

!NSP!RE

the magazine of the BCNF

SENSORY
PROCESSING

A HERO
AMONGST US
LET IT GO

BEST.
CONCUSSION.
EVER.



EDITOR'S NOTE

TO INSPIRE YOU TO BE THE BEST YOU CAN BE.

Expanding our reach into the community has always been a priority for the BCNF. We want the world to know and care about the children and adults battling neurofibromatosis. We want people to hear the stories so they are motivated to take action – to donate, volunteer and get involved.

This month I am excited by the contributions of two new feature writers who have no connection to NF but have shared their wisdom in our pages.

Those of you who saw Mary speak at our symposium earlier this year know she believes that loving yourself, no matter where you are on your journey right now, is the key to making miracles happen. Read her contributions starting on page 6 and check out her new book, *This is About You: Amazing, Weird, Beautiful You* on Amazon.ca

Check out how Anne Sophie Dumetz turned a traumatic concussion into a positive happening in her life on page 30.

The writers who worked on this issue come from across Canada and the US. Suzanne Ledvoy (from Saskatchewan) shares vital information on sensory processing – a topic so many in our community struggle with on a daily basis. Knowing that there are others who understand what you are going through can be both inspiring and helpful. Both Courtney Willoughby

from Alberta and Jaxon's family from the Fraser Valley, open their hearts with brave candour to let others know they are not alone on the NF journey.

We are also very thankful for Patricia Birch's continued support of the BCNF. Read her article on optic gliomas on page 34.

We are rarely prepared for the challenges that happen in our life. Each one of us will experience adversity. Mistakes. Failures. Obstacles. Disappointments. That we can't change. All we can control is how we respond to the event. When we see obstacles in front of us we prolong our suffering. When we opportunity in the adversity we can grow and transform and better our lives. Only you can make that choice.

It is my hope that this edition of INSPIRE magazine will leave you feeling a little happier and more empowered than when you started your day.

You have the power to create the life you deserve and desire, whether you live with NF or not. Choose to be happy. I'll let you in on a little secret: it's a lot more fun!

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Together we can make a difference!

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BCNF
EMPOWERING INDIVIDUALS WITH NF

**WE MUST
BE WILLING
TO LET GO
OF THE LIFE
WE HAVE
PLANNED,
SO AS TO
HAVE THE
LIFE THAT
IS WAITING
FOR US.**

E.M. FORSTER

SENSORY PROCESSING

by Suzanne Lendvoy

I am the mother of a teenager with NF1, and I also happen to be an occupational therapist. When communicating with other parents of children with NF, I quickly came to realize that many (but not all) of our children have varying levels of difficulty with processing sensory information. The following is an overview of sensory processing.

*The term ‘**Sensory Processing**’ (sometimes called “sensory integration”) refers to our ability to take in information through our senses, to organize and interpret that information, and make a meaningful response. Whether playing on the playground, eating your soup, or reading a book, our successful completion of the activity requires processing sensation or “sensory integration.”*

Sensory processing can affect our ability to pay attention, to move our body, and to effectively use our executive function skills. Sensory processing affects how we make sense of the environment, helps us to feel safe, and can affect our social skills and our behavior.

Most of us learned about the 5 senses in school – hearing, taste, seeing, touch and smell. There are a few other senses that occupational therapists refer to when working with those with sensory processing difficulties. This includes the vestibular sense, proprioceptive sense, and interoception. Vestibular sensation is responsible for the way we process movement and balance. It is processed primarily in our inner ear. Proprioception is the sense of joint, tendon and muscle movement. It works together with our other senses to allow us to maintain our posture and create movement. Interoception gives us information regarding the internal state of our body. It is responsible for knowing whether we are hungry, thirsty, tired, hot/cold, exhausted, in pain, ill, need to go to the bathroom, etc. and also helps us to interpret our emotional state.

There are a number of terms that are used to describe those with atypical sensory processing, including Sensory Processing Disorder and Sensory Integration Dysfunction. A person with sensory processing difficulties finds it difficult to process and act upon information received through the senses, which creates challenges in performing everyday tasks.





THERE IS HOPE!

Children with sensory processing difficulties often have problems with motor skills and other abilities needed for school success and childhood accomplishments. Motor clumsiness, behavioral problems, learning challenges, anxiety, depression, social difficulties, learning challenges, etc. may all be a result if sensory processing difficulties are present.

There are some people who tend to be ‘under-responsive’/hyposensitive or ‘over-responsive’/hypersensitive to sensation. Sensory processing difficulties can affect people in only one sense—for example, just touch or just movement—or in multiple senses. They can also be hypersensitive to one type of sensation (e.g. sound), and hyposensitive (e.g. touch) to another sensation. One person with difficulties may over-respond to sensation and find clothing, physical contact, light, sound, food, or other sensory input to be unbearable. Another might under-respond and show little or no reaction to stimulation, even pain or extreme hot and cold. In people whose sensory processing of messages from the muscles and joints is impaired, posture and motor skills can be affected. Other people seem to seek all sorts of sensation by moving most of the time, touching everything they can, and seem to crave stimulation.

Most children with sensory processing difficulties can learn to adapt to how they process information. These children can usually benefit from a treatment program of occupational therapy (OT) with a sensory integration (SI) approach. Over time, the appropriate responses generalize to the environment beyond the OT clinic including home, school, and the larger community. The OT can also provide strategies for home and school that can help with sensory processing throughout the day (and into the night if sleeping is an issue.)

In addition, there is much research that is showing that regular exercise and meditation can assist with our ability to pay attention, to regulate our mood, and to process sensory information more easily. As well, some people respond to changes in diet, taking supplements and/or prescription medications.



Children with sensory processing difficulties can also benefit from environmental adaptations at home and at school that help them deal with various sensory differences more easily. For example, the child who needs to move lots can sit on an air-filled cushion or a rocking chair while doing homework or in the classroom. The teacher can also adapt teaching materials and teaching methods that may assist with these challenges. And of course, these strategies can also work for adults with sensory processing challenges – it just might take longer for the brain to change and adapt as needed.

And this is only the tip of the iceberg in terms of what we know about sensory processing! If you want to read more, here are a few books and websites that might be of interest:

- *Miller, Lucy (2006). Sensational Kids: Hope and Help for Children with Sensory Processing Disorder: G.P. Putnam Sons.*
- *Kranowitz-Stock, Carol (2005). The Out-of-Sync Child Has Fun. New York, NY: Penguin Group Inc.*
- *Yack, E, Sutton, S & Aquilla, P. (2002) Building Bridges through Sensory Integration. Arlington, TX: Future Horizons.*
- *Henry, Diana (2001) Tool Chest: For Teachers, Parents & Students. USA: Henry Occupational Therapy Services, Inc.*
- *Dunn, Winnie (2007) Living Sensationally: Understanding Your Senses*
- *Atter, Elizabeth - Can't Play Won't Play: Simply Sizzling Ideas to Get the Ball Rolling for Children With Dyspraxia Bobula, Jill - Eager Eddy – child's story about a boy who has ADHD*
- *Veenendall, Jennifer - Why Does Izzy Cover Her Ears? – child's story about a girl who has difficulties with sensory processing*
- *Mucklow, Nancy - The Sensory Team Handbook – short book written at pre-teen/teen level. Good short read that covers sensory issues and suggested activities.*
- *Winner, Michelle Garcia – www.socialthinking.com - Some great resources for anyone with social skills difficulties*

- **Alert Program: How Does your Engine Run?**
www.alertprogram.com - Classroom self-regulation program
- **Zones of Regulation** – by Leah Kuypers
www.zonesofregulation.com www.alertprogram.com - Classroom self-regulation program
- **Zone'in Programs** – by Cris Rowan
www.zoneinproducts.com
- **Tool Chest** by Henry OT Handbooks
www.henryot.com - explains sensory processing, and has practical ideas for the classroom and home

Suzanne Lendvoy is an occupational therapist who lives and works in Regina, SK. She works with children and adults in a variety of settings, including those with sensory processing difficulties. If you would like to get in touch with her you can reach her by email at srlendvoy@sasktel.net or on Facebook.

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A photograph of a yellow wall with large, abstract black shapes. The word "Self Love" is written in white. "Self" is in a cursive font, "L" is a large block letter, and "O" is a large circle.

Self Love

Self love is a relatively new movement, even though we've always needed it as a society and individuals. I personally think everything starts with self love, and it's an incredibly important foundation for a life full of happiness, fun, and success. What is it, though? *What is self love?* Self love is a concept, a feeling, and an action all at the same time.

Self love is a concept, where you approach your life with the notion that you are an important and unique individual. You have innate value, independent of your physical appearance and deserve to have a beautiful life. You also accept who you are as-is, even if you have areas of your life you'd like to improve.

WE

Words & Photos: Mary England



Self love is a feeling, where you experience the sensation of being enough. You feel beautiful, worthy, and empowered on a regular basis. You recognize these feelings aren't narcissistic because it's reasonable to want the best for yourself. It's being appreciative of who you are, your talents, and your lifestyle.

Self love is an action, where you take steps to put yourself first. You create self care routines and implement them with priority and urgency. You say no to things that don't serve you in the highest regard. You follow your dreams because you believe in yourself.

1. PRACTICE GRATITUDE ON A DAILY BASIS

Consider keeping some sort of Happy Journal, where you document the good things in your life. This can be in any format from handwritten to digital. Either way, make sure you're at least making a mental note of the good things you're lucky enough to have and experience in this life.

2. CREATE POSITIVE AFFIRMATIONS

What is the best compliment someone could ever give you? Write that down on a piece of paper and tape it to your bathroom mirror. Every time you see it, say it out loud. Writing and speaking positive affirmations have a lot of power for building up our self worth.

3. TELL YOUR INNER CRITIC TO SHUT UP

We all have a voice in our head that's been telling us we're awkward, ugly, and stupid. It's probably been there since around middle school. Tell it to shut up. Treat that voice the way you would someone who is screaming unprovoked obscenities at your best friend in the street. You're not welcome here! (Tip: *Sometimes it helps to name your inner critic to make things more personable.*)

4. ONLY KEEP POSITIVE PEOPLE IN YOUR LIFE

Negative, draining, complaining people will only hold you back. Spending your precious time with people who don't make you happy or inspire you in some way is an incredible waste. On the other side of the coin, if you surround yourself with positive and uplifting people, you'll be more motivated and inspired to go after your own dreams, be productive, and have the kind of fun you want.

(I'd like to clarify that everyone goes through bad days, weeks, and months and someone's negativity could be based on a need for help or a symptom of mental illness. You're an adult and can gauge the situation on an as-needed basis. Always offer support if you can – we would all feel terrible if someone cut us out of their life because we had a bad week!, but remember at some point you have to prioritize your own happiness.)

5. BELIEVE IN YOURSELF ENOUGH TO FOLLOW YOUR DREAMS

Speaking of dreams, you need to let yourself have them. Whatever you daydream about isn't just nonsensical filler for your mind, it's something you wish you had! Allow yourself to entertain the idea you will succeed and create a plan to implement. It's never too late, and if you believe you can do it there should be no reason to hold yourself back.

6. SAY NO WHEN YOU NEED TO

If someone wants you to hang out with them, go somewhere, do them a favor, or work for them and you want to say no, say no! If your gut says no and you cringe at the idea of accepting their offer, that means you shouldn't say yes. It's okay to put your needs first and create an environment and workload that pleases you and doesn't stretch you too thin.

15 Ways To Start Loving Yourself Today

7. DON'T COMPARE YOURSELF TO ANYONE ELSE

In our internet-driven world, it's almost impossible to not have impulsive feelings of judgment and jealousy. There is no reason to ever compare yourself to anyone else, even if your opinion is you're "better" than they are. Everyone is always on a different journey and at different stages. You will get where you need to be if you persevere and believe in yourself, and so will they. Just because someone has more money, Instagram followers, or children than you does not make them better and vice versa.

8. PUT YOUR MENTAL HEALTH FIRST

Depression, anxiety, and mental illness in general are some of the biggest obstacles for practicing self love. Unfortunately, there is a general lack of empathy in society for mental illness, and we make assumptions and accusations without knowledge to back them up. Mental illness of any kind sucks, and I won't ever sugarcoat that. That's why it's important to prioritize your mental health. If you need days to be alone and immerse yourself in your symptoms and emotions, that's completely acceptable. Loving yourself is about believing you're worth the effort of getting help with therapy, medication, and the like. You deserve to be happy.

9. CELEBRATE YOUR UNIQUE ASPECTS AND INNER WEIRDNESS

Loving yourself is accepting who you are, including the super strange parts, too! Actually, your weirdness is what makes you interesting and awesome. Regular is boring, let your freak flag fly!

10. DON'T BEAT YOURSELF UP OVER MISTAKES

We all fuck up. Often over and over again on the same issue. It's okay. Try your best to learn and grow, it'll be okay. You're supposed to make mistakes and it's okay to regret your past decisions because it means you know better for next time! What's not okay is to dwell on the mistakes you've made because it's over and bullying yourself over your imperfections takes away valuable time and energy from your new endeavors.

11. REWARD YOURSELF FOR ANY AND ALL ACCOMPLISHMENTS

Crossing stuff off your to do list or achieving a goal is a big deal. Everything you do right is awesome, and it deserves to be celebrated! Try out different reward systems for yourself, whether it's a physical chart or treating yourself to a fun activity after you do something more difficult. Make it enjoyable for you to succeed and you'll go further faster!

Speaking of action, there are lots of ways you can start (or continue) practicing self love this very moment! Here is a list of fifteen ways you can make a difference in the way you treat yourself and prioritize your own happiness.

12. DON'T CARE WHAT PEOPLE THINK

We don't get anywhere alone, but caring what everyone thinks about your dreams, lifestyle, and decisions is counterproductive to your personal development. If you backpedal after every nay-sayer shouts something negative, you'll constantly be apologizing and second guessing yourself. If you're doing something bold or unusual you will get attention, and with attention comes criticism. There are seven billion people out there ready to judge your every move. Act like they don't impact your outcome and live life how you want.

13. GIVE YOURSELF THE SAME ADVICE YOU'D GIVE TO YOUR BEST FRIEND

We're always kinder and softer to our friends than we are to ourselves. If your friend had a shitty week where she made a ton of mistakes and a series of bad decisions, you wouldn't berate her over it. You would console her and tell her it's going to be okay. You know why? Because it is going to be okay. The same advice you'd give your best friend is the stuff you should be telling yourself in the mirror. Give yourself some slack.

14. CREATE THINGS THAT MAKE YOU HAPPY

Expressing yourself is a vital element to self love. The way you create is drastically different from someone else, it might be outfits, meals, or chapters of a children's book. Creating gives us purpose, having purpose makes us feel fulfilled, and fulfillment leads to happiness. Schedule time to make stuff, whatever that is to you. We are all artists.

15. SPEND TIME ALONE

Date yourself. Go out on your own and find out how you like spending time. It's liberating to be alone and helps you search your soul for what you really adore in this life. Do what you want without the need of company and you will find joy. Doing your own thing with pure contentment will attract the people you need in your life.



BODY POSITIVE

Words & Photos: Mary England

We've come a little ways in the realm of body positivity and I'm proud of us as a society, but there's an enormous road ahead of us. Just because Tess Holliday landed a major contract and is the first size-22 supermodel doesn't mean we can put a neat little check mark in the box next to "Body Positivity" on our to do list.

What would that check mark even represent, though? I'd like to think what we're going for is making everyone feel comfortable, beautiful, and unjudged in their own bodies and there was no stigma against any body type.

The good thing about Tess Holliday shining in the spotlight is she's using her platform to draw attention to companies not having plus size clothing, the stigmas and judgments in the fashion industry and society in general, and start movements like #EffYourBeautyStandards.

Whether or not you think hashtags are stupid and millennial, I hope you'll agree that the concept behind the movement is valid and necessary. The idea is we are

challenging conventional aspects of beauty and re-claiming the feeling of sexy for ourselves, whatever that means for us.

The thing is, our idea of beauty is heavily influenced by society and the media whether we want to admit it or not. It's almost impossible to separate our own vision of aesthetic beauty from what's been shoved down our throats since Day One. I often tell people to spend a lot of time alone, naked, with the body part(s) they have an aversion towards. If you were to spend three days alone at home naked with that body part, would it bother you or does it only bother you when other people see it? What about it bothers you? What about it doesn't "look good"?

It's easy to say "my legs are too knobby", "my nose is too bumpy", or "my waist isn't small enough" but think about why that is. What makes your legs too knobby or your waist too large? Is it a comparison to something else? It must be! If we weren't comparing these body parts to

something else, we wouldn't be able to say they were "too" anything. They would just be.

Most of the time we develop our ideas of beauty from what we see on magazine covers and in movies or TV shows. Do your best to erase what you've learned about beauty and accept your body, and all other bodies, as valid. Whether someone is short, fat, flexible, covered in birthmarks, or bald they deserve to be happy and you have no right to take that happiness away from them. Make everyone feel comfortable in their bodies enough that they want to celebrate them.

How do we erase what we've learned? We start with accepting ourselves, believing we're beautiful, and celebrating our bodies as they currently are. That doesn't mean if you want to exercise, lift weights, improve your flexibility, change your hair color, or wax your legs you can't-- it just means if you gain five pounds or get too busy to go to your bi-monthly waxing appointment you don't lose confidence or esteem in yourself. You love yourself no matter what.

HERE ARE 5 WAYS TO START CHALLENGING BEAUTY STANDARDS!

1. EXUDE INNER CONFIDENCE

First and foremost, you deserve to be confident about who you are and how you look. You have the right to be confident. We have to stop telling overweight people they're brave for posing naked or wearing a bikini to a beach, we have to stop feeling like a woman with a beard is courageous for taking a selfie on Instagram, and we have to stop saying someone is gutsy just because they didn't choose to get fake breasts after their radical mastectomy.

Sure, if you're dealing with self esteem issues, your first time showing up to a pool in a two-piece might be nerve wracking, and you might feel brave for doing it. That's okay! Celebrate your success! I'm just saying there's no need for us to be "wowed" by Lena Dunham's lack of fucks she gives about being naked on her TV show or asking Mindy Kahling how she can be so self-assured. They're badasses, and so are you.

2. WEAR CLOTHING THAT'S NOT "FOR YOUR SHAPE"

Magazines to this day do monthly features on how to "dress for your shape". Here's an in-depth article of how to hide your flawed areas! Are you someone with chunky thighs or a big stomach? These articles of clothing and accessories will accentuate your "good areas" and divert the eye your "problem areas".

If you want to wear a crop top and you don't have a "flat stomach", then wear a fucking crop top. If every magazine insists you have a "pear shape" and should only wear A, B, and C shaped dresses to accentuate the good and hide the bad but you don't like those kinds of dresses, you don't have to buy them. In fact, wearing things that accentuate your "flaws" is a great way to challenge norms and the individuals who are telling you what "not to wear".

That said, if you do like those kinds of dresses then fill your closet with them! Life is about wearing and doing things that make you happy.

3. CELEBRATE "FLAWS"

By "flaws", I mean anything we're told is something we should "take care of" or "remove". Anything they make a cream for at your local drug store because you shouldn't "have that on your body" is something we should start celebrating. Stretch marks, liver spots, wrinkles, birthmarks, dry skin, acne, dandruff, unibrows, and cellulite are all things that might be a natural part of your body that you're told to hide until you can get rid of it.

You are always welcome to buy "anti-aging" creams to delay your wrinkles and do leg lifts to decrease the amount of cellulite in your thighs if those are things that bother you, but don't think for a second that you have to. Go out in the world without covering that part of your body up and see what kind of reaction you get – you might be surprised.

Draw attention to that part of your body, take back the power you let it have over you. Think about what that part of your body means. Did you get those stretch marks from giving birth to another human? Did you get those wrinkles from living a long life you're proud of? These battle scars are a part of your journey so celebrate them like you would a four-year-old's birthday.

4. TAKE SELFIES

Selfies might seem "conceited" and I'm not suggesting you flood your social media feeds with them and only them, but the idea that selfies are conceited is the same thing as thinking self love is vain. Share where you are right now and say and believe, "I'm amazing!" You're important enough to be photographed even though you're not a celebrity on a front cover photoshoot in Hollywood.

Taking a photo of yourself demonstrates that you feel good about yourself and want to share that feeling with the world. Taking a selfie is about saying I'm here now, this is what I look like, and I think I look damn good.

5. TAKE IT OFFLINE

Take the message of self love you preach online to the streets! Tell people they look beautiful in person and have face-to-face conversations about the importance of challenging conventional beauty and stereotypes. Join forces with people in person to say...

The internet is an amazing tool for delivering the message of self love, taking photos that push the envelope, and connecting with a support group who can help you on your journey of empowerment, but that's still only a small fraction of life. I'm not insinuating that the internet isn't "real life" because you know as well as I do there aren't many people who live without it these days, but in-person interactions are still a part of living and a very valuable part at that.

Please just remember you are a beautiful, unique person. Your "flaws" don't devalue you, and your physical appearance will never define you. You are radiant, powerful, exuberant, kind, full of life and surprises. You are more than "pretty" and were meant to be more.



*There is not
good or
but thinking*

~ Shakespeare



to

thing either
or bad

y makes it so.

are (Hamlet)







A Hero amongst us

Words: Sarah Gorden
Photos: Cara Grimshaw

Jaxon Gauthier is a six year old boy who lives with his family in British Columbia.

He lives with neurofibromatosis type one (NF1) but despite his challenges due to NF1, Jaxon enjoys school and playing with his friends like every other six year old.

“He loves playing Lego, colouring, and playing pretend games using his imagination to the fullest,” shares Jaxon’s father, Mike. Jaxon was diagnosed with NF1 when he was just two and a half years old. “We noticed a difference in his walking ability, later to find out he had a leg discrepancy,”

IT HAS BEEN HARD FOR OUR FAMILY TO COME TO GRIPS WITH JAXON'S DIAGNOSIS

Jaxon receives all his care at BC Children's Hospital. At the time of his diagnosis, Jaxon also had many café-au-lait spots. At the age of five, a large plexiform tumor in Jaxon's back was discovered. The tumour runs down through Jaxon's pelvic bone, through the front of his legs, and the back of his thigh, his dad explains. The tumour was causing Jaxon to have severe pain in his leg. The doctors started Jaxon on chemotherapy for the plexiform tumour.

Jaxon also has to take several other medications to prevent the negative side effects of the chemotherapy. He will be having an MRI in February to rule out cancer; which will be determined by the growth rate of the tumour since it was discovered. "This is going to be a very scary time for us, but we are hoping for the best and always looking forward to the future, new treatments, and the ability to hopefully end NF," Mike shares. "The doctors also noticed a small plexiform tumour on Jaxon's hypothalamus (a portion of the brain), and a small abnormality in Jaxon's neck," shares Mike. Jaxon also has minor scoliosis (curvature of the spine), which is starting to become more pronounced as he grows.

Jaxon inherited NF1 from his mother, and several other family members also live with the disorder. "We just want Jaxon to be like the other kids and be able to ride a bike, play soccer, or even just go out for a nice walk without pain," Mike explains. Jaxon has two brothers, one who also has café-au-lait marks and has also been diagnosed with NF1. "At this time, no other problems have been discovered for Jaxon's younger brother Emerson," says Mike.



When asked what advice Mike would offer to parents of children newly diagnosed with NF1, Mike offer this: "Fight for your child. You are the only one who can get things done, believing what you know. You know your child better than anyone. Do not take no for an answer."

Mike explains that his family has fought very hard to fight for his son so that he can have the best medical care and quality of life possible.

"The BCNF has helped us by providing information which is available online for us and other families with the same disorder." Mike shares that he and his family frequently use the BCNF website to keep up-to-date on information and research regarding NF.

Mike shares that although it breaks his heart to witness what people with NF deal with, he will help in any way he can. "I will do whatever I can to make the pain, discomfort, and hurt stop for my family and others living with NF."



UPDATE BY JAXON'S DAD, MIKE GAUTHIER

In October we were given a chance to apply for Jaxon's Make A Wish Foundation as he was undergoing chemo and was under extreme observation for the NF tumours that run up from his back and leg and the one in his head. Jaxon was on heavy medication and it was great to have something to look forward to.

At this time we contacted the Make A Wish Foundation. Our experience here was incredible! From our first meetings they made Jaxon feel extra special bringing him presents and then making his wish to go to Disney World come true. They gave us enough memories to last a lifetime!



A photograph of a weathered blue wooden door set within a brick frame on a stone wall. The door is closed and has a small keyhole on the left side. The wall is made of light-colored stone and has some small plants growing on it. The text is overlaid on the door in a white, handwritten-style font.

WHEN ONE DOOR
CLOSES, ANOTHER
OPENS...

BUT WE OFTEN LOOK
SO LONG AND SO
REGRETFULLY UPON
THE CLOSED DOOR THAT
WE DO NOT SEE THE
ONE WHICH HAS OPENED
FOR US.

ALEXANDER GRAHAM BELL

NF FACTS & STATISTICS

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

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

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

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

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

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

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

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

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

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

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

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

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

MAKE A DIFFERENCE BY DONATING TODAY!



LET

IT

GO!

BY COURTNEY WILLOUGHBY

PHOTO: MATT POLITANO



THE LAST THING ANY PERSON WANTS TO BE IS DIFFERENT.

Conformity and social norms are celebrated, and it seems many people alter themselves to seek validation and acceptance from their peers. It breaks my heart that people who try nothing harder than to be themselves are segregated, and labeled as “different”.

I always used to be afraid that ... to be the “odd man out”. I kept a secret, a mighty big one that is, for 18 years of my life because of my immense fear of people finding out my life story. The last thing I wanted people to know was how my body grew tumors everywhere, how my bones were deformed, how my hormones didn’t work, and how my life had been consumed by severe anorexia and depression. Why was I hiding such an integral part of myself? Because I was afraid that people were going to find out I had neurofibromatosis.

I DID EVERYTHING IN MY POWER TO KEEP MY LIFE A SECRET FROM PEOPLE.

When I missed school because of a doctor’s appointment-told my friends that I was out with the flu! When I went home because my head felt like it was about to explode

from the pain – I was going to the dentist! I was able to lead what really was a second life for almost 18 years before I started to lose sight of who I really was. My life was filled with lies and illusions, and I wanted it all to stop.

My name is Courtney Willoughby. I am 21 years old and was diagnosed with neurofibromatosis when I was three years old. I lived a very normal childhood, and really didn’t know I was “different” until I had a plexiform tumor removed from my back when I was 13. That was when my doctors found an inoperable brain tumor that appeared to be taking my hypothalamus and pituitary gland hostage. Subsequently, my diagnoses included scoliosis, hypopituitarism, growth hormone deficiency, chronic daily headaches, an over active bladder and ribbon rib deformity. Additionally I had tumors located in my abdomen, pelvis, arms, legs and ear. I was absolutely devastated by these diagnoses. I thought that this meant my life was over. In my mind, I was different, and that terrified me. Who was going to accept me now?

I soon began harbouring all of my fears and anxieties regarding my health until those thoughts essentially ate me alive. I was a hermit to my own thoughts. I constantly feared people would find out about my genetic condition, the “thing” that was taking my life over. All I could think about was how unfair my life was. It was unfair that I had to live with this condition. It was unfair that I had seen 36 doctors in only nine years of my life. It was unfair how I had to constantly wake up in pain, and go to bed with the same pain that failed to be soothed by anything. My thoughts took me to some very dark places, places that I never want not to revisit.

I spent about three years of my life in that dark place and then one day I was ready to say “No More!” I was tired of being an inauthentic version of myself. I thought it was time to start coming out of my shell.

It was at this point in my life I had the incredible opportunity to meet Reggie Bibbs. Reggie is the founder of the Just Ask Foundation, and is a valuable crusader in raising awareness for neurofibromatosis.

I can remember every detail of our first meeting of the man that would become my hero. Reggie saved me. After meeting Reggie and hearing him speak about overcoming adversity and embracing your uniqueness, I was inspired to make a change. I came home after meeting Reggie, feeling refreshed. It's like someone hit the "restart" button in my brain. I suddenly felt like a different person.

I came clean with family, friends, and loved ones via a Facebook post. It seemed simple to me, and honestly I didn't expect much of a response. I was however, overwhelmed with the number of people responding and commenting on my post, and even sending me private messages with words of encouragement. This is the point in my life where I decided to "Let it Go" as Queen Elsa said in the movie Frozen.

My philosophies on life changed when I realized my priority in life didn't have to be my neurofibromatosis. I realized that I didn't have to be my diagnosis. Sure, I was a person living with a chronic condition but that didn't take away any of my worth in this world. I realized that people were going to think whatever they wanted about me, and I could try my best to "fit in". Ultimately I realized that I wanted to choose my individuality over conformity.

Let me break something to you gently. You may already know this.

There are seven billion people living in this world, so there is a pretty good chance that a few of those people are going to dislike you. It's as simple as that. So why would you change yourself for those few people, when you could be living a life where you love yourself?!

You are the only you that you get in this world, and you need to love yourself regardless of your flaws and imperfections. You wake up as yourself, and go to bed the same person each day- you can't fight biology. I tried for so long to be a person that I thought everyone else wanted me to be, and ended up completely miserable, isolated and alone. It wasn't until I accepted that I was a worthy individual regardless of my imperfections, that I really began to accept myself for who I was- NF diagnosis and all.

Life is short. I encourage you to be brave. Be courageous. Fight for what you believe in and find your passion in life. We live in a world full of stress and negativity, but no matter how much you worry about the future you ultimately cannot change the outcomes. Embrace the here and now, and be the most authentic version of yourself. Trust me, you just might like what you find when you leave your insecurities behind.

Courtney is 21 years old and was diagnosed with neurofibromatosis at the age of 3. After struggling with her diagnosis for several, she is now a passionate advocate for self-acceptance and overcoming adversity. She's turned her own battle with her health into a story that she hopes will inspire others to create change within themselves or in their own communities.

Check out Courtney's blog:

courtneys-column.blogspot.ca



“We make the biggest
impact in the world
by sharing our full self.”

~ Rebecca Campbell

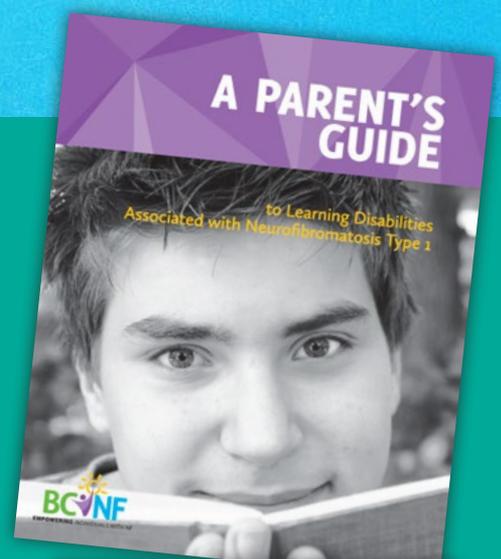
FEATURED RESOURCE

A Parent's Guide to Learning Disabilities Associated with Neurofibromatosis Type 1

By the BC Neurofibromatosis Foundation

This book is uniquely designed as a resource for parents of children with both NF1 and learning disabilities. Whether your child is just entering kindergarten, or is in their high school years, parents will find relevant material and strategies in this guide to help their student excel with their education. Inside you will find information on:

Explaining NF1 to Teachers, Social Challenges Common to NF1, Attention Deficit Disorders and NF1, Psychological Implication of Learning Disabilities , plus much more. **The book is available to download free from the BCNF website.**



FREE DOWNLOAD

THE ART OF STILLNESS

ADVENTURES IN GOING NOWHERE

by Pico Iyer
Reviewed By Desiree Sher

In the stillness beauty lies.

In a time where we have more ways than ever to connect many of us are feeling the pressure to unplug and retreat from the digital world and the frenzied pace of our lives.

In Pico Iyer's little book, *The Art of Stillness*, he offers up the idea that to find happiness in life we should go nowhere and do nothing.

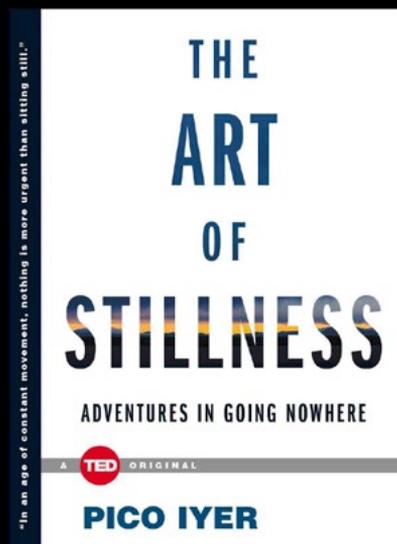
His message of stillness is contrary to the messages we receive that to succeed we must not rest. We wear our badge of busyness with honour – always striving to do more, achieve more and be more. We are afraid if we slow down we will be left behind.

But because of the constant noise and chaos many of us are feeling the pull to slow down and retreat into the quiet. In my own world I regularly satisfy my thirst for stillness through yoga, meditation retreats, nature walks and regular Internet detoxes.

The Art of Stillness paints a picture of why so many – from Marcel Proust to Mahatma Gandhi to Emily Dickinson – have found richness in stillness. Ultimately, Iyer shows that, in this age of constant movement and connectedness, perhaps staying still is a more exciting prospect, and a greater necessity than ever before.

In 2013, Pico Iyer gave a blockbuster TED Talk. This inspiring book expands on a new idea, offering a way forward for all those feeling affected by the frenetic pace of our modern world. You can also watch Pico Iyer's TED Talk [here](#).

"The point of gathering stillness is not to enrich the sanctuary or mountaintop but to bring that calm to the motion, the commotion of the world." ~ Pico Iyer





CANADIAN FIRST:

UHN OPENS MULTIDISCIPLINARY CLINIC ON GENETIC DISORDER

The Elisabeth Raab Neurofibromatosis Clinic, the first-in-Canada multidisciplinary clinic for adults with neurofibromatosis that will focus solely on this genetic disorder, is now open at Toronto General Hospital, thanks to a generous donation by an anonymous donor.

An estimated 10,000 Canadians are living with neurofibromatosis, a disorder that disturbs cell growth in the nervous system. The disease can be difficult to diagnose, since all body systems can be involved, either directly or through neural or vascular influences.

The clinic will advance treatment and understanding of neurofibromatosis in three key areas:

CLINICAL CARE On an outpatient basis, the clinic will assess, monitor and care for individuals from across Canada and North America living with neurofibromatosis, and speed up the accurate diagnosis of those exhibiting symptoms related to this condition.

CLINICAL RESEARCH Clinical research focused on the patients visiting this specialized clinic will help provide a better understanding of neurofibromatosis, how many people are affected by it and how to develop new and improve existing treatments for the disease.

BASIC SCIENCE Scientific research in the laboratories of the Centre for Research in Neurodegenerative Diseases (CRND) and the MARS building will seek to better understand the genetic foundations of neurofibromatosis; how neural dysfunction occurs; and find possible ways to halt or reverse nerve damage.





GLOBAL IMPACT

The **Elisabeth Raab Neurofibromatosis Clinic** was spearheaded by Dr. Michael Baker, Rose Family Chair in Palliative Medicine and Complex Care at UHN, who passed the torch to Dr. Vera Brill, co-director of the clinic along with Dr. Gelareh Zadeh, a neuro-oncology neurosurgeon at Toronto Western Hospital.

“The clinic will offer a multidisciplinary team from neurology, neurosurgery, neuro-oncology, medical genetics and genetics counseling,” says Dr. Brill who is also Head of Neurology, UHN and Interim Medical Director of the Krembil Neuroscience Centre.

“We must always look for ways to improve the care for patients who suffer from a chronic disease, and we now have that chance thanks to this incredible commitment from this generous donor.”

“The opening of this clinic marks a new stage in treatment of adult neurofibromatosis,” adds Dr. Zadeh. *“We hope to move the field forward and have global impact by eventually curing neurofibromatosis,”*

Reprinted with permission from “The Brain Campaign”, newsletter of the Toronto General and Western Hospital Foundation, December 2015.

BEST. CONCLU EVER.

**3 LESSONS ON HITTING A WALL AND
MAKING MY MESS, MY MESSAGE.**

By Anne-Sophie Dumetz



CONCUSSION.

It's 8 a.m., a sunny August morning in Kelowna, BC. The sunny beach next to the house is still quiet, but my mind is already fuller than the beach will ever get that day.

And I don't know it yet, but I'm about to change my own life, by walking right into a wall.

Literally.

"Shit, we're late. Do you have his socks?"

I race up the stairs, family and work logistics battling each other in my head:

"Where's the drop off? What time's that meeting? I have to promote my webinar. Crap, I forgot to get back to Jane. What am I looking for again?"

I'm an entrepreneur who helps ambitious women birth their big dreams... And that morning, I was unsure how to fulfill mine and get it all done.

Glancing down at my phone as I rush to get my son's socks, I don't see the wall, a walk head first into it...

And then, you'll never be the same again

(alleluia!)

Five months on, I'm still not fully recovered. The right side of my brain tingles and hurts often. I can't focus easily. My energy tanks randomly. It's been

more challenging to run an online biz when screens hurt my brain.

Yet, that concussion is the biggest gift I received in 2015. No shit.

Maybe you, too, have had your life interrupted by a concussion, shocking news, or an invisible trauma.

And feared nothing would ever be the same again.

Or felt lonely, discouraged, drained. And perhaps secretly lost hope you'd ever build the dreams you had.

If that's the case, read on.

Because it's in the moments when we feel empty that we get a whole new opportunity to refocus, refuel, and rekindle our truest dreams.

Now, I don't know what your story is, or what trauma could've happened.

Some things are incredibly challenging to recover from – and it sucks.

My hope is that these words can provide a little buoy of hope for the future on days when the present just seems to NOT be a gift.

TOP 3 LESSONS FROM BEING STALLED

GIVE UP THE NEED TO BE RIGHT

This one sucks. I've been so hard headed about "knowing" how to take care of myself.

Clearly, that was BS. I needed to hit a wall to make myself pause, and reconsider the way I lived and worked.

It was time to learn to work better, because I couldn't do as much now.

So I changed my ways. I slotted in daily self-care rituals to work on my beliefs, meditate and be with my soul. I added creativity and art back in my life. And when I did that, my productivity, success soared.

Lesson? You don't need to be, do and have it "ALL" to be a success. Choose wisely, focus, rest... and do less better.

ASK & RECEIVE LIKE A ROCKSTAR.

Before, I often turned down help "I'm good! I've got this."

But now, I know that's saying yes to help for small and large things will make my life easier. Plus, people who care love to help and it makes them feel good to be kind and caring for me. So now, I ask for what I want, and I receive it with an open heart. Win-win!

BE YOUR CHANGE & LEARN TO LOVE ALL OF YOU

... especially the part you don't like

Six weeks after my hit-the-wall-shit-I've-broken-my-brain moment, I went from ashamed to angry. Pissed with my inner ambitious ass-kickin' woman who was in such a rush that August morning... and who feels restless following doc's order to "do nothing."

But anger doesn't solve problems like these... Love does.

To build the dreams I thought are on pause, I have to learn to love all of myself fully. Especially the ambitious, superwoman part that's burned out before and hit a wall this time.

To do that, I have to feel everything: The anger, fear, doubts, resentment and shame... And learn to see that fiery part of me as the rocket fuel to building my dreams. Without that side of me, the loving, caring part of me that's a breath of fresh air to the world just can't fire up her big dreams.

The lesson? Pour yourself a cuppa honesty. Take a good look at all of you and find a compassionate way to move forwards in your life anyway, and still build your big dreams. Just make sure they're the right ones.

ONE LAST THING

**VOW TO
NEVER,
EVER, EVER,
EVER...
GIVE UP ON
YOURSELF
OR YOUR
DREAMS.**

They've shown up for a reason. They might feel bigger than you now, but I promise this will all make sense. Sometimes, life stalls us when we build the wrong dreams and need to re-align. That's what happened to me.

Since then, I've been able to build **MORE** in **LESS** time by **BEING** the change I craved... Join me and other female changemakers about how we stopped building the wrong dreams, despite everything – we have good stories that'll change your life, I promise.
shesachangemaker.com

I'M
AWESOME

...

BUT I'M NOT
SUPERWOMAN!

-AnneSophieDumetz.com

BIO

Anne-Sophie Dumetz is a Mindset, Magical Marketing and Growth Coach for Emerging Female Changemakers, who are ready to build businesses, grow their impact, income and influence, online.

She's the Founder of the She's a Changemaker community, where she brings together female entrepreneurs who are ready to stop building the wrong dreams and start changing their worlds by building businesses that grow them, and change lives.

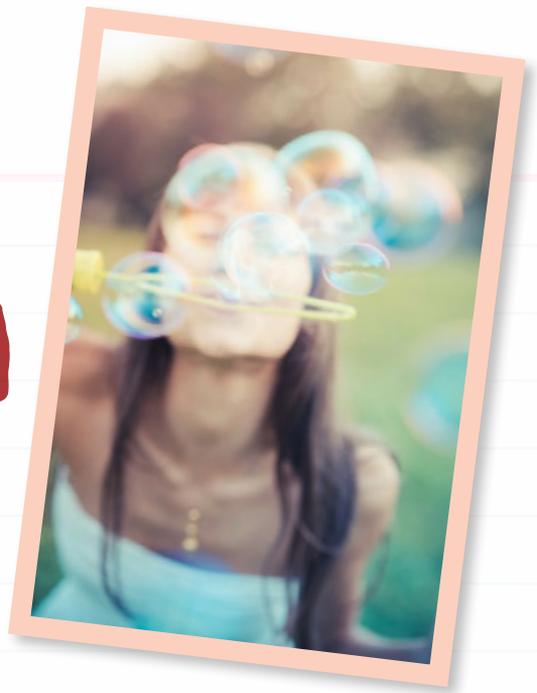
Access inspiring interviews and content at

shesachangemaker.com



Choosing Happiness in Tough Times

by *desirée sher*



Hearing the diagnosis that you or a loved one has neurofibromatosis can be devastating.

During my years at the BCNF I heard many parents equate living with NF with living with a ticking time bomb. "We hold our breath fearful every day that our child will get another symptom of NF." Feelings of fear, anger, and grief often accompany the diagnosis and can spiral into depression if the focus remains on the negatives of living with a chronic disorder.

Telling someone in his or her dark moment to choose to be happy isn't always well received. Yet it is in the challenging moments that keeping a positive outlook can be the most important.

When life is challenging how do you choose to be happy?

It's not always easy to choose happiness when you are facing a life with NF, but it is possible.

Shawn Achor, a Harvard researcher and author of *The Happiness Advantage*, tell us that you can be happier despite your circumstances.

By teaching someone to raise their positivity in the present, the brain experiences what Achor calls a happiness advantage, which is your brain at positive performs significantly better than at negative, neutral or stressed. Your intelligence rises, your creativity rises, your energy levels rise. You feel happier.

There are a number of scientifically-proven ways, that you can rewire your brain to become happier. Committing to the following five activities and doing them for 21 days in a row, you can actually rewire your brain to be more optimistic.





Give Thanks

Everyday for the next three weeks, write down three things that you are grateful for before you go to bed. Studies have shown that after doing this for 21 days, people's brains begin to retain a pattern of scanning the world for the positive first, instead of the negative, making them much happier.

Have Fun

Spend 15 minutes a day doing a fun, mindful activity such as gardening, going for walk or a workout. Research has show than performing such pastimes is the equivalent of taking an antidepressant, decreasing the likelihood for depression and despair. Exercise teaches your brain that your behaviour matters and it helps you solidify the connection between your actions and their rewards.

Journal

Everyday for three weeks spend two minutes writing down a very detailed description of something positive that happened to you within the past 24 hours. Since our brain doesn't distinguish between visualization and actual experiences, this activity allows your brain to relive it, doubling your pleasure!

Meditate

Mediation allows your brain to get over the cultural ADHD that we've been creating by trying to do multiple tasks at once. People who meditate are better able to cope when life puts them in a middle of a storm. You don't need fancy robes or incense. Just get quiet and pay attention to your breath, inhaling and exhaling mindfully for two minutes. When your thoughts distract you just bring your attention back to your breath.

PERFORM A RANDOM ACT OF KINDNESS

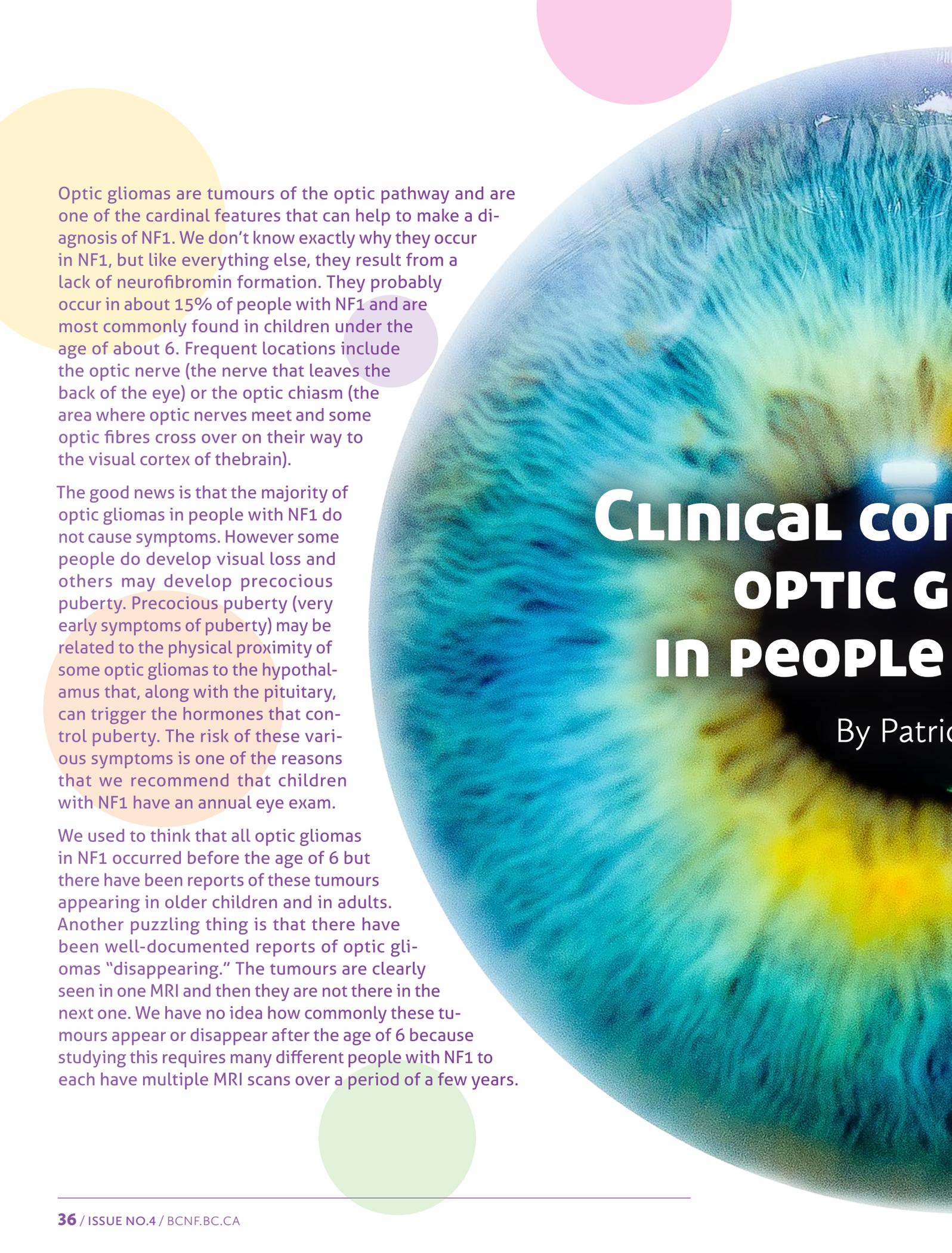
It doesn't matter if your act of kindness is buying a coffee for the person after your in line, volunteering, or sending a positive email. Achor gets people, when they open up their inbox, to write one positive email, praising or thanking someone in their social support network." A little kindness goes a long way in sending a ripple of happiness out into the world.

Do these activities for the next three weeks, and you will begin to see a lasting shift in your mindset towards increasing your happiness and positivity. Like any muscle, the more you work it the stronger it gets. Choose to work your happy muscles and staying positive in the tough times will get easier.

Desirée Sher is the Executive of the BC Neurofibromatosis Foundation. She is also a life coach passionate about inspiring, empowering and supporting others to expand their happiness and create purposeful lives filled with passion, joy and abundance.

Learn more about her or order her book, Refuse to Sink at





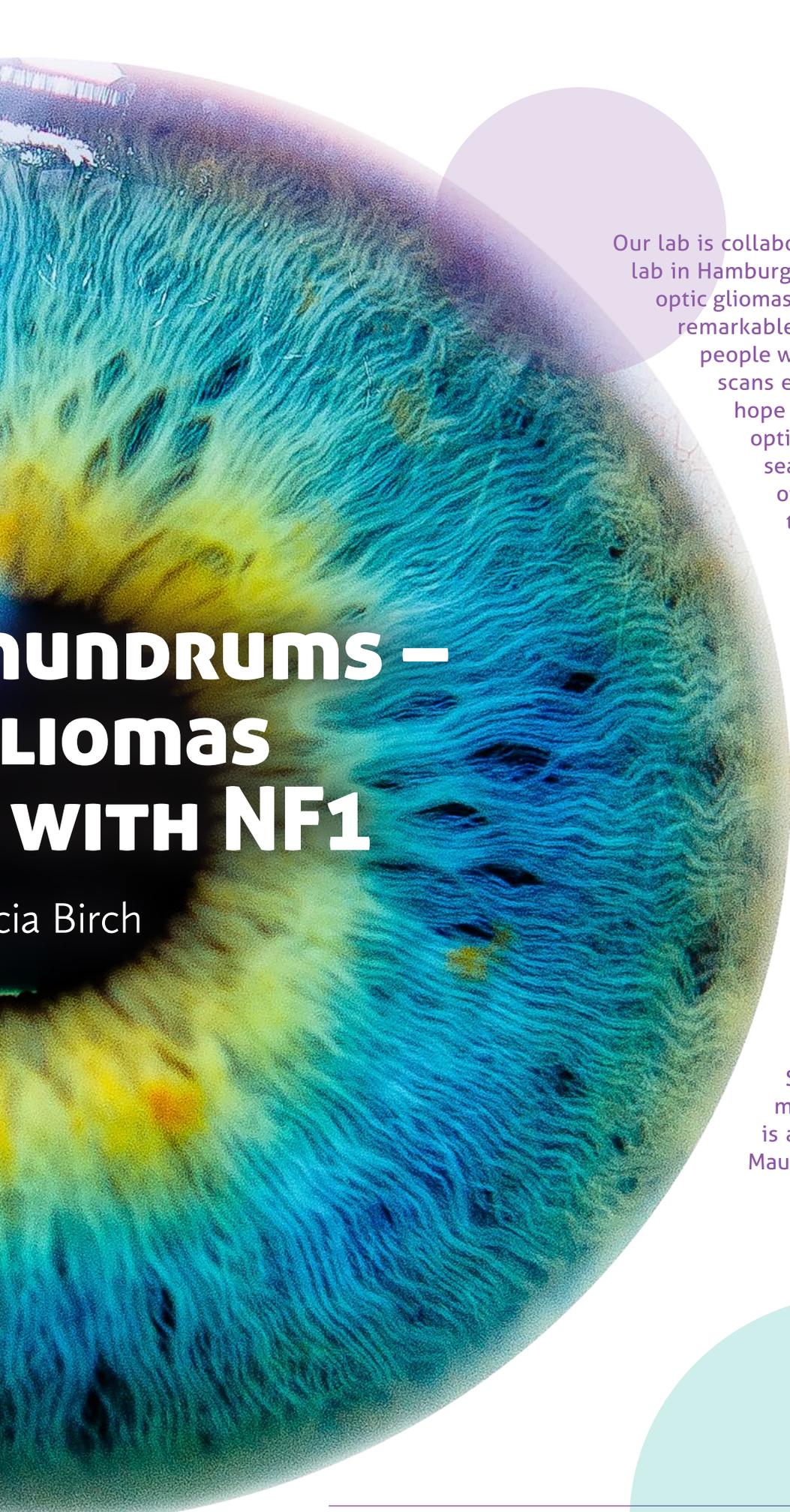
Optic gliomas are tumours of the optic pathway and are one of the cardinal features that can help to make a diagnosis of NF1. We don't know exactly why they occur in NF1, but like everything else, they result from a lack of neurofibromin formation. They probably occur in about 15% of people with NF1 and are most commonly found in children under the age of about 6. Frequent locations include the optic nerve (the nerve that leaves the back of the eye) or the optic chiasm (the area where optic nerves meet and some optic fibres cross over on their way to the visual cortex of the brain).

The good news is that the majority of optic gliomas in people with NF1 do not cause symptoms. However some people do develop visual loss and others may develop precocious puberty. Precocious puberty (very early symptoms of puberty) may be related to the physical proximity of some optic gliomas to the hypothalamus that, along with the pituitary, can trigger the hormones that control puberty. The risk of these various symptoms is one of the reasons that we recommend that children with NF1 have an annual eye exam.

We used to think that all optic gliomas in NF1 occurred before the age of 6 but there have been reports of these tumours appearing in older children and in adults. Another puzzling thing is that there have been well-documented reports of optic gliomas "disappearing." The tumours are clearly seen in one MRI and then they are not there in the next one. We have no idea how commonly these tumours appear or disappear after the age of 6 because studying this requires many different people with NF1 to each have multiple MRI scans over a period of a few years.

CLINICAL CORRELATION OF OPTIC GLIOMAS IN PEOPLE WITH NF1

By Patricia...



DRUMS – GLIOMAS WITH NF1

cia Birch

Our lab is collaborating with Dr Victor Mautner's lab in Hamburg, Germany to better understand optic gliomas. We have access to Dr Mautner's remarkable set of MRI data on almost 600 people who have had an average of three scans each, and by analysing these, we hope to answer many questions about optic gliomas. There is much basic research to be done. For example, one of the first things is to develop criteria for measuring and defining optic gliomas: At what point is an optic nerve just "thickened" and at what point does that thickening become an optic glioma? Do people with NF1 have naturally thicker optic nerves than people without NF1? Dr Mautner's data will enable us to define this, will enable us to describe the frequency of optic gliomas in people of all ages, and to document how often optic gliomas appear or disappear after early childhood. This is just another key to unlocking the secrets of NF1. The person doing much of the work on this project is our new graduate student in the Friedman Lab, Laura Sellmer. By a remarkable alignment of stars, Laura is German, so is able to read and translate all Dr. Mautner's reports!



**I AM NOT
WHAT HAPPENED TO ME.
I AM WHAT I CHOOSE
TO BECOME.**

~ C.G. Jung

JOIN THE BCNF STAFF IN AUSTIN TEXAS FOR THE 2016 NF FORUM

Hosted by the Children's Tumor Foundation, this event features NF experts from around the world who will cover the most current information on NF including how to manage the symptoms of NF, the latest in imaging techniques and updates on treatment strategies. Participants will have opportunities throughout the sessions to ask questions and

explore ways to contribute to expanding the knowledge of NF and enrolling in research. There will be fun activities, meals, social time with friends and family, and much more!

Learn more at ctf.org/nfforum
or call 844-473-3959 to reserve your tickets.



2016 NF FORUM

For patients and families living with NF

JUNE 17-19, 2016 / JW Marriott / Austin, TX

ctf.org/nfforum



INSPIRE OTHERS TO MAKE A DIFFERENCE

RUN, JOG OR WALK WITH THE
BCNF AT THE 2016 SCOTIABANK
HALF MARATHON AND
5KM CHARITY CHALLENGE

SUNDAY, JUNE 26TH

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!

