrid was able to find resources and, most importantly, friends.

"Meeting other people with NF was, at first, devastating. I cried for days thinking about the ways in which my girls would be affected [by the disorder] down the road. It was very shocking. But then, I started to get used to it. You wrap your head around it. And you focus on the every day and hope for the best."

"I met amazing people – people who were in the same boat as us. I met my friend Ivan very quickly through BCNF; he was a huge support. Seeing someone with NF who was always so upbeat and full of life was a great experience for the girls. It helps you realize that you can be positive with these challenges, too."

"When the girls were around twenty-three years old, the fibromas started to appear overnight by the hundreds. And naturally, people stare. Not everyone knows what [the condition] is. Young children are the best, cause they'll just joke about the fibromas, or ask outright."

Of course, raising her twins, Ingrid hit road bumps along the way – as any parent does. Her and her husband's consistent positivity and strength has kept the family happy and striving, even if in recent years, the increasing numbers of fibromas occurring on the girls' skin has provided additional hurdles.

Rather than teach her daughters to shy away from situations where they may be asked about their condition, Ingrid takes people's curiosity as an opportunity to spread the word about NF. "People need to know what it is. It's helpful to talk to people about it and explain – because next time they see someone with the condition, they can recognize the disorder and understand."

At a conference once, Ingrid remembers being shown a brass statue meant to represent life with NF. "It was a person wrapped in cloth, in hiding. It broke my heart. That type of living kills your spirit. I want my girls to be brave and live fully – not hide under some cloth. My biggest fear is that they will feel they have to hide."

Ingrid recalls taking her daughters to Switzerland, where they went shopping and found beautiful bikinis. “I realized I couldn’t over-think these small things, like whether or not to let them wear the bikinis out to the beach. If they want to wear them, then of course I should let them – even if it will show off their condition.”

Through this mentality, she has taught her girls traits and virtues that any mother should hope to impart to their children: self-esteem, openness, and the pursuit of joy.

“The girls love to socialize. We travel. We’ve been to Europe three times. And they love working with children.”

While Ingrid has worked to ensure Anina and Alexa live fulfilling lives, she has experienced frustration at the lack of local treatments available for the disorder. In particular, she’s had great difficulty finding plastic surgeons in BC who will treat patients with NF.

“Research is good, but we also need to find people who are willing to help treat and remove the fibromas. There’s a piece of equipment we need, that I haven’t been able to find in BC. It would make such a big difference to so many people,” she explains.

In a society that places such high value on physical appearance, patients’ quality of life can be vastly improved once cosmetic treatments are made available for the disorder. It is therefore understandable that a mother would search high and low for a centre that will address these physical concerns for her two daughters. And perhaps it is because of the existing stigma around physical ‘defects’ that the girls have found such solace in a local anime community.

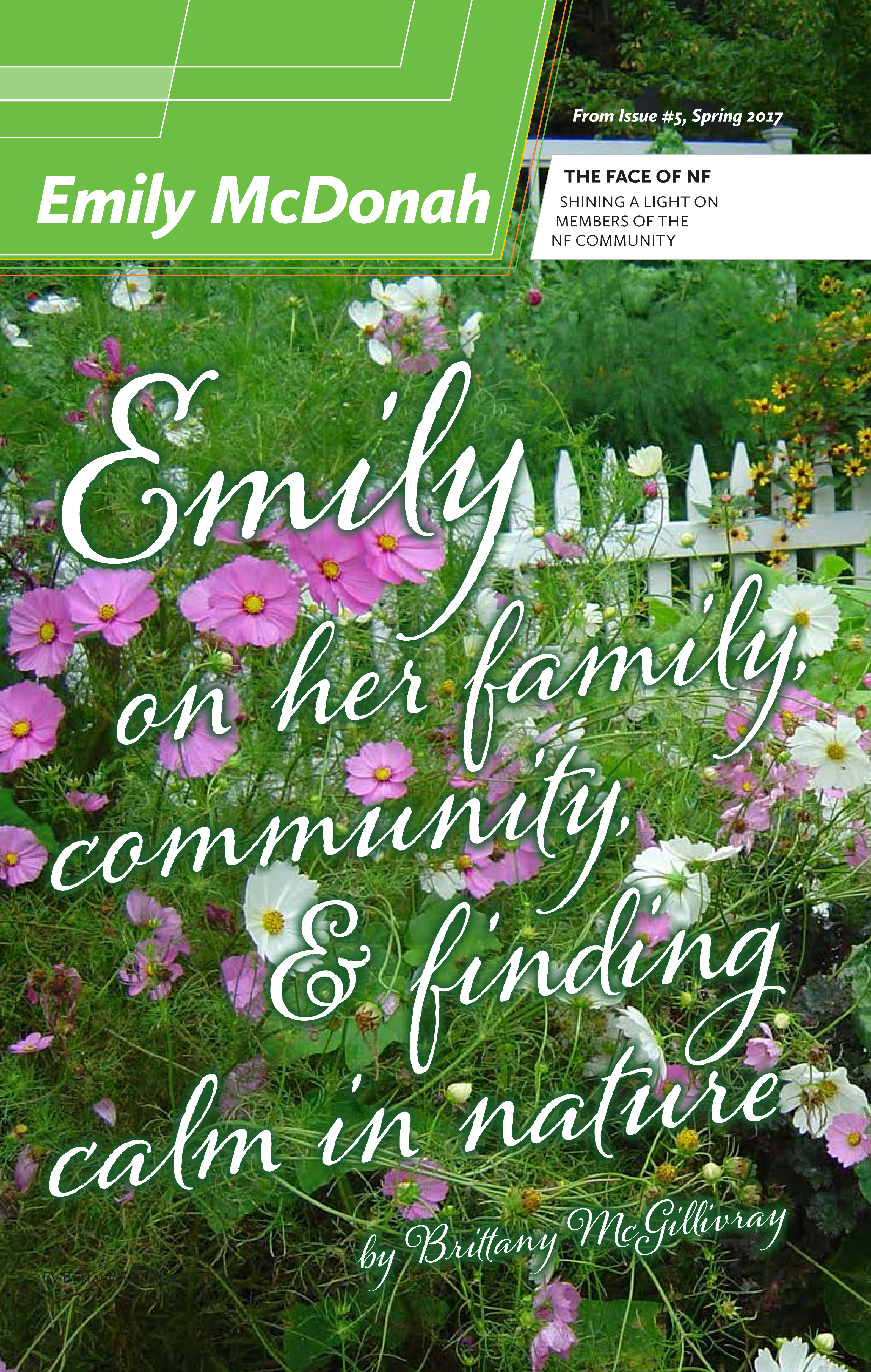
“Through a friend, Alexa and Anina started going to these anime gatherings. We’d make elaborate costumes for them to wear. They’d love it. Kids would rush up to them and beg for their photos, and they would come home and say ‘Mom, it was so great! Everyone wanted to get their pictures taken with us!’

When asked for words of advice for parents currently raising children with NF, Ingrid’s amazing energy shines through yet again. “You have to stay social. We have a lot of learn from each other [in this community]. We socialize a lot, we hike, and we bike. We live busy lives. And in many ways I’m very lucky, because my girls have each other throughout all this.

“We’ve found a lot of people in this community that are going through this alone. That’s where BCNF has been so amazing – the girls have loved connecting with other young people at the social, and at the Scotia Bank run. They’re looking forward to more events like those in the future.”

At the end of the day, its Ingrid’s gratitude and strength that has taught the girls to embrace life in the face of difficult challenges. “We’ve been blessed with amazing friends and family. And we have to be grateful – we have to look at all the wonderful things we do have, and the quality of life we have here. And we take it day by day.” •

PHOTO THIS PAGE: DESIRÉE SHER



From Issue #5, Spring 2017

THE FACE OF NF
SHINING A LIGHT ON
MEMBERS OF THE
NF COMMUNITY

Emily McDonah

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."

Tammy Schoyen in 2022

What have you missed the most through the pandemic?

Going to church. My friend's mum was the one of the people I was most happy to see. She was 101 years old when she passed and was Inspiring to me. I was able to attend her 100 birthday befor the lock downs happened, I also missed my lady's group they have bin supportive of me through my youngest chemo when he had to go through treatments. And have encourage me to talk more about my and share my story with the church. And also getting back into painting again.

What makes you feel successful in dealing with NF and life?

Not looking back at the past being mor vocals with my dr and people around me.with help from my pastor at my church we wrote about me and my struggles with nf and also put in some resources and some YouTube links they can watch.then there is my oldest son who put the word Tomur he did not spell it tumour and had a arrow pointing to his tumour that is on his knee in his words it funny.

What or who are you enjoying connecting with the most now?

Having lunch out with friends and just going for walks and seeing people and Picnics.

Hudson Rowe in 2022

What have you missed the most through the pandemic?

Connecting with family members and doing hobbies such as traveling, doing exercises bodybuilding, dining with loved ones and friends. All activities which makes me happy were missing.

What makes you feel successful in dealing with NF and life?

I accepted the situation I was in and made progress after I completed it and fully transform to a new person.

What or who are you enjoying connecting with the most now?

I like connecting with my friends and some of the family members to be specific.

COMING OUT OF THE SHADOW.

Leah Dixon in 2022

What have you missed the most through the pandemic?

Watching my children having a normal childhood.

What makes you feel successful in dealing with NF and life?

I was diagnosed with NF when I was two years old, growing up my biggest challenges were the learning disabilities that come along with NF. I really struggled with school and with making friends. I never thought I'd be able to graduate and find a career, I never thought I'd be able to find someone who would love me for who I was. But I did graduate, not only high school, but I finished college with honours, and had a successful career in mental health. I also found love and started a beautiful family, having 3 wonderful children, one who unfortunately inherited NF from me, but we don't let NF stand in our way of happiness.

What or who are you enjoying connecting with the most now?

My family, always.

COMING OUT OF THE SHADOW.

Katy Levesque in 2022

What have you missed the most through the pandemic?

I have missed the connection with friends and family the most. Along with missing in person school as it helps aid my success and maintaining knowledge.

What makes you feel successful in dealing with NF and life?

I have support from friends and family which is a big part of my happiness and success. Through counselling and conversation it helps me deal with the difficult times in living with my condition.

What or who are you enjoying connecting with the most now?

My dog, aunt and my grandmother. They have always been there for me especially in the pandemic which brings me joy.

Stacey Strike in 2022

What have you missed the most through the pandemic?

Throughout the pandemic I have missed travelling the most. I was very fortunate to still be able to visit family but I have missed taking trips to new destinations or visiting some of my favourite places.

What makes you feel successful in dealing with NF and life?

To feel successful in dealing with NF I really feel that I need to be a strong advocate for myself. I was not diagnosed with NF until I was 33 and it came as a complete shock. Since then, I have researched as much as possible on NF, I have joined support groups like the Tumour Foundation BC to help guide and support me in my journey, and I have found and continue to search for the best health care professionals that can help me in my health journey. Before I was diagnosed with NF1, I was always very active and I enjoyed lots of physical activities including marathon running, hiking and trail running. When it comes to participating in these sports, I do my best not to let my NF affect my attitude so I can continue doing what I love.

What or who are you enjoying connecting with the most now?

Throughout the pandemic, I have gained a lot more confidence in exploring the outdoors and the beautiful mountains of BC. I find it very comforting to get outside and explore what nature has to offer.

From Issue #6, Summer 2018

FINDING RAINBOWS in a world with NF

Q&A with author

Emily Owen

My name is Emily Owen.

I live in the U.K and I have NF2. I was diagnosed at the age of sixteen with no family history. I am now deaf and have limited mobility.

What do you wish people knew about NF2?

I would like people to have heard of it. It may seem a small thing, but just to have 'NF2' being spoken and recognized would be a great thing. Many of my friends had never heard of NF2 until my diagnosis (I hadn't either). Now, if they send a text which includes 'NF2', I feel really pleased!

Tell us a unique fact about NF2.

NF2 affects everyone differently. So it is unique to everyone. That is a fact I wish I had known from the outset, so I didn't draw comparisons. What does or doesn't happen to someone with NF2 may or may not happen to me.

You have faced many obstacles. What has been the hardest part of your NF journey?

Learning to accept that there are things I can no longer do. Acceptance makes life easier, though.

"God, grant me the serenity to accept
the things I cannot change,
Courage to change the things I can,
And wisdom to know the difference."

~ Reinhold Niebuhr

How did you move past the diagnosis to find joy again and discover your rainbows?

I learned to let go of things I'd had before my diagnosis. For me, that meant changing my life plans, as they became unrealistic. For others, they can achieve their life plans despite their diagnosis. As I said before, NF2 is different for everyone.

I made finding rainbows a deliberate choice. No matter how hard life gets, there is always something good to find.

What do you do on the days you feel discouraged?

There's a song in the musical 'Annie', with the lyrics, "The sun'll come out tomorrow". I remind myself when I do have bad days, every day is not a bad day. And maybe tomorrow won't be one.

What is one wisdom you would share with parents whose child just received the NF2 diagnosis?

Ask questions. No question is ever too silly to ask.

I think of it like putting petrol in a car. You may not need to make a car journey right then but, if there comes a time when you do, it helps to have petrol in the tank.

You may not need the information you gather, but you've got it just in case. Prepare for as much as you can, but always hope for the best: that's my motto.

What tips would you offer someone who is thinking about writing their NF story?

Be absolutely sure that what you include in the book is something you are happy to have out there for anyone to see. Know why you are writing it. Then, start writing and see where it takes you.

Have you ever regretted exposing yourself or your diagnosis to the world?

Regret would not be the word. It did take me many years to be able to write my story, though. I am frequently surprised when people I've never met before know things about me! I forget that people read my book, to be honest. I was very clear in what I was willing to include in the book.

What made you want to write *Still Emily*?

I didn't want to write it. I resisted for 20 years. In the end, I said "yes". I wanted to show that there can be hope in dark times (not just NF2 dark times). My story is not a 'happily ever after' story. I still have NF2. Life is still difficult. I still have dark times. But, if we can learn to glimpse hope and joy and rainbows in the darkness, the darkness is not so dark.

What keeps you up on down days?

A cup of tea. (Though to be fair, a cup of tea is rather essential on any day!) Flowers. A text from a friend. Reading a book. These are all moments of 'up' in the 'down'.

Also accepting that down times will happen – NF2 can be pretty horrid, after all.

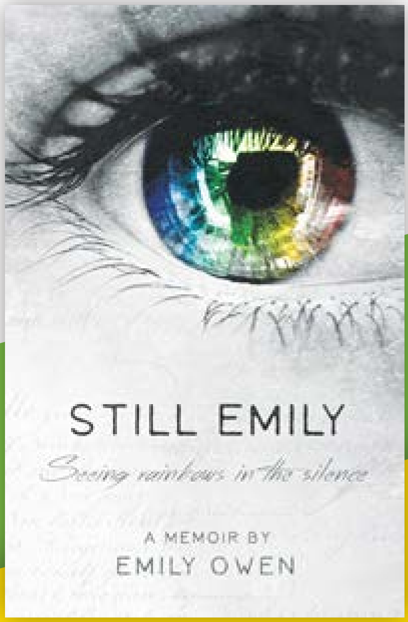
And I remember that God is with me; nothing is so bad that He walks out and leaves me to it alone.

What has been some of the best medication you have tried? Have you ever done a clinical trial?

I take Gabapentin for nerve pain. I wouldn't like to be without that medication. It really helps me, though it took a while to get the correct dosage. For me, too much of it makes me even dozier than usual!

I have done a clinical trial. Unfortunately it adversely affected me, so I had to stop before I completed it. I know other people who do trials successfully, and I am very grateful for people who do them. I often think that the treatments I receive probably came about because someone did a clinical trial. Having said that, for me it is important not to feel 'guilted' into doing a trial. They are not for everyone.

Check out Emily's book on Amazon or order from your local bookseller.



What is the best part of having NF2? The worst?

The worst? Not being able to hear. And never knowing whether my scans will provide good news or bad news.

Best? Seeing how nice people are. I can honestly say I have never had anyone unwilling to help me.

Are there any current medical advancements you wish you could have chosen?

I think, had there been a treatment that could save my hearing, despite other side-effects – and knowing what I know now about hearing loss – I'd have given it a go.

Has your facial paralysis improved with therapy?

My facial paralysis improved with surgery, though I know people who have had fantastic results from therapy. My surgery was a hypoglossal nerve graft, which means they grafted a nerve from my tongue into my facial nerve. My paralysed side still does not achieve symmetry when I smile but, at rest, it is now fairly symmetrical.

How long did it take you to learn American Sign Language?

Well, I learned BSL (British Sign Language), but I guess the learning process is similar! It took me a long time, and I am still by no means fluent. When I was learning, I always worried that I was not getting it 'right'. That my hand shapes were wrong, my syntax was wrong, everything was wrong. Then one day I realised that it doesn't need to be perfect. I just need to communicate. After that I found it easier to go with the flow a bit more. I'm sure I still make lots of mistakes but if I can be understood and understand others, that is more than enough for me.

I would encourage people who are diagnosed with NF2 to learn to sign; it's a good skill, whether or not hearing loss eventually occurs.

What advice would you give to someone with NF1 or 2 who is trying to decide if they should have children?

I don't feel qualified to give someone advice on that. Each person must make their own decision. If someone were trying to decide, I might remind them that there are people available to help talk things through. I'd also be happy to talk with them myself. But the decision is for them to make.

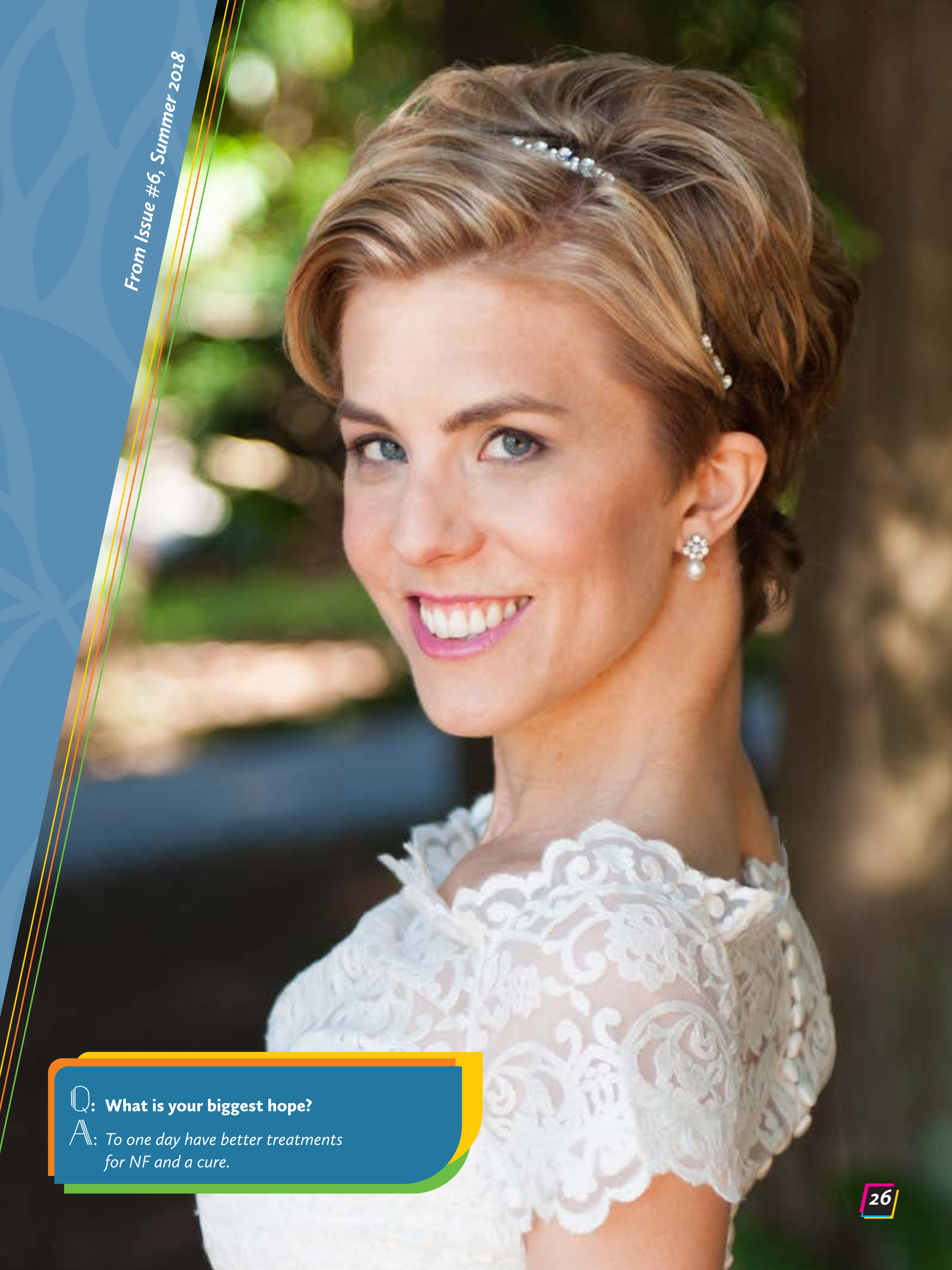
What's next for you?

I hope to carry on writing and speaking. But NF2 may decide otherwise! At the moment my NF2 is behaving quite well, but as my surgeon put it, "that doesn't mean I should be complacent."

One thing that is next for me is to continue not being defined by NF2. NF2 is a part of me but it is not all of me. As I wrote in my book, Still Emily, 'NF2 affects me, but it doesn't define me – unless I let it.'

NF2 is a difficult minefield to tread, and there are often no clear-cut answers. I hope and pray that as you navigate the minefield, you will find rainbows to help you along the way. •

From Issue #6, Summer 2018



Q: What is your biggest hope?

A: *To one day have better treatments for NF and a cure.*

WELCOME TARA

We are excited to welcome Tara to the staff of the Tumour Foundation in her new role as our Social Media Coordinator. You may recognize Tara, as she has been a long-time volunteer.

Her first involvement with the charity was as the *Face of NF* on milk cartons, and bus ads when she was just six years old. Her involvement continued at the NF summer camps, a speaker at our symposium, and a leader of our youth programs.

Tara lives with Neurofibromatosis type one (NF1). She knows firsthand the challenges of living with this disorder and brings her extensive knowledge of navigating the educational and medical maze to her new role.

In order for our readers to learn a bit more about Tara we asked her to answer a few questions about her life outside of NF.

Q: **What or who inspires you in life?**

A: *Those that strive to make a difference in other people's lives.*

Q: **Do you have a favourite quote?**

A: *"We are perfect in our imperfection."*
~ Megan McCafferty

Q: **Where do you go to rest and replenish yourself?**

A: *I stay in with my husband and my dog Enzo when I need to pause and reset. We recently got our patio all set up, so we enjoy relaxing up there, watching the planes come in and out.*

Q: **What book are you are reading now?**

A: *Something in the Water by Catherine Steadman*

Q: **What are you most proud of?**

A: *The home that I've built with my husband and our dog.*

Q: **What makes you angry?**

A: *Fox News and hypocrisy.*

Q: **What are your top 3 favourite films of all time?**

A: *The Princess Bride, Forrest Gump, and The Big Sick (not necessarily in that order)*

Q: **What is the luckiest moment of your life?**

A: *It is not so much a moment, but my entire life. I feel lucky to have such a wonderful medical team that has helped me deal with the complexities of NF.*

From Issue #7, Fall 2019

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. •

FROM THE EDITOR

DESIRÉE SHER

The end of an era.....

When we first had the vision a decade ago to launch a magazine that would support, educate, and inspire families, the world was becoming increasingly digitized. It was a bold move for a charity to create a printed magazine. Unfortunately, faced with increased printing costs, a shortage of writers, and a decline in families willing to share their story, publishing the magazine has become increasingly challenging. As such, this is our final edition of *Inspire* magazine.

The nine *Inspire* issues we produced would not have been possible without the contributions of the individuals, families, and writers from across the globe who bravely shared their NF journey – both the arduous lows and the celebrations they experienced along the way. The NF journey isn't one you can prepare for but it is made easier when you know you aren't alone. We have been honoured to be on that journey with you, our readers.

WE'RE IN THIS TOGETHER

Tumour Foundation
of BC

Editor
Desirée Sher

Copy Editor
Maya Kennedy

Design
Oculus Design

For Further Information:
Tumour Foundation of BC
19172 West 4th Avenue PO,
Vancouver, BC V6G 2J7
Toll Free: 1-800-385-2263
connect@tumourfoundation.ca

Look for us on Facebook & Twitter

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