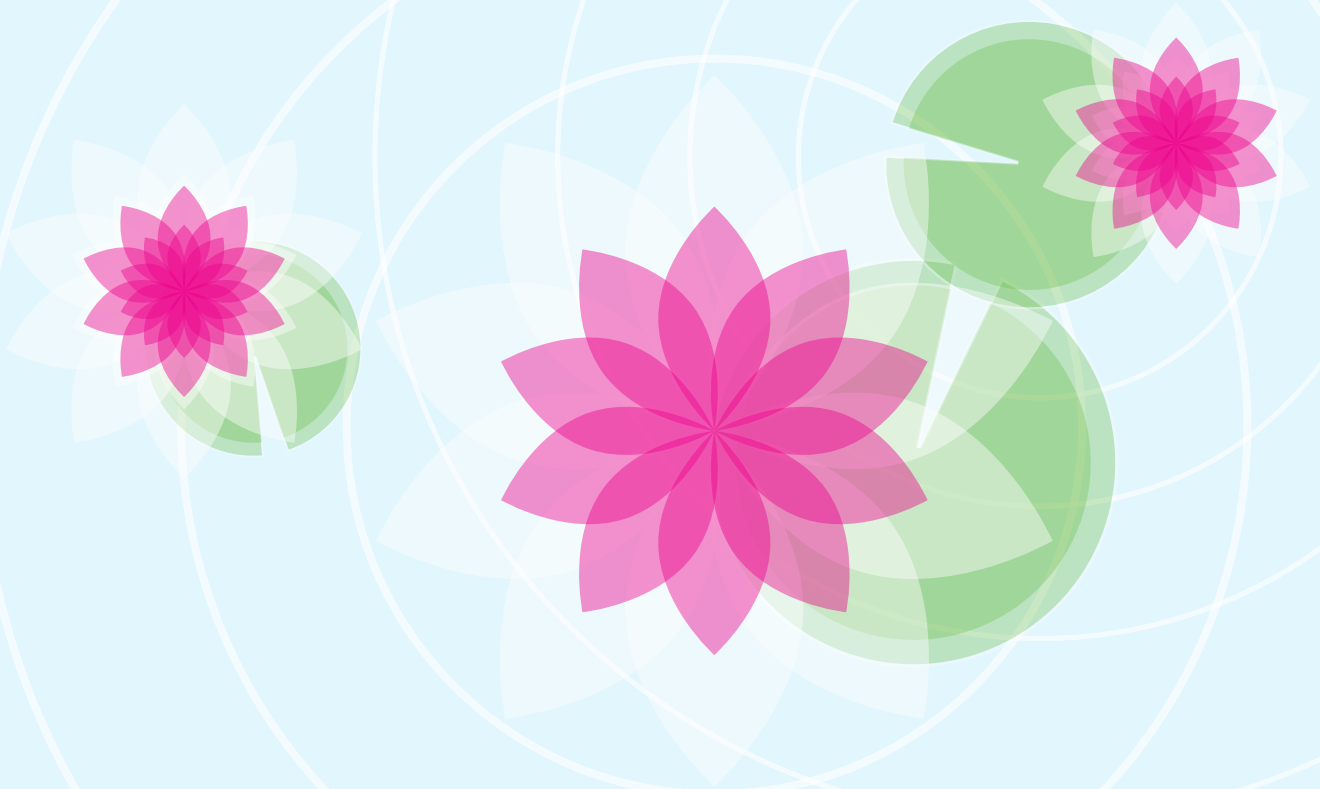


ISSUE NO.3 / SPRING 2015

!NSP!RE

the magazine of the BCNF



THE WELLNESS ISSUE

BEAT THE
WINTER BLUES

RAISING
CHILDREN
WITH NF

PAIN
IN NF

EDITOR'S NOTE

TO INSPIRE YOU TO BE THE BEST YOU CAN BE.

This is our first Wellness issue and I am so excited to share our ideas and action steps on living a healthy happy life despite the challenge of living with NF, or any other obstacle that may have shown up in your life.

Both Doug Hamilton and Ingrid Nagy's messages of positivity will inspire you to look at your own attitude. Are your doubts and fears limiting you or are they moving you forward to live your best life?

There are great ideas in this issue on how to connect with others for support. Many adults with NF isolate themselves but closing yourself off from others can lead to depression and other health issues. Read *Reaching Out, Rising Up* (page 6) for simple steps to help you stay connected to others.



Pain is a common challenge for individuals living with NF. Inside this issue you will find an insightful article (page 16) from the researchers at the National Institute of Health on how to manage pain and increase your satisfaction with life.

Living with NF isn't always easy but how you react when adversity shows up in your life makes a difference in the life you live. We hope that the articles and stories in this issue will help inspire you to live your best life possible.

Desirée Sher
Executive Director
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CHIEF CONTRIBUTORS



SARAH GORDEN

Sarah lives in Westbank, B.C. with her husband Hans, newborn daughter Lydia, and two cats and a dog. She is thirty years old and has dealt with NF2 since she was thirteen. She enjoys graphic design, writing, being outdoors, and is looking forward to her role as a new mom.



BRITTANY MCGILLIVRAY

Brittany was born and raised in B.C. with a BA from McGill University in English Literature and Communication Studies. She is a firm believer in the power of positive thinking.

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Together we can make a difference!

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The BCNF continues to need your support. If you enjoyed this magazine and would like to make a contribution to future issues please donate at: www.bcnf.bc.ca/donate


BCNF
EMPOWERING INDIVIDUALS WITH NF

THE FACE OF NF

SHINING A LIGHT ON
MEMBERS OF THE
NF COMMUNITY

The BCNF welcomes Gerry Stolz from Kelowna, BC, to the role of Vice-President. He was elected as Vice-President in the fall of w2014. "Instead of just being a member, I wanted to be more involved in decision making. I want to help shape future plans for the BCNF," shares Gerry.

From 1984 to 2010, Gerry was the regional manager of the Canadian Institute for the Blind (CNIB). He has numerous years of experience in operational management, program development, fundraising, staff/volunteer training and management, and community relations.

Gerry originally got involved with the BCNF because his wife, Linda, has neurofibromatosis type one (NF1). "Both my wife and I wanted to learn more about this condition, so the BCNF was one resource we found online. As we visited various doctors, we learned how complex this disorder is," Gerry shares.

Gerry was invited to the BCNF board back in 2013, but had visited the website many times prior to get information on the disorder. When asked what his inspiration for being involved is, Gerry says "I feel that for those living with NF, the BCNF is a good resource for them. I want to continue to help shape the organization over the upcoming years."

A portrait of Gerry Stolz, a middle-aged man with grey hair, wearing a black leather jacket over a white shirt. He is standing outdoors in front of a large tree trunk. The background shows some greenery and a cloudy sky.

**GERRY
STOLZ**

BRAVELY *FORWARD*

Ingrid Nagy on
Raising Children with NF



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 care-free 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.

At the end of the day, it’s 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.” ■

“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.”





REGISTERED DISABILITY SAVING PLANS (RDSP)

Before the Registered Disability Savings Plan (RDSP), individuals and families had few options to plan and save for the financial well-being of an individual or family member with a disability.

People with disabilities and their loved ones face a distinct set of financial challenges throughout their lives. To help address these challenges, the Government of Canada introduced the Registered Disability Savings Plan (RDSP) in 2008. Designed to help build long-term financial security for disabled persons, the RDSP makes it easier

to accumulate funds by providing assisted savings and tax-deferred investment growth.

KEY BENEFITS OF AN RDSP

- Money contributed grows tax free.
- Anyone can contribute to an RDSP with the written consent of the account holder.
- Contributions can be matched, based on family income, with up to \$3,500 a year in Canada Disability Savings Grants (CDSG) and up to \$1,000 a year in Canada Disability Savings Bonds (CDSB).

- The total lifetime contribution for each beneficiary is \$200,000, with no annual contribution limits.
- If a parent or grandparent passes away and has a financially dependent child or grandchild, they can transfer up to \$200,000 of their RRSP/RRIF or RPP to the dependent's RDSP on a tax-deferred basis.

To learn more RDSPs the Plan Institute is offering free workshops across BC and tele-seminars in 2015. Contact them at PlanInstitute.ca or call 604-439-9566 to register.

PlanInstitute.ca



Check out Calm.com to add more peace to your world. Offered both as a web application and iOS app for your mobile phone, this powerful free meditation app will increase your inner peace in as little as two minutes a day.

On the site and mobile app, you choose from several relaxing nature scenes, then select between a 2, 10, or 20 minute session. A narrator walks you through a relaxation sequence, telling you to close your eyes, relax your shoulders, focus on your chest, notice sensations, and so on. Birds, ocean waves, and other natural sounds add to the peacefulness.

If you prefer no voiceover or want a more rigid meditation tool, Calm also is behind the Do Nothing for 2 Minutes website. This site offers a seaside scene with crashing waves that counts down from two minutes but doesn't let you move your mouse or keyboard during that time or else the timer starts over.

Add meditation to your day and you will improve your health and wellness, improve your memory and increase your productivity.

Need
a Little More
CALM
in Your Life?



Calm.com



DoNothingFor2Minutes.com





REACHING OUT, RISING UP

Whether dealing with a health condition or not, one thing remains true: there are always ways for you to take more charge of your life and maintain a better sense of mental wellbeing and physical comfort.

One of the easiest, most gratifying ways to improve your wellness is to connect with others and learn how to ask for help and support from those around you.

As we grow older, we often maintain both a large group of acquaintances and contacts, while solidifying a smaller a core network of close friends we feel we can rely on. These people may be our siblings, old friends, members of a club – usually, we connect best with those who we have a shared history with, and who have remained a constant throughout periods of change in our lives. It is important to remember that, regardless of how frequent we see the people we care about most, it is okay to ask these people for their help when you need it.

Increasingly, research is pointing to the health benefits of fostering these close relationships. Mental Health America reports that 71% of people surveyed gained emotional support from friends or family during tumultuous times. Their research points to the extended health benefits of connecting with others – including living a longer life, and maintaining a lower blood pressure.

Even conversing over the phone or email can improve our mood, and alter our feelings of anxiety. Feeling overwhelmed and isolated? Try making a list of people who you feel comfortable with – the ones who you can truly be yourself around, who you can confide in, and who you can be emotional around. Don't worry about the size of the list – rather, focus on feeling gratitude that you have even one other human whose well-being you care deeply about and who cares similarly for you.

Remind yourself to refer back to this list, and try to reach out to at least one loved a day. Even sending a hand-written letter or card can forge a sense of connection and remind you of your larger network of friends and acquaintances that value and appreciate you and your concerns.

The flip-side of seeking help from a friend? It benefits the other person, too. Think about how you feel after helping a loved one figure out a difficult problem or listening to them vent about their day on the phone. Do you feel exhausted? Sure, sometimes. But above all you are left feeling useful, trusted and appreciated. These moments work to give us purpose, remind us of our values and strengths, and help us realize that we don't have to face all life's obstacles alone. Our problems need not be our secrets – rather, they are reasons to reinforce our interpersonal relationships and allow ourselves to feel supported, compassionate and grateful.

So rather than feel like a burden or a bother, seize the chance to build upon these connections by showing that you trust someone enough to confide in them. Ask a friend to go for coffee, and be honest if you have any specific ways in which you want support. Even saying

your problem out loud, whether is an emotional struggle (“I’ve felt isolated when dealing with my recent health changes and I would love to make more time to see my family”) or even a logistical hurdle (“I need someone to drive me to fill my prescriptions from the doctor”) makes the issue at hand immediately less daunting and troublesome.

If you feel that you don't have many people in your life, or want to find new friends to connect with, consider joining a club or a support group. Finding people who share your interests, or who have experienced similar specific health challenges, will help you ease feelings of loneliness and build comfort and confidence with your peers. It is never too late to realize that you are not alone, and there are always (always!) people fighting a hard battle that we can learn from and build strength with.

Being strong isn't facing life's obstacles single-handedly; being strong is realizing that it's okay to rely on others, vocalize your concerns, and gain hope and empowerment from your relationships. So go ahead, reach out – your friendships, health and happiness will thank you for it.

**"MENTAL HEALTH AMERICA REPORTS
THAT 71% OF PEOPLE SURVEYED
GAINED EMOTIONAL SUPPORT
FROM FRIENDS OR FAMILY DURING
TUMULTUOUS TIMES."**





WINTER BEAT THE BLUES

Do you have the “I can’t wait for winter to end” blues? Are you feeling tired and listless? Are you staying in bed, missing your workouts, outings with friends, and reaching for sugary treats for an energy boost?

You are not alone.

The doldrums caused by Mother Nature biologically affects one in 4 of us starting in October and ending in later spring.

When you feel too tired to engage in your life you are missing out on fun and joy that is yours to experience. There are many ways to bring more energy and vitality into your life allowing you to feel happier and more

excited about the days ahead. Here are a few of my favourite energy boosting strategies that may inspire you to get moving and live your best life possible.

1

EAT GOOD FOOD. Our body needs fuel and the type of fuel we put into our body greatly affects our energy levels. Try to avoid fast food, processed oils, sugar, trans fat, and junk foods. Try replacing your snacks with whole foods found in nature. (Chocolate croissants and donuts are not whole foods!). Add vegetables to your diet and increase your protein intake. Eating a little protein (lean meats, nuts, beans) with every meal will help to keep blood sugar and energy levels steady.

2 SLEEP. You've heard it before: 7-8 hours a sleep a night is important for good health and strong energy levels. I completely understand when people say that sometimes 8 hours of sleep is simply not possible. Yet making sleep a priority is one of the best ways to increase your energy. If you are short on sleep try a quick nap to help your body rest. Even a 20 minute nap will leave you feeling refreshed.

3 DRINK WATER. Drinking water is one of the best things you can do to increase your energy. I know from experience it is also one of the hardest to stick too. Besides the countless trips to the bathroom that you will make as you initially increase your water intake, many people crave something more than plain old H₂O. Try adding lemon, mint or cucumber slices to your water to give it a little kick. Water can improve your mood, give you energy, decrease fatigue, and much more.

4 MOVE YOUR BODY. Our bodies weren't designed to sit all day. They were created to run, jump and play. Fatigue and low energy can be your body's way of calling out for you to get moving. When you exercise you're not only keeping your body fit you are also moving your emotions through your body, which keeps you healthy. Find something you love to do whether it's hiking, yoga, dancing, or walking and you are more likely to stick with it. Best part of exercise is that the more you move, the more energy you have. (Join the BCNF Team for a 5km walk on June 28th and meet new friends too!)

5 DO A MENTAL CHECK-IN. A key to restoring your energy is to become conscious of your thought patterns and how they may be affecting your health. Negative self-talk and critical thinking can drain your energy leaving you feeling depleted and beaten up. Try to quiet your mind and check in to see what you tell yourself during the day. We have over 60,000 thoughts a day and 80% of those are mostly negative. That can be a real downer! Try positive self-talk mantras such as: "I feel energetic and alive", "I choose to think thoughts that serve me well", "my body is my vehicle in life; I choose to fill it with goodness". Your self-talk creates your reality. Choose positive encouraging thoughts and you will feel happier.

6 HUG A TREE. Spending even five minutes in a green space is enough to give you that feel good factor. Researchers in Japan found massive health improvements when people got out and walked in nature. They call it *Shinrin-yoku* or forest bathing.

No green space where you are? Go stand outside and feel the sun on your face or the rain on your cheeks. This simple act will improve your mood.

7 DETOX FROM DIGITAL. While being online is a great way to stay connected with family and friends, too much time on social media sites can also leave you feeling burnt-out and stressed-out. Put your phone away, shut down your computer and take the time to look up and connect with family and friends in more meaningful ways. Even a 24 hour break from digital tools can improve your happiness and inner peace.

8 FIND A PASSION. Find something you are passionate about and go try it. This could include cooking a new recipe, joining a run group, trying a new workout class or joining a book club. When you venture out of our comfort zone and try something new you will feel energized and excited about life again.

9 HELP OTHERS. Doing something for others is good for your mind, body and spirit. When you help others you stop focusing on yourself, reduce the negative internal chatter and release feel good hormones that increase your self-esteem, and your well-being. (The BCNF is always looking for volunteers!)

10 LAUGH. Many studies have shown that a good belly laugh lifts your mood and immune system. Researchers have also found that the benefits start even before you begin to laugh and stay high for up to 24 hours after. So grab your favourite person, a bucket of popcorn and play your favourite comedy. You'll be healthier and happier for it!

The winter blues affect many people to varying degrees, but they are manageable. However, if you're experiencing symptoms of prolonged lethargy or depression that are disruptive or debilitating please speak to your family doctor.



Writing
to
Wellness

With so much focus on your physical well-being, it is easy to forget to pay attention to the wellness of your spirit and the strength of your imagination. These days, so much of our idea of “health” is measured by the ability and functioning of our body, our energy levels and our ailments or symptoms. However, it is crucial to also nurture our inner spirit – the side of you that finds yourself doodling on the side of a to do list, repeating poignant song lyrics to yourself, or immersed in the words of a brilliant book. Especially when we feel that our control over our physical well-being is challenged or limited, turning to the creative side of our selves, and challenging our inner artists, poets and creators, can have astounding effects on our overall happiness and wellness. In particular, writing can help us both access our creative spirit, while regaining a sense of control over our mind and moods.

Sure, not all of us are born with an innate knack for the creative arts. Maybe our drawings look more like stick figures and we can never win a game of Pictionary without frustratingly slamming down the pencil and pad. That's okay. Being creative isn't necessarily about being the most skilled or eloquent. Rather, it is about expressing yourself – about realizing that there is a part of your brain that benefits from the exercising your imagination.

The easiest way to activate these parts of your brain is to start writing. Whether you feel inclined to write poems, letters, fiction or fact doesn't matter. That's the brilliance of writing – you get to control the world you create, the pattern of the words on the page and the trajectory of the narrative or story. You get to envision a reality in a limitless world. It is in this way that writing allows not only a freedom of creativity but also an endless degree of control – you get to own a world of words, that belongs to you and no one else.

Start small – grab yourself a notebook, a pen find a comfy place to sit. For ten minutes, just write whatever comes to mind. It doesn't matter how it sounds just now – resist the urge to edit, reflect or proofread. Just let the words flow onto the page and see where they take you. Experiment boundlessly – try rhyming words, creating mind-maps, even doodling the alphabet. Studies have shown that even just printing letters on a page ignites activity in the part of your brain that helps you think and write creativity. So if you feel stuck, just get your pen moving and allow yourself time to get going – ideas will eventually come, and the accompanying feeling of inspiration will be surprisingly freeing and invigorating.

Start small –
grab yourself a
notebook, a pen find
a comfy place to sit.
For ten minutes, just
write whatever comes
to mind.

Many times, writing also helps us make sense of our experiences. Recent research at the University of Austin, Texas has suggested that expressive writing can help ease stress and trauma. Journaling can help you organize your feelings, realize your thought patterns, and ultimately help isolate the things that make you happy or anxious. Through this self-knowledge you can go on to mindfully steer yourself towards positive thoughts and experiences, and manage your negative encounters or thoughts.

Health.Harvard.edu/healthbeat/writing-about-emotions-may-ease-stress-and-trauma



PERSEVERANCE and Positivity



“THERE’S
NOTHING LIKE BEING
TWENTY-NINE AND GETTING
TOLD YOU ONLY HAVE SIX
MONTHS LEFT
TO LIVE”

“There’s nothing like being twenty-nine and getting told you only have six months left to live,”

Doug Hamilton says over the phone, his voice rich with the dramatic irony of the situation. You can almost picture him smiling.

“Nothing like it. But here I am, alive forty-three years later. I’m 72 now.”

Doug Hamilton’s story is a remarkable one. In 1971, he was faced with an impossibly difficult decision. Upon the discovery of a large tumour in his right leg, he was given the option to have an extensive amputation, which would leave him without his right leg, thigh and hip, or else undergo a potentially difficult surgery to remove his hamstring and sciatic nerve.

“I asked my doctor which option would give me the better chance of survival. He said neither. So I thought, I may as well keep my leg.”

Additionally, he was told, he would need a leg brace to walk for the remainder of his now greatly shortened life.

In many ways, Doug was very lucky – his charismatic nature helped him to immediately bond with a new young surgeon at his hospital, Dr. Don Morrow, who provided him with amazing support and treatment.

“Don offered to send me out of town for treatment. But I figured I’m in a little town, I know the people in this town, and if I’d left I never would have had a single visitor during recovery. So I asked Don if he thought he could do the surgery himself, and he said sure.”

Doug was operated on three times by Dr. Don Morrow at the Queen Victoria Hospital in Revelstoke, British Columbia. His hamstring muscle and sciatic nerve were removed, and a biopsy was performed.

NCE

The results were harrowing: Dr. Morrow informed Doug that he had a malignant neurofibrosarcoma – an incredibly rare diagnosis, as only 7% of that particular type of tumour are found to be malignant.

Doug remains grateful to Dr. Morrow today. “If Don hadn’t been at the hospital, I doubt very much I’d be alive,” he admits. “He’s a wonderful man, and a wonderful surgeon.”

As for the 29-year-old Doug, even a terminal illness couldn’t extinguish his fiery spirit. “I did the inevitable while I was in the hospital,” he admits, somewhat sheepishly. “I fell in love with one of my nurses. We dated for a short time, and then she broke up with me.”

“I REMEMBER THINKING TO MYSELF, ‘THIS IS NOT GOING TO BEAT ME.’”

Doug spent around 60 days in the hospital after his operation.

He owned a small service shop at the time, and was eager to get back to work – even if he was under orders not to.

“I don’t know for sure, but to be honest I think the doctors thought I’d never leave the hospital. But one day I asked, ‘Can I go home doc?’ And off I went.”

Maybe he was feeling lucky from his speedy recovery, but Doug decided to enter a local radio contest to win a bus trip to Lake Tahoe. And perhaps Doug was overdue for the odds to be in his favour – he won the contest.

“So I went on the trip, and I had a riot, as one would if they thought they didn’t have long to live.

It was fantastic. But my leg brace kept breaking. Back at home I would fix it myself in the service shop, but on the trip I got stuck of it. I cut it off, threw it up on the rack on the bus and forgot about it up there.”

“Actually, I don’t know what eventually happened to it,” he muses. “It probably ended up in the trash.”

“I DON’T KNOW FOR SURE, BUT TO BE HONEST I THINK THE DOCTORS THOUGHT I’D NEVER LEAVE THE HOSPITAL. BUT ONE DAY I ASKED, ‘CAN I GO HOME DOC?’ AND OFF I WENT.”

And so, in spite of the doctors’ predictions, Doug had already defied the odds: he was walking freely, without the help of a brace.

Even now, Doug’s strength is so evident that one can hardly doubt that his survival and success has been contingent upon his upbeat attitude and relentless optimism:

“I remember thinking to myself, ‘This is not going to beat me,’” Douglas recalls. “I’m 100% a strong believer in the power of positive thought.”

Today, he spread this optimism to others fighting cancer. “I offer cancer counselling, and that’s one of the things I always say to people: ‘Tell yourself you’re going to beat this.’ Sometimes you’re bang on, and sometimes you’re not. Cancer is a horrible disease. But you must stay positive.”

Beyond his work as a cancer counsellor, Doug’s years spent battling NF have enabled him to better support and benefit his community. In particular, he has formed a cancer support group that meets in Revelstoke at the Hillcrest Hotel on the first Tuesday of every month. These meetings perfectly exemplify the true spirit and support that cancer patients receive and offer to each other within the Revelstoke community.

"The hotel managers really take care of us. We all have a free chocolate moose, and we celebrate whoever has a birthday that given month," he explains.

The support group works to fundraise for members undergoing cancer treatment. Specifically, it tries to mitigate the financial burden caused on patients that have to commute to other hospitals, due largely to the fact that chemotherapy is no longer available at Revelstoke's Queen Victoria hospital.

"We raise funds for members to go to other hospitals and get treatment. Every now and again someone will get a rare cancer and have to travel far, and we help them with cash from our club. Sometimes its to Edmonton or Vancouver for extensive treatment. Other times, we pay for a driver to take people to appointments in Salmon Arms, Kelowna..."

"We've been trying to get chemotherapy treatment back into our hospital," Doug explains. "Our MLA, NDP Norm Macdonald – a wonderful man – has been doing everything he can. He will do anything to help anyone, regardless of their politics. He's one of those people."

"I'M 100%
A STRONG BELIEVER
IN THE POWER OF
POSITIVE THOUGHT."

It is clear that Doug himself is 'one of those people', and a true pillar of support within his community. Despite his constant gratitude and humility, it is evident through his stories that his work continues to make a real and crucial difference to others fighting the disease.

"If you live in a town like this you've got to do something to give back. I've done a lot of things here that I probably never would have done if I lived in a bigger city. And after tomorrow night's fundraiser, the club should hopefully be good for money for a couple years."

The fundraiser he's referring to is a sit-down dinner and silent auction held at the Saturday night bingo on September 20th. "We got about 95% of the businesses in town involved in the auction. We've never done this type of event before. It should be a fun night."

"My good friend, Wayne Wood, was recently diagnosed with intestinal cancer. I'm hoping that with tomorrow's fundraising we'll have enough money to really help him out with the treatment."

"The club keeps growing- there's always someone getting cancer," he notes.

Of course, life with NF still presents challenges for Doug. Recently, he's had 8 larger lumps removed. Luckily, they've all be benign. He is health conscientious and takes great care in maintaining a healthy diet and lifestyle:

"I went to see a Naturopathic doctor. Turns out I'm allergic to whole wheat, eggs," he says, "So I take care to not eat those things. And I walk every day."

"After all, I'm 72 now. I have been a Cancer survivor for 43 years. Not bad, for someone who was once told they had six months to live." ■

"AFTER ALL, I'M 72 NOW.
I HAVE BEEN A CANCER SURVIVOR
FOR 43 YEARS. NOT BAD, FOR SOMEONE
WHO WAS ONCE TOLD THEY HAD SIX
MONTHS TO LIVE."

LOOKING FOR ON-LINE SUPPORT?

Connect with others living with NF at inspire.com

Inspire is a site that provides a safe and secure place to support and connect with others.

Highly recommended by those who use it!


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INSPIRE OTHERS TO MAKE A DIFFERENCE

RUN, JOG OR WALK WITH THE
BCNF AT THE 2015 SCOTIABANK
HALF MARATHON AND
5KM CHARITY CHALLENGE

SUNDAY, JUNE 28TH

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:
canadarunningseries.com/svhm

**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!

PAIN IN NF-1

*By Staci Martin Peron, PhD and Andrea Baldwin, CRNP
National Cancer Institute, National Institutes of Health*

One of most common challenges for individuals with NF1 is living with chronic pain. By definition, chronic pain is persistent pain that continues for weeks, months, or even years. This occurs when the pain signals within a person's nerves continue to fire, and the severity can vary by

individual. In general, it is estimated that about 25% of the general U.S. population ages 20 and over report pain lasting greater than 24 hours. In patients with NF1, estimates of those experiencing chronic pain range from 35-53%.

IMPACT OF PAIN ON DAILY LIFE

The conditions and symptoms described above emphasize the major challenges faced by people with NF1. Not surprisingly, researchers have found that more severe symptoms, including pain, are associated with diminished quality of life among adults and children with NF1. Further, more severe pain has been found among children who have more symptoms of depression and anxiety. According to questionnaires completed by parents of children with NF1, the children with worse pain have a harder time

keeping up with activities of daily living, such as dressing, grooming, and getting along with peers. These research findings seem to suggest that pain has a negative impact on things like emotional functioning and quality of life. However, the relationship seems to work both ways. That is, many people report that their pain feels worse when they feel sad, when the quality of their relationships is poor, or even when they have an overall decrease in life satisfaction.

COMMON CAUSES OF PAIN IN NF1

What are some of the NF1-related symptoms and conditions that cause pain? Probably the most common of these is **plexiform neurofibromas**, or PNs. PNs are benign tumors comprised of a proliferation of cells in the nerves. They are found in about 30-50% of people with NF1. Most often, they grow rapidly during childhood, although they may go for years without being detected.

Up to half of people with NF1 may experience **recurrent headaches** that are severe enough to interfere with their daily lives. These headaches can begin during childhood, and are typically described as migraines or tension headaches. An occasional cause of headaches in adolescents and adults with NF1 is an adrenal tumor called a pheochromocytoma. This is an endocrine tumor that causes an excess of catecholamine.

About one fourth of people with NF1 develop **scoliosis** or other orthopedic problems. Scoliosis often is treated with surgery and corrective braces, both of which can be quite painful and can negatively impact a person's quality of life. Another orthopedic condition that occurs in a small number of people with NF1 is called **pseudarthrosis**, a problem that can lead to pain and fractures of the long bones that don't heal. Other causes of spinal pain in NF1 are **spinal tumors**, **dural ectasia** and vertebral damage resulting from **osteopenia**.

Glomus tumors are noncancerous tumors that appear on fingers and toes. They are rare compared to PNs, but cause extreme pain when they occur. Gastrointestinal complications in the NF1 population can be caused by neurofibromas in the stomach and are sometimes called **abdominal migraines**. These are also uncommon in NF1, but when they occur they can lead to severe pain.

Given the many pain-related symptoms and complications in individuals with NF1, it is important to let your doctor know about any pain you have. It is ideal to work with a physician who has expertise in NF1. If your doctor does not have experience with this disease, it may be worthwhile to seek out someone who does.



TREATMENT FOR PAIN

MEDICAL

Many researchers are developing and investigating drugs that they hope will prevent tumor growth and ultimately shrink the size of PNs. But right now, the main treatment is surgical removal of the tumors. Because these tumors grow along the nerves, surgery can be complicated and may be avoided altogether if the risk to loss of function is too great. Also, many times the tumors (and associated pain) return after surgery.

NF1-related symptoms sometimes can be managed with pain medication, including nonsteroidal anti-inflammatory drugs (NSAIDs, such as ibuprofen), anticonvulsants (such as Neurontin), and narcotics (such as morphine and oxycodone). But these options are not perfect. Many people taking these medications experience side effects, such as loss in appetite, constipation, nausea, rash, mood or sleep disturbances. Moreover, the medications do not always get rid of pain completely. In fact, researchers have noted that children with NF1 taking pain medication rated their pain higher than those not on pain medications. In our own experience with patients who come to the NIH, we frequently meet people who complain of pain despite taking pain medication. Moreover, these individuals often have been experiencing pain for a number of years and have considerable difficulty coping with their pain.

PSYCHOLOGICAL TREATMENTS

So far, no research about psychological methods for managing pain in NF1 has been published. However, techniques that have been found to be helpful in people with other chronic pain conditions may offer some guidance.

There are several types of stress management techniques that can be helpful for people with pain due to a variety of conditions. Progressive muscle relaxation and guided imagery have been used with some success in patients with cancer, osteoarthritis, and recurrent abdominal symptoms. Another option, mindfulness-based treatments, teaches individuals to focus on present moment sensations with an attitude of acceptance and without judgment. These techniques are becoming increasingly popular, as a growing body of research supports their effectiveness with chronic pain patients.

Cognitive-behavioral therapy (CBT) involves trying to change the way a person thinks about his or her pain, realizing how those thoughts impact behavior, and then gradually working towards a return to normal functioning. A related technique, Acceptance and Commitment Therapy (ACT), focuses on helping patients live a full, satisfying life doing the things they value the most in spite of their pain. Another technique that is often effective is biofeedback, which involves

teaching a person to regulate their bodily responses to pain, such as muscle tension, heart rate, and brain waves. Many of these techniques are paid for by insurance, although coverage varies widely. Some companies may be more likely to help with the cost if the technique is part of a comprehensive psychological treatment plan rather than a specific pain coping technique in isolation.



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Check page 15 for details

PHYSICAL ACTIVITY

Yoga has been found helpful among adults with arthritis, low back pain, and other conditions. Its benefits include a reduction in pain severity and an increase in one's ability to accomplish day-to-day tasks. Given that many individuals with NF1 are limited in their ability to play sports or do aerobic exercise; this may provide a suitable alternative. More vigorous physical activity can reduce pain in various disorders, but exercise programs should always be tailored to the individual's functional abilities and discussed with physicians before starting.

Any of the above techniques should be done in consultation with an appropriate health professional, such as a physician or psychologist. No treatment works well for everyone, but many people with chronic pain benefit from finding the medical and/or psychological treatment that is right for them. Also, it is very important to inform your doctor immediately of any new pain or if your pain increases, especially if the pain emanates from a known PN since new or worsening pain could indicate tumor growth or a malignancy. In addition, tell your doctor if you have any change in your ability to accomplish normal activities of daily living. Even though doctors do not have all the answers, it is important for patients to work with their physicians as a team and to be actively engaged in their own care. ■

RESOURCES FOR PAIN

Check out these sites that offer information and tools for coping chronic pain.

The Pain Toolkit.

paintoolkit.org

This is a great place to get started! It's free and can be downloaded in a few minutes.

Overcome Pain Live Well Again.

canadianpaincoalition.ca

These are archived webcasts to help people understand pain and provide optimistic guidance about pain self-management techniques. They are available on the Canadian Pain Coalition (CPC) website.

Chronic Pain Lecture Series

albertahealthservices.ca

Alberta Health Services has this series available for free online. Watch this BBC documentary on pain entitled "The Secret World of Pain"

Chronic Pain : The Journey Forward

cirpd.org

The Canadian Institute for the Relief of Pain and Disability have podcasts from the webinar series "Chronic Pain : The Journey Forward" available.

PAIN CENTRES

CHANGEpain changepain.ca

This multi-disciplinary clinic with a team of like-minded clinicians and support staff share a mission to relieve pain earlier. A referral is needed from your family doctor to attend this clinic located in Vancouver.

St. Paul Hospital Pain Centre offers pain education day programs. For more information call 604.682.2344 Ext. 63276.

Fraser Health has opened the new Multidisciplinary Chronic Pain Clinic in the Jim Pattison Outpatient Care and Surgery Centre. 604-585-4450. For information on that and other programs call General Information at 1-877-935-5669.

On Vancouver Island: go to the VIHA website. viha.ca

VIHA has 3 pain clinic locations under a regional program in Victoria, Nanaimo and Comox.

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BCNF'S NEW PREZ: FOTO SUKANEN

Foto Sukanen was one of the founding members of the BCNF back in 1984 and was on the board for about two years at that time. She took a break, but re-joined the board in 2011 as vice-president. Foto retired from her job in October 2014, and has now taken on the position of president of the BCNF. "I felt I had the time to devote to the leadership position as the President of the BCNF. It was a natural step from vice-president to president. I also feel that it is time for me to do more for the BCNF," she shares.

Foto lives with Neurofibromatosis type one (NF1) and was featured in our first issue of *INSPIRE* magazine. She knows first-hand what it is like to live with the disorder which will aid her in her role as president. When asked what her hopes and goals are for the BCNF moving forward, Foto shares "I hope that the BCNF continues to be able to provide information to individuals or family members who are living with NF. We rely on the donations from individuals so we can provide information to the NF community."

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



Q

What or who inspires you in life?

Q

Do you have a favourite quote?

A

"Never give up; never surrender."
(from *Galaxy Quest*)

Q

Is there a place in BC you like escaping to?

A

Pacific Sands resort just south of Tofino is our little paradise. There is nothing like winter storm watching.

A

The youth of today. I have met some very awesome young adults and am encouraged by their enthusiasm, optimism, and energy for their communities.

Q

What are you most proud of?

A

I can't say I am proud of anything. I guess it is because I was raised to be humble.

Q

What makes you the angriest?

A

Violence against humans and animals.

Q

What are your top 3 favourite films of all time?

Q

What is your biggest hope?

Q

What is the luckiest moment of your life?

A

Meeting the love of my life, John.

A

Silent Running, Nebraska, and The last Mimzy.

A

A cure for NF, or at least better knowledge about NF and treatment in the health care community.

Q

Book you are reading now?

A

At the moment none. I tend to get wrapped up in a book and not do anything else until I am done reading the book. I have one waiting for me: *Annabel* by Kathleen Winter.

Editor's Note:

We are excited to have Foto as our new President and hope that 2015 will bring many positive things to the BCNF and the entire NF community.

WHAT'S COMING DOWN THE PIPELINE IN NF THERAPIES

The chart shows all the drug treatments being tested for different conditions in NF1 and NF2 at the present time.

Phase 0 is very early stage testing,

Phase 1 tests for drug safety, and

Phase 2 tests whether the treatment works.

(Sometimes 'Phase 1' and 'Phase 2' are combined as 'Phase1/2'.)

Phase 3 tests whether the new treatment is better than existing treatments.

This clinical pipeline includes completely new drugs, as well as variations of existing drugs, and new uses of existing drugs. Many of these potential treatments came out of research sponsored by the Children's Tumor Foundation.

A Few Notes:

'Targets' are the part of the disease process that the drug tries to stop.

'Agents' are the drug names.

'Phases' are the current stage of research. The higher the number of the Phase, the closer the treatment is to being approved for use in NF patients.

To find out more about any of these clinical trials in the U.S., go to ClinicalTrials.gov and search for the name of the drug, and NF. You can also find more information at NFRegistry.org by clicking on **Clinical Trials** on the menu bar.

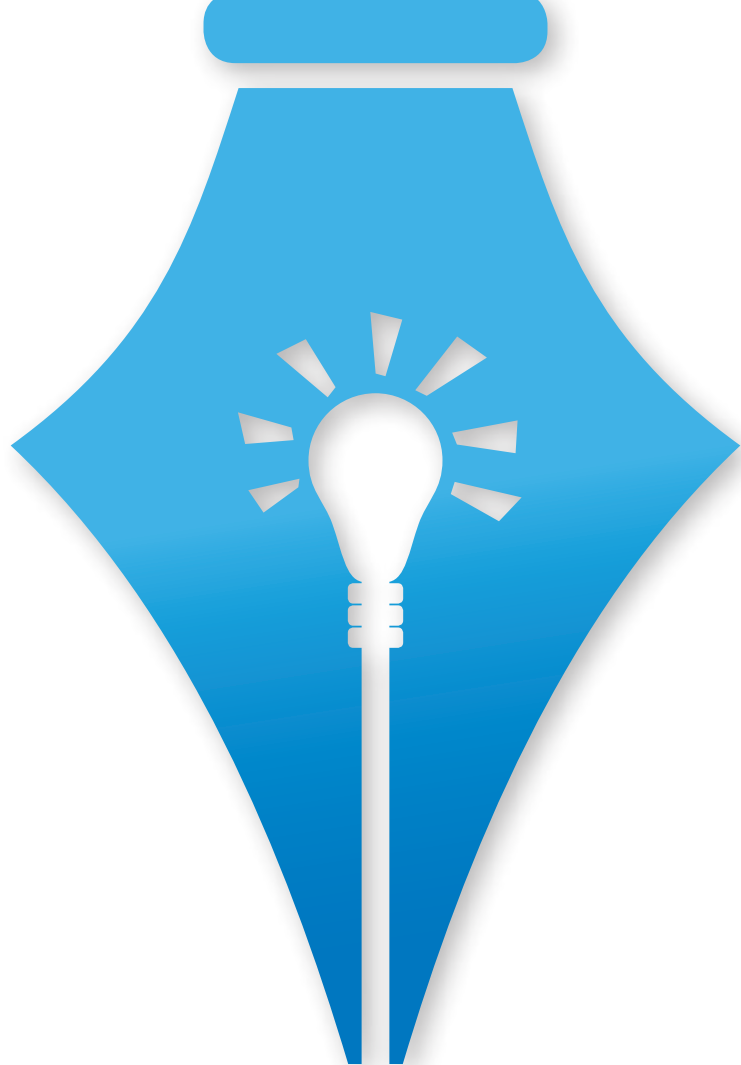
LG Glioma	TARGET	Agent	Phase 0	Phase 1	Phase 1/2	Phase 2	Phase 3	Patients
(EU Trial: NO, IE)	Chemotherapy mTOR Anti-angiog, pro-Apopt, anti-Infl, Immuno-Modulatory MEK	Vincristin, Carboplatin, Etoposide Everolimus (RAD001) Lenalidomide Selumetinib (AZD-6244)						
Plexiform								
Adults Children, Young Adults (EU Trial: ES) (EU Trial: IT)	Antiprolif, Antiangiogenic Antiprolif, Antiangiogenic Tyr-Kinase Tyr-Kinase mTOR Tyr-Kinase MEK Tyr-Kinase MEK MEK	PEG-interferon α-2b PEG-interferon α-2b Imatinib Imatinib Everolimus (RAD001) Sutent/Sunitinib MEK162 Cabozantinib Trametinib (GSK-212) Selumetinib (AZD-6244)						
MPNST								
	Hedgehog + γ-secretase Tyr-Kinase + Chemo Tyr-Kinase + Chemo mTOR + HSP90	Vismodegib, RO4929097 Pazopanib, Gemcitabine, Docetaxel Pazopanib, doxorubicin, ifosfamide Sirolimus, ganetespib						
Others								
Autism (EU Trial: UK) Bone Issues Learning Dermal	HMG-CoA Reductase Vitamin D HMG-CoA Reductase Photosensitizer (PhotoDynamic Therapy)	Simvastatin Cholecalciferol (Vit.D) Lovastatin Levulan						
NF2								
Cutaneous Schwann Cutaneous Schwann Vestibular Vestibular Vestibular Vestibular (EU Trial:UK) Vestibular (EU Trial:UK) Vestibular Vestibular, Meningioma	mTOR mAb anti-VEGF Antiangiogenic VEGF/PDGF mAb anti-VEGF Tyr-Kinase (BCR-Abl) Multi-kinase inhibitor EGFR-ErbB2 mTOR	RAD001 (everolimus) Bevacizumab (Avastin) Endostatin (YH-16) Axitinib Bevacizumab (Avastin) Nilotinib Sorafenib Lapatinib RAD001 (everolimus)						

“This pen has completely transformed the way I study. I’m an auditory and visual learner, so when I write the notes and am able to go back, look at my notes, and hear what my professor is saying at the same time is very beneficial! This has saved my grades in several of my classes.”

~ Taylor S.

A Smartpen is a high-tech writing tool that records spoken words and synchronizes them with notes users write on special paper. It looks like a regular pen but with the Smartpen the student can record everything a teacher says and later replay any part of a lecture by tapping the pen's tip on words written throughout the class.

Smartpens make note-taking less stressful by eliminating the fear of missing anything said during a class or meeting. They also remove the time-consuming task of transcribing a complete lecture by enabling students to access any part of a recorded lecture by merely tapping on words. Digitized notes are also easier to store, organize, search, and share.



HOW SMARTPENS CAN HELP STUDENTS WITH LEARNING DISABILITIES

Students with learning disabilities such as dyslexia sometimes struggle to keep up with class lectures. In the time it takes to hear, process, and write down information, the professor has often moved on to the next point.

With a smartpen, a student can outline key concepts by writing bullet points or symbols, e.g. a leaf representing photosynthesis. Providing easy access to any part of the lecture can enhance note-taking skills and build confidence and independence.

For post secondary students (including those who qualify to receive audio-recorded lectures), a smartpen can sometimes replace a personal note-taker – a low-tech solution many disability service offices assign to students to make classes accessible.

Smartpens aren't cheap. They cost about \$150 but for many students they are making a difference in increasing confidence, reducing anxiety and improving grades. Smartpens are available at a variety of Canadian retailers.

The BCNF has a pen available if you would like to try it out before investing in this educational tool.

In our first issue we featured Gail Appलगren and Tim Golumbia's love story. We are so excited they were willing to share with our readers how their life has changed over the last year.

Love Conquers All

~ By Sarah Gorden

In June 2013, Tim moved from his home in Nanaimo, British Columbia to Edmonton, Alberta to be with Gail. A year later, on August 3rd, 2014, they were married. Tim describes his wedding day as "amazing!" He says his wife's vows were very touching and shares the highlights. "She mentioned how she loves my warmth, my big and caring heart, and how I understand her," Tim recalls. In Gail's vows, she mentioned that she appreciates how Tim sees beyond her bumps and loves her for who she is. Tim had never thought of that, as it is in his nature to see people for who they are. Another highlight of the wedding to Tim is when his niece Emily sang "At Last" by Ella Fitzgerald. "I admit; I had tears in my eyes. After hugging Emily, I had to kiss Gail," Tim shares.

Gail also shared her take on the wedding. She explains that the wedding was casual and intimate with just close family members and friends. This is just the way they had envisioned it. The wedding was held in Tim's sister Joanne's backyard in Mill Bay, British Columbia. "Tim and Joanne have a very close relationship, so she was thrilled to plan and host our wedding," says Gail. Gail tells how a highlight for her was that their friends stayed at the same cottages where her and Tim were, so they got to enjoy their whole wedding weekend together. "On Sunday, the day of the wedding, the sun shone brightly as everyone made their way into the backyard." Gail shares that a close friend of hers played John Denver's "Annie's Song" on her flute as Tim and his best man walked across a path of flower petals to start off the ceremony. "My dress was a simple, off white short dress with embroidered flowers. I had flowers through my long hair and carried a gorgeous bouquet. We stood as our family and friends surrounded us in a circle of support." After the ceremony, the newlyweds and their loved ones celebrated with amazing food, speeches, singing, and

dancing. "It was the best wedding I have ever been to" is the comment that we get from everyone, Gail shares.

When asked if being married has changed their relationship, Gail says she doesn't feel that it has. "We had a strong, loving relationship before the wedding, and my love continues to grow stronger every day." She shares that Tim often brought her flowers at work before they were married. Her coworkers warned her that this might stop after they got married, but Tim still lovingly delivers Gail flowers. Tim shares that having Gail as his wife instead of his fiancé makes things seem warmer and closer. "It also made me feel closer to her family. Having so many of her family members meet my family was so special. I think the coming together of our families also created an even stronger bond," Tim shares.

When asked what the best moment of their wedding day was, Tim says that it is hard to choose just one thing, as the whole day was amazing. "One thing that does stand out is when I turned and saw Gail walking towards me with the flowers in her arms, and a huge smile. She looked so beautiful with her hair done with flowers." He shares that he kissed Gail before they even had permission more than once, as they were just so happy. Gail recalls a photograph that was taken of her and Tim kissing after their vows. "There is this "ray of sunlight" that reaches down and gently touches the top of my head. In my mind, this is a sign from my family and friends who are no longer with me, looking down on the day and giving their blessing to me!"

When asked if Tim has any advice for people with NF looking for love, he advises to not work too hard to find it. "It will come. Do not settle for someone you do not really like because you want a relationship. Happiness in love is possible," Tim shares. "Having NF may have its bumps, but NF is why I have an amazing wife!"

When asked her advice, Gail shares "It will happen for you. Never give up hope. I knew in my heart and soul that I would meet someone and fall in love," she says.



INSPIRATIONAL READS

TOTAL RECOVERY: SOLVING THE MYSTERY OF CHRONIC PAIN AND DEPRESSION

By Gary Kaplan, D.O. and Donna Beech

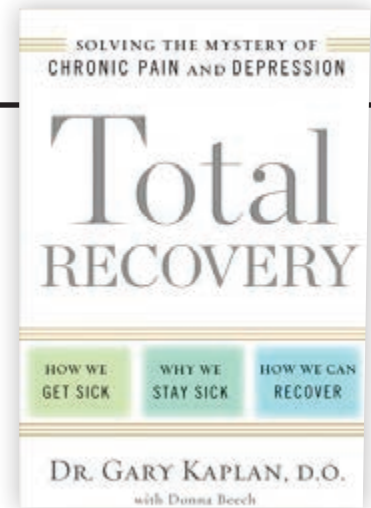
In his book, *Total Recovery*, Dr. Gary Kaplan argues that we've been thinking about disease all wrong. Drawing on dramatic patient stories and cutting-edge research, Kaplan hypothesizes that chronic physical and emotional pain are two sides of the same coin. New discoveries show that disease is not the result of a single event but an accumulation of traumas. Every injury, every infection, every toxin, and every emotional blow generates the same reaction: inflammation, activated by tiny cells in the brain, called microglia. Turned on too often from too many assaults, it can have a devastating cumulative effect.

The result, Kaplan believes, can cause mysterious chronic pain, depression, anxiety disorders, headaches and post-traumatic stress disorder- alone or in combination with dozens of other problems that can be caused by chronic neuroinflammation.

Though this idea may sound far-fetched, recent research has shown that inflammation from elsewhere in the body can spur microglia activity in the brain.

Conventional treatment for these conditions is focused on symptoms, not causes, and can leave patients locked into a lifetime of pain and suffering. Dr. Kaplan's unified theory of chronic pain and depression helps us understand not only the cause of these conditions but also the issues we must address to create a pathway to healing. With a new framework in place, Kaplan provides keys to recovery.

Available wherever books are sold.



HELP SPEED UP A CURE FOR NF

People with NF often told to “watch and wait” and often feel powerless in fighting this disorder. Now you can get active and get involved by joining the NF registry.

The NF registry was started in 2012 to benefit both scientists and patients. It is an initiative of the Children's Tumor Foundation to create the largest worldwide database of individuals with NF so that together we can speed the development of promising new treatments. The NF Registry seeks to match patients with trials and make it easier for people living with NF to find

opportunities to get involved with research. It is a way to better understand the "natural history" of the disorder, and why the symptoms of NF can be so different from person to person. It also lets patients see the "big picture" of the group as a whole by viewing Registry charts and graphs. All information is confidential. By sharing your experience you can learn how your symptoms

are like others and about clinical trials (new potential treatments). The key to NF treatments lies within you – researchers can't deliver treatments without committed volunteers. An active and committed patient community is the key to finding treatments.

Get involved today at

NFRegistry.org





CHARITY DINNER & AUCTION

Don't miss your opportunity to support kids battling NF. Dress down in your favourite jeans and have fun bidding on unique items while enjoying a fabulous dinner overlooking Vancouver's stunning vista.

Funds raised are used to support the BCNF's youth programs including summer camp and educational scholarships, as well as support the initial stage of developing the first NF clinic in Canada.

Saturday, April 25, 2015
6:00 pm to 10:30 pm
at The Diamond Ballroom
(Granville and 8th Ave)

Get your tickets today at
bcnf.bc.ca/go/auction

Early Bird Price: \$80 ends Apr 10

