ISSUE NO.2 / SPRING 2014

!NSP!RE

the magazine of the BCNF

CELEBRATING 30 YEARS

STAYING AFLOAT DURING THE TOUGH TIMES

NF RESEARCH: WHERE ARE WE NOW?

USING MINDFULNESS TO STAY HAPPY

EDITOR'S NOTE

TO INSPIRE YOU TO BE THE BEST YOU CAN BE.

That was our goal as we launched the first edition of the magazine and from the comments and feedback we received, you were.

It was wonderfully uplifting for our team to hear how much you enjoyed the premier issue. Here are just a couple of the comments we received.

*"I absolutely *love* the Inspire magazine! BCNF has set the bar quite high with this! Kudos to your team!"*

C.L., Children's Tumor Foundation New York City, NY

"Wow! Wonderful newsletter. I think it's really important to have some of those pictures in it and to have those inspiring stories – there is life after NF. Well done."

Y.G., Vancouver, BC

"Boy, was I impressed with the new newsletter. Just fabulous! Really enjoyed it and read it cover to cover as soon as I got it in. Thank you for this publication."

R.P., Delta, BC

The BCNF exists to inspire, support and empower you. You are our community and our family. And this year as we celebrate our thirtieth birthday we hope you will celebrate, engage and grow with us.

After 30 years the BCNF has a new logo. The Board felt it was time to make a change and freshen up our look. We are excited to launch the new look of the Foundation with you. Check out page 6 to see more. There will be more exciting birthday surprises that will be rolled out as we move forward in 2014. Stay tuned to the website to learn when we will be coming to your community this year.

We are also thrilled to launch our Youth Leadership Project: New Beginnings, which will focus on developing life-long leadership skills, teamwork and independence in young adults. The program kicks off March 29th so if you are between the ages of 16-30 turn to page 6 to learn more about this exciting new program.

This magazine is for you. We want to continue to inspire you to live the best life you can, whether or not you are affected with NF.

We hope you will continue to send us your comments, your favourite inspirational places, and story ideas.

Desirée Sher
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INSPIRE MAGAZINE
ISSUE NO.2 / SPRING 2014

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Look for us on Facebook & Twitter

Together we can make a difference!

We would like to thank the B.C. Gaming Policy and Enforcement Branch, Community Grant Program for supporting the BCNF's programs.

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BCNF
EMPOWERING INDIVIDUALS WITH NF

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!

ROSS PHILLIPS

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

LOOKING FORWARD TO TODAY

Danielle Catharina Lyons, known as "Dani," is a four year old little girl who lives each day to the fullest and enjoys each moment. She is a carefree child who looks for the fun in each day. Dani has a twin sister, Paige, and an older brother named Brandon. Dani's mother, Andréa, shares her experience with Dani's recent Neurofibromatosis Type One (NF1) diagnosis and how it has affected her family.

Earlier this year, Dani visited a dermatologist at BC Children's Hospital for an unrelated issue. It was then that the doctor noticed café-au-lait spots, bone deformities on her legs, a larger head circumference and some developmental delays as compared to her twin sister. The doctor suggested that they explore the possibility that she may have NF1 and that she be seen by an ophthalmologist to see if there were any eye abnormalities that are associated with NF1. At their visit to the ophthalmologist on April 23, 2013, it was discovered that Dani has Lisch nodules on both of her optic nerves and the unfortunate diagnosis of NF1 was confirmed. From that moment, the Lyons' family would be forever changed.

Although the news was shocking and upsetting to Dani's mother Andréa, within 24 hours she jumped in with both feet ready to face the situation head on. "When I found out – I was really fairly quick coming to terms with it. As a parent all you want to do is take away their pain and you would gladly exchange places with your child so they do not have to feel one iota of suffering," explains Andréa. "However, when I learned about NF1 and learned that there was no cure, I was quick to decide that I was going to learn all I could, be an advocate for raising funds, and help mitigate any symptoms for her the best I could." Andréa quickly learned about the NF foundations in the States and was in contact with research centers at BC Children's Hospital. She even signed up for a marathon and immediately started an awareness campaign and fundraising.

At the time of this interview, Andréa has fundraised just over $7,200 and has two more fundraisers planned for the near future. All of the funds raised will go directly to the BCNF.

DANI ISN'T CONCERNED PAST THE END OF THE WEEK. SHE IS JUST LOOKING FORWARD TO TODAY – WHAT FUN SHE WILL HAVE AND HOW HAPPY SHE CAN BE IN THE MOMENT

"We have reached out to our local community including fire fighters and friends, and they have come back in spades with their generosity," tells Andréa. Andréa is quite familiar with the local fire hall, due to her involvement with Search and Rescue and her career in emergency management. After being featured in her local newspaper to highlight an upcoming fundraising event, she received a call from her local fire hall. "They expressed their sadness when learning of Dani's condition, and asked that I bring Dani down to the fire hall for something." When they arrived, all three of Andréa's children were treated to fire truck tours and even got to pull the fire truck out of the hall with the lights on. "Then the crew on shift presented Dani with a card (inside was a $500 cheque) and a stuffed Dalmatian dog with a fire hat on – which hasn't left her side."

Another fundraising contributor is Andréa's staff at BC Hydro where Andréa was a profiled employee for a few weeks and was able to promote the cause. Through this, she managed to raise approximately $750. A local grocery chain called Thrifty Foods has also been a huge support. Through their generosity, approximately $3,000 has been raised at fundraising events.

WORDS BY SARAH GORDEN / PHOTOS BY SAM CHUA

When asked about the challenges their family has faced since Dani's diagnosis, Andréa explains how hard it is to wait for doctors' appointments and not knowing what to expect for her child's future. "It's like watching a storm come in off the ocean... you don't know if it's going to hit the shore or just sit out on the water," Andréa shares. "Right now we are waiting to see if there is another wave coming at us and getting ready to batten down the hatches in case the storm does rage."

Like all mothers, Andréa has hopes and dreams for her daughter. "When I first learned of the diagnosis, my heart stopped for a moment and I wondered if I would ever be able to see my little girl walk down the aisle and get married – funny how I went straight to that life event, but nevertheless I did." Andréa shares that in the short amount of time since Dani's diagnosis, her daughter has taught her a significant lesson: to live each day to the fullest and be happy in the moment. "Dani isn't concerned past the end of the week. She is just looking forward to today – what fun she will have and how happy she can be in the moment," shares Andréa. "I hope for her to continue to live in the moment and take each day as it comes in her determined little way." Dani has already expressed interest in becoming a doctor and likes to "treat" everyone in the house. "She has a little doctor's kit and puts Band-Aids on her siblings."

Andréa hopes that Dani finds her passion in life and follows it with every fibre of her being, despite the inevitable challenges she will face from NF.

DANI LYONS

30 YEARS OF ACHIEVEMENT

THIS YEAR, WE CELEBRATE 30 YEARS OF SERVING THE NF COMMUNITY!

1984

The seed was planted and work to establish a foundation began.

1985

First NF support group meeting founded by Paul Ralfs with support from Dr. Judith Hall, University of BC, Medical Genetics.

Board of Directors established.

1991

Medical Advisory Board formed.

Resource lending library established.

1993

Founding member of the International Neurofibromatosis Association.

Completed a Physician Awareness Campaign to 6,000 physicians across the province.

1997

Hired first part-time executive director.

First Canadian educational youth event for kids with NF: 'Day at the Lab'

1998

Received largest donation in BCNF history of $100,000.

BCNF initiates the development of a national NF organization.

2000

Launched first Canadian NF Camp Scholarship Program.

Office moves to Victoria.

2006

Organization moves out of office and becomes a 'virtual' organization.

2007

Launch of first Canadian Education Award for Youth Living with NF.

2008

Published NF information in three additional languages: Simplified Chinese, Mandarin and Punjabi.

1986

Registered as a non-profit organization.

First newslettter published.

1988

Recognized as a charitable organization by the Government of Canada.

1990

Moved into first office in Vancouver.

Organized first NF Symposium in conjunction with University Hospital.

Published first newsletter.

1994

Establish a toll-free 1-800 line.

Participated in the first Lucerne milk carton awareness campaign.

First support group meeting held for parents of children with NF in Vancouver.

First support group meeting held on Vancouver Island.

1995

Donated first research grant to NF Clinical Database at the University of British Columbia.

Kicked of the first Jeans for Genes dinner & auction fundraiser.

Launched the first medical symposium.

BC Transit public awareness campaign initiated.

1996

First Kick-a-thon fundraiser held in Vancouver.

2002

Launched Children's Tumour Research Program that awarded $20,000 to NF Research.

2003

Published 'Understanding Neurofibromatosis' – first Canadian NF youth resource.

2005

Developed the highly coveted resource, 'A Parent's Guide to the Learning Disabilities Associated with NF1'.

2010

Partnered with NF Canada for first national symposium.

Launched Support Through Technology online video support project.

Engaged community using social media tools.

2012

Partner with Scotiabank for our first Charity Challenge Vancouver Half Marathon.

2013

Launch of the Clothing Bin Collection Program.

Recycling program reaches over $70,000 in revenue.

LOOKING TO THE NEXT 30 YEARS

We are excited to unveil a new logo for the BCNF.

The Board of Directors wanted a fresh new design which the public would associate with an energetic, caring and fun organization dedicated to empowering, inspiring and supporting the NF community.

Working with designers and members from our community we created a new logo that captured our mission: to inspire people to live their best life with NF. We hope to move individuals from living in the shadows with NF to reaching out and shining their own light onto the world.

We are creating merchandise with the new logo, which will be ready for you to purchase in early spring. You can check out our website and social media pages for more information as the items become available.

BCNF

EMPOWERING INDIVIDUALS WITH NF

NEW BEGINNINGS

A Transition Event for Young Adults with NF

Come and participate in our newly-developed and inspired event! It's all about transitions - entering into that new phase of life that can sometimes be confusing.

Participants will be invited to end old ways of "being" that are not serving their highest intentions and ponder goals for living a thriving life with NF. The message here will help you move forward with an introduction to a new blueprint for the next phase of your life.

The atmosphere will be relaxed.. Conversation and discussion mixed with activities, food and fun will help arm you with tools for your future!

1 WHO:
Youth aged 16 - 30

2 DETAILS:
11 am - 4 pm: The Main Event [includes lunch]
5:30 pm: Dinner at Cats Social House
7:30 pm: Comedy Improv Theatre Sports

3 DATE:
March 29, 2014
Vancouver, BC

4 COST:
$10.00

PENCIL IT !!!

RSVP: Desiree Sher -- desiree@bcnf.bc.ca [Before Mar. 21, 2014]

Keep connected at: http://www.bcnf.bc.ca
Sponsored by BCNF

COURTNEY WILLOUGHBY

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.

WORDS BY **SARAH GORDEN**


Mi

nd Over Matter

using mindfulness to stay happy

The mind is a busy place. It seems we're all carrying around a mental to-do list, an overwhelming tally of things we've forgotten to do, and an ever-growing anxiety towards the future. Sometimes it becomes hard, through all the daily stresses and concerns, to live in the moment. How do we turn off our incessant mental chatter, and regain our control of the present?

When the fear of the unknown or the future can feel overwhelming, it is important to take a moment to pause, breathe, and access your emotions and surroundings in the present. Staying mindful of yourself and the world around you, and realize that you have the power to change your thoughts and reactions.

What does it mean to stay mindful? The concept of mindfulness is really quite simple – it's the practice of consciously staying aware and interested in the present moment. It's about staying grounded in the here-and-now, and realizing the different factors that affect one's thoughts and feelings at any given time.

The key to mindfulness is to remain non-judgmental of yourself and your own thoughts. It is the act of deliberately noticing our experience and reactions, with intent and purpose, but also with patience and kindness. This takes some time and practice: we have to re-train our brains to react to external stresses and internal habits. For example, rather than automatically feel irritated when we're stuck in traffic, staying mindful asks us to listen to our habitual thoughts and gives us the opportunity to change them. Why are we feeling irritated? Is the traffic jam something we have the power to change in the present moment? If not, why do we waste our time feeling negative and stressed? By noticing how our brains are wired to interpret and react to different stimulation, we can consciously guide our thoughts towards more positive outcomes.

The concept of mindfulness is really quite simple – it's the practice of consciously staying aware and interested in the present moment.

It's simpler than you think. Try these easy steps:

1. *Allow yourself to slow down and notice your environment.*
2. *Breathe deeply for 20 seconds.*
3. *Think about how slowing down and breathing made you feel. Was your brain busy dwelling on something else? What did you notice about your surroundings? Were you drawn to the physical space around you, or did you notice the ambient sounds in the room?*

This small act alone is an act of mindfulness, and shows that you have the power to steer your own attention towards the current moment. Once you realize this, you can keep yourself from dwelling on the past, worrying about the future, and hindering your enjoyment of the present. Mindfulness helps us avoid needless stress and allows us to connect better with our loved ones, focus on the task at hand, sleep and eat better, and overall live more fulfilling and successful lives.

While there are many challenges we all have to face, we have the ultimate control to deal with these hurdles and make affirmative decisions along the way. By realizing that you have the power to take charge of your thoughts, you will empower yourself to make the most of the present moment, to honour your body, and to feel happier in your day-to-day life. Stop, observe, breathe, and reflect. Try it.

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

ANDREA MEADOWS

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."

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

"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."

WORDS BY **SARAH GORDEN**


"MY DREAM
IS TO HEAL."
WASHINGTON

RYAN

Ryan is a grade ten student from Vancouver Island, living with Neurofibromatosis Type Two (NF2). He loves video games and sports and is a walking encyclopaedia when it comes to sports teams and players, especially hockey. Ryan's favourite team is the Washington Capitals and he even had a *Make-A-Wish* trip granted to meet his favourite player, Alexander Ovechkin.

Ryan's mother, Simone, shares her son's experience living with the disorder and how it has affected his and their entire families' lives.

"Ryan was seven years old when he was diagnosed with NF2," shares Simone. Initially he was misdiagnosed with Cerebral Palsy due to the symptoms he was experiencing. "He was falling down all the time, and after bringing him to the foot specialist, it was found that his entire left side was very weak." She recalls wondering why it was taking her son so long to learn to tie his shoes and button up his own pants. "He had compensated so well with his right side that the weakness on his left side went unnoticed." Ryan was put into casts and then into a brace to correct his walking, but by the end of the summer things had gotten worse. "His first day of school he could not even hold his head up to sing *O Canada*," Simone recalls. It was after this incident that Ryan was rushed in for an MRI where a tumour the size of a grapefruit was discovered to be compressing his spinal cord. "He was rushed into surgery." Unfortunately, this surgery was not the end of Ryan's fight with NF2; throughout the years, more tumours have appeared and continuously grown. "His journey with NF2 has been one that has been a struggle at times, but one that has thankfully been closely monitored by the many amazing doctors he has seen."

Simone recalls how difficult the first few years of Ryan's diagnosis were on her family. "Our younger son had to go on the back burner many times while dealing with surgeries or appointments for Ryan. You can imagine the strain dealing with a sick child has on a relationship. I cannot speak for everyone in the family, but for me, it has made me realize that nothing in life is guaranteed, especially your health."

Simone hopes that her son's future will be fulfilling and filled with happiness. "I remember when he was born, counting his little fingers and toes and counting my blessings that we had a healthy baby, and while things did not turn out the way any parent would ever imagine or want, he is here with us and he is a handsome and strong young man. I hope that as he becomes an adult he finds someone wonderful to share his life with and to be by his side throughout this journey and to make him always look up and live life to the fullest."

Simone shares the most profound moment in her son's journey with NF2. "The kids in class had made kites to send up to heaven with their wishes." Most children wished for typical childhood pleasures like puppies and Lego sets. "Then I got to Ryan's kite. On his kite was a little box with a First Aid symbol and it said simply, *my dream is to heal*." She still has the kite to this day.

"I cannot make this go away for Ryan and I know that both his father and I would take it on in a heartbeat to spare him. All we can do is hope that Ryan's journey with NF2 has as few hurdles as possible and that someday a cure is found."

WORDS BY **SARAH GORDEN**

THERE'S AN APP FOR THAT

BY SUZANNE SORENSEN-DESORMEAUX

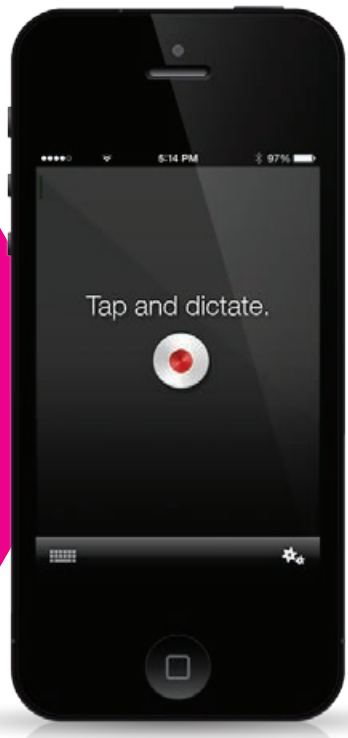
Have your kids been bugging you for an iPad, iPod or iPhone? Here are a few apps I have found helpful for my son who has NF.

These are just a small sampling of the apps available – for a more comprehensive resource, check out the fabulous Common Sense Media "Power Up! Apps", for kids with special needs and learning differences. This is a great website for exploring apps for you and/or your child: *commonsensemedia.org/guide/special-needs/*

DRAGON DICTATION

Dragon Dictation is a super easy-to-use voice recognition application that allows you to easily speak/dictate and instantly see your text and then send it via SMS/text, email messages and even through social networking on Facebook and Twitter accounts.

Available on the iTunes App Store
PRICE: FREE



SIMPLEX SPELLING HD

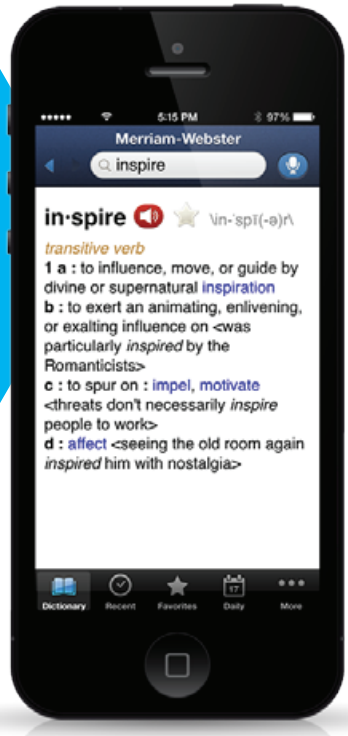
Simplex Spelling HD - Dolch Sight Words With Reverse Phonics uses incredibly rich, educationally sound, powerful tools to teach high frequency words.

Available on the iTunes App Store
PRICE: $4.99

MERRIAM-WEBSTER DICTIONARY

This app is powered by Dragon Dictation. When used with a microphone (e.g. iPhone, iPod 4th generation and up) kids can speak the difficult word they don't know how to spell and the word comes up with a definition. You can use the speaker icon to hear the word to be sure it's the word the child was looking for. This app is also useful for English homework looking for synonyms and antonyms.

Available on the iTunes App Store
PRICE: FREE



4 PICS 1 WORD

This app is a fun puzzle game that asks you to guess a word based on the pictures you see.

Available on the iTunes App Store
PRICE: FREE

FLASHCARDS DELUXE

Flashcards Deluxe is an easy to use, yet powerful flashcard app which you can use to study just about anything you want.

Available on the iTunes App Store
PRICE:
FREE LITE VERSION
$3.99 FULL VERSION

HOW TO STAY AFLOAT DURING THE TOUGH TIMES

BY DESIRÉE SHER

PHOTO: DOMINICK TYLER

TOUGH TIMES DON'T LAST. YOU THINK THEY WILL WHEN YOU'RE IN THEM. BUT THEY DON'T.

When life throws you into a storm you didn't ask for, you are faced with a choice: sink into despair or learn to ride the wave of change.

Finding your way through a storm - whether it is a health or financial challenge, a loss of a job, or the breakdown of a relationship, isn't always easy or a clear and simple path. But if you can successfully find your way through, to a place where you can navigate the turbulent waters and see the opportunities and gifts that lie within, you'll bounce back from the change quicker, higher and happier than before.

If anyone had told me that I would lose my mother, my financial standing, and a very important relationship all in a three-month span my response would have been one of shock and disbelief. I would have severely doubted that I had the strength or the resiliency to survive one of these life events - let alone all three in such a short time span.

Yet I did survive, and you will too.

Not only will you get through these defining moments of impact but you will also grow from them if you can choose to.

Here are a few tools that helped me say yes to change and can help rise back to the surface – and beyond – after these challenges.

STOP RESISTING

This was a hard one for me but when you say yes to change and surrender to it you are choosing to say yes to a peaceful and happy journey down this path. When you change your relationship to the unpleasant experiences, if you can resist them less, you can diminish the added layers of suffering that come from your own reaction, and the recovery time will be shorter.

GIVE YOURSELF PERMISSION TO FEEL YOUR FEELINGS

Don't judge the emotions that surface. While you may have been conditioned to believe crying is a sign of weakness and to keep negative emotions to yourself, when you hold your pain inside you are prolonging the healing journey. I know many people who busy themselves and engage in addictive behaviours to numb themselves to their feelings. It only prolongs the pain. Release the feelings and let the emotions pass.

YOU ARE NOT ALONE

Everyone comes to a place in life where they are faced with a life-shattering event. Reach out to close friends instead of shutting down. A little support from friends, your pastor, a counselor or a support group can help you and encourage you through the dark times.

LEARN OR REPEAT

When you experience a life-altering event there are lessons unique to you in the experience that you are to learn. Pay attention. If you ignore the lessons you'll find yourself in the same situations over and over again. (Trust me on this!) Make space for some quiet time so you can reflect inwards and do the self-inquiry required for serious personal growth.

LET GO

Wishing things were different or focusing on what happened doesn't change the past or your current situation. But when you keep it alive in your mind, replaying it over and over, it's like having a ball and chain that follows you around wherever you go, dragging you down. And this negativity will

affect your future. So let it go. The guilt, the resentment, the hurt, the fear, the anger, the expectations, let it all go and open your heart to accept what is. Be open to what is right in front of you. It may not make sense right now but it will with time.

AN ATTITUDE OF GRATITUDE

Taking time to pause and notice the abundant gifts that are all around can move you out of living in fear to living in love. When you do this on a regular basis you train yourself to look for and see the wonder and beauty that surrounds you. Filling your heart with appreciation for all the experiences, opportunities and gifts in your life will not only transform your life, making you happier and more content, but it will also have a ripple effect on those who live and work with you. Get out a journal or piece of paper and make giving thanks a daily practice.

BREATHE DEEP

As simple as it may sound breathing deep can return you to a place of calm and joy. When you get stressed your breath becomes constricted and shallow increasing the stress and anxiety you feel. When you engage in mindful breathing you release tension. Take time throughout your day for a 'breathing break'. Pull your breath in slowly and deeply into your belly, hold and release. (A mantra that helps me stay focused- good air in, bad air out.) Repeat for a few breaths and throughout your day when you need to reconnect with your inner calm.

GET OUTSIDE

During the tough days head outside and embrace Mother Nature. Stroll along the beach, take a walk in the forest, lie on the grass and watch the clouds. Feel the sun, the wind, the rain and you'll feel instantly calmer.

SILVER LININGS

Choosing to see the bright side of life lessens the physical and emotional pain. Often you can't see the silver linings when you are in the middle of the storm but if you look for the gifts you'll be surprised to find that there isn't just one, but many. If you need help finding it ask a happy person to help you. A fresh perspective can help you to identify the blessings.

HAVE FAITH

Everything will be ok, maybe different than you expected, but it will be ok. Believe this and you will get through the storm.

It takes courage to get through the tough times. But you can do it. Don't let the setbacks prevent you from living your greatest life. There will always be obstacles on the journey but you can overcome them and grow from them and live a better life than you ever thought possible.

YOU ARE DOING BETTER THAN YOU THINK.

HANG IN THERE.

RESOURCES TO HELP YOU THROUGH THE STORM

BOOKS

Adaptability: How to Survive Change You Didn't Ask For, M.J. Ryan

Broken Open: How Difficult Times Can Help Us Grow, Elizabeth Lesser

Bouncing Back: Rewiring Your Brain for Maximum Resiliency and Well-Being, Linda Graham

Secrets of Simplicity: Learn to Live With Less, Mary Carlomango

ONLINE

soundstrue.com

Sounds True is a site offering many free tools for healing, relaxation and celebrations including two free streaming channels with music and interviews with top authors, teachers and spiritual luminaries.

Desirée Sher *is the Executive Director of the BC Neurofibromatosis Foundation. She is also a certified life coach working with individuals who are ready to go from dreaming big to living big. Her book,* **Refuse to Sink: Truths for Tough Times**, *will be available on Amazon this spring.*

Dominick Tyler *is a U.K.-based photographer whose work explores the relationships between people and their environment and often focusses on the experiences of indigenous communities around the world.*

JEREMY DE SILVEIRA

In June, 2008, Jeremy De Silveira was awarded an Educational Scholarship from the BCNF, which he went on to use at the British Columbia Institute of Technology (BCIT) after graduating from high school. Jeremy finished a program in Computer Systems Technology in December, 2012. "I heard about the scholarship during my senior year of high school and I thought I'd try applying for it because I knew I wanted to go to college. I didn't want NF to hold me back," tells Jeremy.

After completing the program at BCIT, Jeremy immediately began his search for employment in the computer industry, but unfortunately has not been able to find a job in that line of work. "It seems every employer is looking for past experience in the field, so I started looking for jobs in other areas," Jeremy shares. He was determined to obtain work and was employed at a grocery store. Unfortunately, due to a lack of understanding and patience regarding NF by his boss, Jeremy was recently laid off. Jeremy continues to work on broadening his computer skills on his own time in order to increase his employment options.

NF has affected Jeremy's mental processing and his ability to retain information which has been a challenge in his schooling. "In high school, I had the challenge of keeping up my good grades by spending so much time on my homework that I didn't have much of a social life." He also had to overcome struggles in college at BCIT. "The workload at BCIT for the full time program got too overwhelming for me in the third semester." Jeremy decided to finish the rest of the courses on a part-time schedule. It took quite a bit longer, but the important thing was that he succeeded in completing the program despite the struggles NF brought his way.

In addition to his learning disabilities, Jeremy was bullied growing up due to speech delays. "I had a hard time making friends and keeping them all throughout school," tells Jeremy. "Since I was bullied so much, I became very shy which is something I'm still trying to overcome." Jeremy shares that he still sometimes has trouble speaking clearly and articulating his thoughts, especially when excited or upset.

Jeremy enjoys playing video games, anime, and everything related to computers. He has overcome many obstacles and has not let NF stop him from achieving his goals. His strong work ethic and determination in life are to be admired and will take him far.

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

NF RESEARCH: WHERE ARE WE NOW?

Thanks to Patrice Pancza, Research Program Director, at the Children's Tumors Foundation in New York for answering our questions.

NF1 has long been known as a disorder without treatments. How close are we to having treatments available for people battling NF1?

While it is difficult to say how truly close we are to finding treatments for individuals battling NF1, there certainly is cause for optimism that we may be within 5 years of an FDA-approved treatment for at least one of the many complications of NF. There are currently over 40 clinical trials underway which are testing various therapies for all types of NF tumours, NF1-related bone complications and learning disabilities. The real breakthroughs will likely come from the combination therapies where studies are showing preliminary indications of greater efficacy towards tumour shrinkage vs. single drug therapies. In addition, the drug discovery process is becoming more efficient than ever before, in that we are now connecting the preclinical studies to the clinical trials so that we can make more informed choices about which compounds to test. For a list of clinical trials that are currently recruiting, go to nfregistry.org

What's the most promising treatment you're aware of that the NF community should get excited about?

There are a number of potential treatments that are showing promise. Among these are:

- *Gleevec to treat plexiform neurofibromas has worked dramatically, but only for a few patients. A follow-up trial is ongoing to understand why.*
- *Avastin has shown efficacy for some patients with NF2.*
- *A combination therapy (hsp90+ rapamycin) being tested and funded by CTF has shown much promise in treating MPNST's.*
- *A new gene was discovered for Schwannomatosis – CTF will invest in the translation of this discovery into clinical benefit.*
- *Many new targets were discovered over the past year – for MPNST and plexiform neurofibromas. Investments in biology will be made to transform these discoveries into clinical benefit.*

CTF has committed $30 million over to a research investment plan. What do these initiatives include?

CTF has awarded more than $30 million in research grants since our inception in 1978, an investment that has led to more than $200 million in government funding in the past 10 years. The Foundation's strategic plan aims to accelerate drug discovery by identifying gaps NF research and addressing those gaps by partnering with academia, industry and government.

Our research funding programs include:

- *Young Investigator Award (YIA) – funds basic, translational and clinical research in all forms of NF. This grant is designed to attract young researchers and clinicians to the under-studied field of NF. Two of our past YIA grantees contributed to the discovery of the genes that cause NF.*
- *Drug Discovery Initiative (DDI) – seed funds early-stage studies that provides a platform to researchers to attract follow-on funding for promising studies from larger sources*
- *NF Preclinical Consortium (NFPC) – a multi-center collaborative that conducts preclinical drug testing and clinical trials. (completed in 2013)*
- *Clinical Research Awards – funds pilot clinical trials and clinical-enabling studies*
- *Schwannomatosis Awards – to accelerate basic research in this area and toward identifying candidate drug targets.*
- *NF Registry – patient-driven registry to identify NF population and gather information for clinical trial recruitment*
- *NF Biobank – accessible tissue bank to store and characterize NF1, NF2 and schwannomatosis samples*
- *NF Clinic Network (NFCN) – the first nationwide network of 44 clinics dedicated to improving clinical care and establishing best practices for treating those with NF.*
- *Consensus meetings are financially supported – NF Conference, workshops, etc.*
- *Through our new strategic plan over the next five years (2013–2018), CTF is committed to investing an additional $30M towards research. In addition to our current programs, we have launched or are negotiating to launch the following new initiatives:*
- *Neurofibromatosis Therapeutic Acceleration Program (NTAP): a three-year partnership between CTF and Johns Hopkins University for continued funding of NF1 preclinical studies.*
- *Synodos for NF2 – a multidisciplinary,collaborative effort to accelerate drug discovery for NF2 treatments.*
- *Contract Awards to CROs to identify and validate NF drug targets.*

How can Canadians gets involved and make difference to NF research?

One of the most important ways for any individual with NF to make a valuable contribution to NF research is to enroll in the NF Registry. The Registry was launched in 2012 by the Children's Tumor Foundation to empower the patient: the Registry will serve to let people know about new clinical trials, or new potential treatments for NF; provide patients with facts and figures about the NF community; learn how NF changes over a person's lifetime; help researchers understand what makes one person's symptoms different from another's; and better inform qualified NF researchers from all over the world about issues people with NF care about the most.

You'll be an important member of the team, along with top researchers and clinicians and helping drive us toward our shared goal of finding safe and effective treatment options for all of the complications of NF.

Enroll today!
nfregistry.patientcrossroads.org

AT LEAST TWO DIFFERENT GENES PREDISPOSE TO SCHWANNOMATOSIS

BY PATRICIA BIRCH

A second gene for schwannomatosis was reported at the October 2013 American Society of Human Genetics annual meeting. The research was by Dr. Ludwine Messiaen (University of Alabama) with contributions of clinical samples by many colleagues across the USA and Canada, including Dr. Linlea Armstrong from UBC.

Schwannomatosis is a condition with symptoms in common with NF2 but without bilateral vestibular schwannomas, the ear nerve tumours that are characteristic of NF2. Until now, only half of people with clinical schwannomatosis could be diagnosed by a genetic test that looks for a mutation in a gene called SMARCB1. No mutation is found in this gene in the other half of people with clinical symptoms of schwannomatosis. Dr. Messiaen therefore thought that there must be another gene responsible for the condition in some of the remaining 50% of people.

Dr. Messiaen therefore tested 20 people with clinical schwannomatosis who had no mutation in SMARCB1. She determined that 16 of these 20 people had a mutation is a different gene, called LZTR1. This indicates that there is a second major gene predisposing to the condition we call schwannomatosis. LZTR1 is another tumour suppressor gene and is involved in cell cycle regulation. It is possible there are other genes involved that will be discovered in the future

Why is this discovery important? Sometimes, early on in a condition, it s not possible to be certain whether a person has NF2 or schwannomatosis, particularly in people without a family history. Without a firm diagnosis, genetic counselling cannot be provided to help predict the course of the disease, including whether or not someone is at risk for vestibular schwannomas that can, for example, lead to deafness and other complications.

This type of research is also the way in which we increase our understanding of all of the neurofibromatoses. The difference between NF1 and Legius Syndrome is another example where we have teased apart different conditions with overlapping symptoms. If we are to provide treatments, it is crucial to understand what we are treating: Something that works on one condition may not work on a different disorder.

As yet there is no separate name for the sub-type of schwannomatosis that is caused by a mutation in LZTR1.

Patricia Birch is the Lab Manager and researcher at Friedman Lab. Her career includes obstetrical and outpost nursing; genetic counselling; and projects in HIV, SARS, and avian influenza. For the last 20 years, however, most of her efforts relate to neurofibromatosis.

KEEPING THE DREAM ALIVE

Editors Note: To continue the momentum of our clinic dream we've invited a member of the NF community to share their experience of the Johns Hopkins Comprehensive Neurofibromatosis Center in Baltimore.

My name is Bronwyn Slobogean. I recently moved back to Vancouver after two and a half years in Baltimore, Maryland and Toronto. When I was living in Baltimore, I was fortunate to be a part of the team at the Johns Hopkins Comprehensive Neurofibromatosis Center as a neurosurgery physician assistant. Based on this experience, I was eager to become involved with the NF community in BC when I returned to Vancouver. I've been asked to share a bit about my experiences working in the clinic.

The Johns Hopkins Comprehensive Neurofibromatosis Center is a Children's Tumor Foundation NF Network Affiliate Clinic that provides care for children and adults with NF1, NF2, and schwannomatosis. The core team of the Johns Hopkins Comprehensive Neurofibormatosis Center consists of an adult neurologist, an adult neurology nurse practitioner, a pediatric neurologist, a neurosurgeon, and a genetic counselor. One morning per month, the neurologists, neurosurgeon, and genetic counselor see patients in the same clinic location. During a typical visit, the patient will see his or her neurologist to discuss concerns, screen for new symptoms, and discuss medical and surgical treatment options. Patients then see other members of the team, as necessary. For example, a particular tumour may be causing a patient discomfort, and the patient may wish to meet with the neurosurgeon to discuss surgical options. Or a patient may wish to meet with the genetic counselor to discuss genetic testing for NF or issues surrounding reproduction. Beyond the core team, the providers have networked with health care providers in other specialties at the hospital such as ophthalmology, radiology, oncology, and otolaryngology (ear, nose, and throat surgery) to provide care for the NF clinic patients.

In addition to clinical duties, the providers at the Johns Hopkins Comprehensive Neurofibromatosis Center are dedicated to participating in clinical research to advance knowledge of NF1, NF2, and schwannomatosis. They also hold patient and family information sessions and other networking opportunities for clinic patients.

Comprehensive multidisciplinary care is being used in various areas of medicine, ranging from NF and cystic fibrosis to diabetes and cancer. The purpose of these comprehensive multidisciplinary care is to improve patient care by enhancing communication and collaboration between primary care and specialty care. Furthermore, it allows providers to become an expert in a particular area. Whereas other providers may only see a few patients with NF over the course of their career, providers in dedicated NF clinics routinely see many patients with NF. This exposure allows providers to become more knowledgeable about issues facing patients with NF. Another benefit of a dedicated NF clinic is that it provides an opportunity for patients to network with each other and exchange information, if they wish. Patients who attended our information sessions and networking sessions frequently commented that they valued these opportunities to meet other people with NF.

WHAT INSPIRES YOU?

KRISTI HOPKINS

MOM, AUTHOR AND NF ADVOCATE

thrivingwithneurofibromatosis.blogspot.ca

WHAT INSPIRES YOU?

I am inspired by knowing that I am making a difference by keeping my attitude positive and setting an example to others. A THRIVING LIFE is possible, if you just change the way you look at your "burdens". 'Thriving with Neurofibromatosis' doesn't mean I am happy all the time, however it has set a precedent that I work towards. Even on my "bad days", I try to find hope and reason, and maybe even a lesson, in what is happening.

Sharing these challenges with families who are going through the same things, is hopefully showing they are not alone. That there IS hope.

IF YOU HAD A MOTTO WHAT WOULD IT BE?

"THRIVE ON" of course. It has become a staple in my life. A bar to reach every single day. These two words, for me, have so much meaning behind them. No matter how tough life gets....No matter the news we get from MRI's or tests... We know our Spirit is stronger than any diagnosis.

WHAT IS YOUR BIGGEST HOPE?

My biggest hope, is that I am living up to God's plan. I feel great knowing that even after I die, I have left my mark on this world, in a positive and loving way. I hope that when people Google 'Neurofibromatosis', they find my positive part of the world, and go away feeling better about a life with NF... and find a friend who understands and accepts them.

LUCKIEST MOMENT OF YOUR LIFE?

I would have to say the "A-HA" moment, when I opened my eyes and changed my attitude. The day I created "Thriving with Neurofibromatosis" and began a journey that would go on to touch so many lives. I feel very blessed when I get an e-mail from a family who happened to stumble upon my blog, and feel better, as they read my stories.

There is nothing better than hearing from these people, who tell me they have found hope after reading my book, or blog posts. I have made many friends through this process, which is just wonderful!

WHAT BOOK ARE YOU READING?

Not currently READING a book... However, I am WRITING another book! I hope to have it released in 2014!

REGGIE BIBBS

NF AWARENESS ADVOCATE, SPEAKER

reggiebibbs.com

WHAT INSPIRES YOU?

I am inspired by my friends that have NF. The way they seem to forget their own problems, and how I see how they are supporting the thing I do. I'm so encouraged by this. It makes me want to do more. I feel like I'm not doing enough.

IF YOU HAD A MOTTO WHAT WOULD IT BE?

Two things. JUST ASK! and Making Things Happen.

WHAT IS YOUR BIGGEST HOPE?

A cure for NF.

LUCKIEST MOMENT OF YOUR LIFE?

This is true. My luckies moment is having the courage to feel comfortable about traveling all over the world and speak to anyone who will listen about how you can happy life living with the unwanted disorder of neurofibromatosis.

WHAT BOOK ARE YOU READING?

I just finished reading *Crime Beat* by Michael Connelly.

JOIN US FOR THE
17TH ANNUAL
JEANS FOR GENES DINNER
AND AUCTION

SATURDAY, MAY 3RD, 2014
CFB Esquimalt, Wardroom, Victoria
Early bird tickets $80 to April 1st.
To order visit bcnf.bc.ca

GO OUT SIDE AND PLAY

BY DESIRÉE SHER

Turn off the computer.

Close your Facebook, Pinterest, Twitter , Instagram and move away from your phone. It's time to take a break.

We live in a highly digital world. While many of us are required us to use the internet daily for work, we now readily turn to emails, social media and text for our communications, sometimes more so than face-to-face contact. I'm a good example of someone with a past addiction to the internet. It was easy to justify as my work is online based but I wasn't aware of how bad of a junkie I was until I overheard my daughter tell a friend that my hobby was my phone.

Research shows that heavy technology use is linked to sleep disorders, stress and depression. A report by Nokia unveiled that we typically glance at our smartphone 150 times a day, even taking our phone with us to the toilet. Do you look at your partner or child that often in a day? I know I didn't.

On a recent holiday to the U.S. I left my phone and laptop behind and when I returned I was surprised at how truly rested and recharged I felt. The peace and stillness that came from being disconnected for just a week made me vow to continue my digital breaks by disconnecting every weekend. It took time for clients and friends to accept that I truly was not going to return an email or tweet an update, but they did, and my world did not cave in.

The hardest part of detoxing from technology was deciding to do it and sticking to the plan. Our excessive connectivity has created a false urgency where we feel the need to know what's happening every minute of every day, lest we miss something important. In my detox I also discovered that my constant online connectivity was not as useful as I had originally thought. It was actually really distracting. Once I started to curb my online time I found myself more productive, my thoughts and creativity flowed and I got more of the important work done.

Our constant access to technology, even when we are on the go, makes it an easy distraction. It's a quick fix to numb ourselves to whatever pain or anxiety is rising up in our lives, becoming a compulsive act not a conscious choice. But there's so much we can gain from taking a break and seeing the world with our full attention.

For our health we need to disengage from the devices designed to keep us connected. If unplugging for a whole weekend isn't possible, try taking a 30 minute digital break even once a day. Go for coffee or a walk and leave your phone behind. You'll be giving yourself the gift of improved health and your loved ones the gift of your full attention.

Set a date to detox and begin.

INTERESTING FACT

The term "nomophobia", the fear of being without mobile phone contact, was coined in 2008 after a UK study revealed that more than half of the population polled feared losing phone signal, running out of battery or losing sight of their phone.

PLACES THAT INSPIRE

"Being on the water in my kayak or on my paddleboard restores my sense of inner peace and calm. Whether I am on a river, lake or ocean doesn't matter. I am always at my happiest when I am one with the water."

Desiree Sher, Executive Director, BCNF

We'd love to learn about your favourite place. Send us your photos of your favourite inspirational place and we'll publish it in our next newsletter.

Email info@bcnf.bc.ca with your photo (JPEG format, best quality setting, large size). Due to space and resolution requirements, not all images can be printed.

FEELING INSPIRED TO MAKE A DIFFERENCE? RUN OR WALK FOR NF

SCOTIABANK VANCOUVER HALF MARATHON JUNE 22, 2014

The BCNF is putting together a team to run or walk our third Scotiabank Half Marathon. This event is a great opportunity to meet others, get fit, and raise funds for the NF community. Last year's events raised almost $16,000 for the BCNF and this year we are aiming higher!

Don't let the half marathon title scare you. You can also participate in a 5km event. It's all about having FUN and making a difference for those living with NF!

HOW DOES IT WORK?

Sign up to run or walk the event then set a fundraising goal. It's that simple.

By raising a minimum of $200 we'll pay your registration to the event. That means no cost to you to participate in this awesome event. It's FREE.

Not keen to run or Walk? We still want you: volunteers are needed to cheer on our participants along the route and host the information booth on event day. So either way come join the fun!

We'll celebrate our fundraising and training with a pre-race pasta dinner. It's a fun night to meet other participants and celebrate your fundraising success.

IT'S EASY TO JOIN!

Contact the BCNF at info@bcnf.bc.ca and let us know you want to join the team. We will send you a promotional code that will allow you to register FOR FREE.

WE NEED EVERYONE'S SUPPORT IF WE ARE GOING TO MAKE A DIFFERENCE FOR THOSE AFFECTED WITH NF. COME RUN, WALK AND CHEER TEAM BCNF ON JUNE 22!