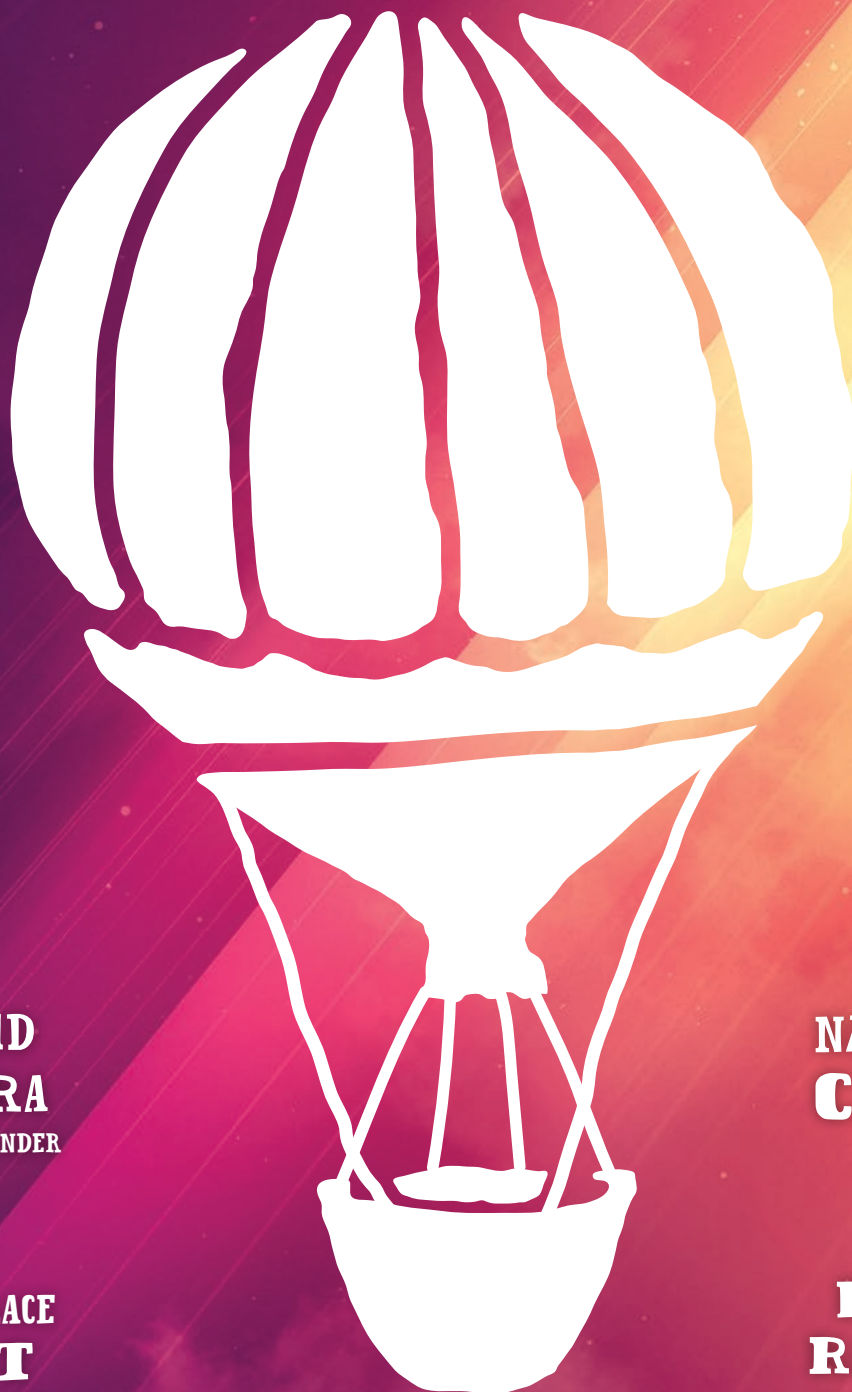


ISSUE NO.6 / SUMMER 2018

THE MAGAZINE OF THE TUMOUR FOUNDATION OF BC

!NSP!RE



**THE END
OF AN ERA**
FAREWELL TO OUR FOUNDER

**MARK YOUR PLACE
CONTEST
WINNERS**

**NAVIGATING
CHANGE**

**FINDING
RAINBOWS**
IN A WORLD WITH NF

EDITOR'S NOTE

FINDING SILVER LININGS



Looking on the bright side of life isn't always easy but there, in the silver linings of dark clouds, we can find the sunshine and rainbows.

Since our last issue we have had both dark moments and happy times at the Foundation office.

With the passing of our founder, Paul Ralfs, on February 9th, we had to look beyond the darkness. It was hard to say good-bye to a man who had spent his entire adult life supporting the NF community. Paul's belief that with so many people in BC living with NF – 1 in 3,000 – there was no need for anyone to battle NF alone, changed the experience of families living with this disorder in British Columbia and beyond.

In this issue you will find rainbows and sunshine in the contributions of young Cheyanne who asked to share her story, our new staff member Tara Sellers, and Emily Owen, who has a book about overcoming the challenge of living NF2. All of three of these beautiful young women share how they live joyful lives despite the NF diagnosis.

At the 2018 symposium many of our presenters shared mindfulness meditation as tool to cope with pain and difficult times. With so much research supporting the benefits of engaging in a regular meditation practice it is hard to ignore this topic.

If you missed the symposium, you will find some great tips on how to start meditating within this issue.

Work on moving the clinic initiative forward continues. There is a proposal for a NF clinic in front of the Hospital Executive of the BC's Children Hospital and Women's Health Centre site. We will update you as soon as we know if it is accepted.

As the legend goes, at the end of every rainbow is a pot of gold. And this year we found ours!

Through three successful fundraising events along with some unexpected donations we were able to relaunch our research program. As we go to print we are exploring a partnership with the Rare Disease Foundation's microgrant research program to stimulate researchers to study NF.

Life with NF isn't always an easy journey but when you look for rainbows instead of dark clouds life gets a little more fun!

DESIRÉE SHER

Executive Director

desiree@tumourfoundation.ca

INSPIRE MAGAZINE ISSUE NO.6 / SUMMER 2018

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EDITOR

Desirée Sher

CONTRIBUTORS

Desirée Sher

Emily Owen

Sam Chua, Photography

DESIGN

Oculus Design + Marketing

FOR FURTHER INFORMATION:

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

Look for us on Facebook
& Twitter

Together we can make a
difference!

*We would like to thank
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**Tumour
Foundation
of BC**

EMPOWERING INDIVIDUALS WITH NF



***If I cannot do great things,
I can do small things
in a great way.***

MARTIN LUTHER KING JR.



Paul Ralfs

The End OF AN ERA

BY DESIREE SHER

With a heavy heart I share that our founder, Paul Ralfs, died on February 9, 2018.

It was Paul's belief that no one should travel the NF journey alone. This inspired him to start a support group in 1984, and then establish the British Columbia Neurofibromatosis Foundation, now known as the Tumour Foundation of BC.

In those days, his office was his living room and he used a typewriter to create mailing labels and newsletters. He worked tirelessly for thirty-two years, reaching out to families, medical professionals, and educating the community about neurofibromatosis. He had a love of presenting (a skill he acquired through decades involvement with Toastmasters), and he always jumped at an opportunity to speak about NF.

When I came to work at the charity in 1997, Paul was still a powerful presence. He always kept us on track at meetings with his intricate knowledge of Robert's Rules of Order. (I would often tell him the process wasn't important as long as we reached the goal. Thankfully, he refused to listen to this young Executive Director!) He would often call me to just check-in, I came to appreciate and admire his deep love for the charity and the NF community.

When the Board moved the Foundation to Vancouver Island in 2000, Paul and I began to share monthly lunches. He enjoyed the outings at White Spot and then Bubby Rose's. I always was eager to meet with him and share my ideas and challenges. I would always leave our lunches inspired, with a fresh perspective, and creative ideas flowing.

The charity was Paul's baby and if I ever had doubts about a program or direction of the Board, I would consult with him. I knew he would be honest as he never had a personal agenda except to connect and educate people affected with NF. He would always ask me, "How does this serve the community?"

He once told me it was great that we had created a summer camp and an educational scholarship program for youth, but I must never forget that adults with NF also need ongoing support and connection. And while he believed investing in research was important, he also knew it was not going to alter the NF journey in his lifetime.

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PAUL DIDN'T
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TO CHANGE
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OF LIVES.

However, our recent work towards establishing a NF clinic excited him. It was the one endeavor he fully supported and would always break into a huge grin when I shared an update. He told me he was proud of my perseverance. That was all I needed to keep going!

In the last two years, Paul and I met less often as he was repeatedly hospitalized with pneumonia. Eating challenged him and our lunches eventually stopped. Yet, there were many afternoons that we could call each other to just talk.

His commitment to the NF community has carried on even in his death through a sizeable donation he left to the Foundation.

We should all be as fortunate as Paul and have a passion that carries us through life – in good times and bad. Paul didn't just live with NF. He used the disorder as a catalyst to change thousands of lives with his belief that no one with NF should walk the journey alone.

The NF community in BC will forever be changed because of Paul Ralfs. We will continue onwards with his mission to support, educate, and inform the world about NF.

FINDING RAINBOWS

in a world with NF

Q&A with author
Emily Owen



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

What do you wish people knew about NF2?

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

Tell us a unique fact about NF2.

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

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

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

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

~ Reinhold Niebuhr

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

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

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

What do you do on the days you feel discouraged?

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

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

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

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

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

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

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

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

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

What made you want to write *Still Emily*?

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

What keeps you up on down days?

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

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

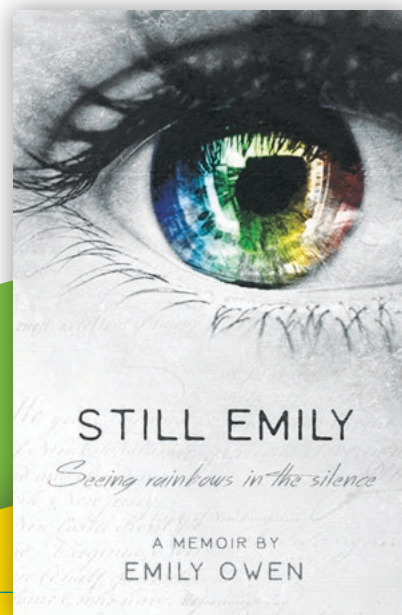
And I remember that God is with me; nothing is so bad that He walks out and leaves me to it alone.

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

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

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

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



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

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

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

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

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

Has your facial paralysis improved with therapy?

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

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

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

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

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

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

What's next for you?

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

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

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

You can reach Emily at emily@emily-owen.co.uk



WHERE
ARE YOUR
RAINBOWS?

Meditation

and Improving Your Mental Health

by Desirée Sher

“One does not practice meditation to become a great meditator. We meditate to wake up, and live, to become skilled at the art of living.”

~ Elizabeth Lesser

Meditation is no longer considered solely a practice reserved for monks on mountain tops. Scientific studies and brain imaging over the last decade have shown that meditating actually changes your brain, and with it, the way your body responds to stress.

With an estimated one in five people in the work force experiencing some degree of a mental health issue, (*Mental Health Experience in Canada's Work Place, 2017*), meditation is now considered a therapeutic tool for dealing with anxiety, depression, and pain. Workplace stress is a top cause of mental health problems and illnesses. A regular meditation practice creates a relaxed state, which lowers the physical and emotional consequences of stress.



Meditation is an easy to use practice that helps put you in control of your mental health.

If you've never meditated before, I invite you to start with just two to three minutes of mindful breathing.

Sitting in stillness, without your phone, is going to feel like an eternity at first. But as you get use to concentrating on your breath and stopping your mind when it wanders, you can increase your time. The point of focusing on your breath is that every time you bring your attention back to your breath, you work your attention muscles. Over time, your focus, concentration, and attention span will improve. In addition you will receive other benefits of meditation which include: reducing stress, lowering your blood pressure, decreasing your sensitivity to pain, strengthening your intuition, increasing creativity, and boosts to your self esteem and confidence, to list just a few.

How Do You Meditate for the First Time?

- *Set a timer so you don't have to keep checking your watch!*
- *Sit or lie comfortably. This is important so move around until you feel at ease.*
- *Your legs can be folded or extended with your feet planted on the floor.*
- *Rest your hands softly in your lap.*
- *Close your eyes and begin to turn your attention inwards.*
- *Take a couple deep breaths in and exhale completely. Then let your breath fall into its natural rhythm.*
- *Now bring your attention to your breath as it enters through your nostrils. Notice now the body moves with each inhalation and exhalation. Notice your breath as it leaves the body through the nose.*
- *When your mind wanders, gently bring your attention back to your breath again and again until your timer sounds. This is meditation.*

Here are five tips to help you get started:

Start Small

Begin with just a couple minutes of mindful breathing every day. You don't train for a marathon race by running out at full speed right from the couch. Small steps will move you towards your goal and won't overwhelm you.

Schedule It

Set the intention to meditate daily. Put in on your calendar or set a reminder on your phone.

Link to Another Habit

By linking a new habit to an existing one you increase your chances of success. Take a look at your day and explore where meditation might fit your routines. Can you meditate in the morning after using the bathroom or before you open your laptop? Will it work best at night after you brush your teeth? Explore.

Find Sacred Space

Claim a spot in your home or office where you won't be disturbed. Make it special by adding a cushion, blanket, candles or photos, anything that makes the space sacred for you.

Seek Support

Share your goal to meditate with people who will support you. Find an accountability partner who will check up on you. When we declare our intentions, we are making a vibrational commitment to follow through.

Desirée Sher is a meditation teacher, life coach and inspirational speaker when she's not supporting families at the Tumour Foundation. Desirée has been meditating for over a decade and has shared her passion for meditation as a tool for transformation on her podcast, on the stage, and in her personal coaching business. You can follow her on Instagram for daily inspirational messages @desireesher

Photo: Jean Gerber (via Unsplash)



MEET CHEYANNE Q&A



PHOTOS: SAM CHUA

Q: How old are you?

A: Nine – almost ten.

Q: What type of NF do you have?

A: Type 1.

Q: Can you describe it in a few words?

A: It's a genetic disorder that weakens my muscles and affects my nervous system.

Q: How did you find out you had NF?

A: My mom told me after she found out from Children's Hospital.

Q: How does having NF make you feel?

A: Happy and sad at the same time.

Q: What is something you like to do with your family?

A: Family game night, camping and movie nights and cuddles.

Q: Do you have any brothers or sisters?

A: Yes I have one younger sister.

Q: Does she have NF too?

A: No.

Q: What is the best part about visiting the doctor?

A: Everyone is so nice to me and I get to miss school.

Q: What is your least favourite part about visiting the doctor?

A: It can be uncomfortable when I have to get needles in my arms or wires on my head.

Q: What makes you happy?

A: My mom because she makes me feel better about my NF.

Q: Do you ever get scared? What do you do?

A: Yes, I cuddle my mom.

Q: Does having NF make anything harder to do?

A: Yes, like riding a bike and running and going up and down stairs and walking too long.

Q: What makes you feel better when something hurts?

A: Resting, taking a break. P.S. NO Band-aids!

Q: What is your favourite thing to do at school?

A: Play with my friends and doing art, gym and library.

Q: If you had one thing to say to other kids about NF, what would you say?

A: Don't worry – you're not alone and don't forget to wear blue and green on NF day!

Q: Is there something important you want to tell us about NF or your story?

A: I may have NF but it won't stop me from doing whatever I want.

*Editor's note: We are so grateful that Cheyanne wanted to share her thoughts about living with neurofibromatosis. Part of creating awareness about NF is having the community come forward and share their story. **Three cheers for Cheyanne!!***

WELCOME TARA

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

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

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

In order for our readers to learn a bit more about Tara we asked her to answer a few questions about her life outside of NF. You can reach Tara at tara@tumourfoundation.ca

Q: What or who inspires you in life?

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

Q: What are you most proud of?

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

Q: Do you have a favourite quote?

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

Q: What makes you angry?

A: *Fox News and hypocrisy.*

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

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

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

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

Q: What book are you are reading now?

A: *Something in the Water
by Catherine Steadman*

Q: What is the luckiest moment of your life?

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



Q: What is your biggest hope?

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



THEY DID IT!



They ran, walked and pushed strollers through the Scotiabank Half Marathon and 5km Charity Challenge on June 24th.

We are so proud and deeply grateful of our team's hard work training and FUN-raising on behalf of the children and families affected with NF.

\$15,704 WAS RAISED FOR OUR RESEARCH PROGRAM!

YOU CAN, TOO!

**RUN, JOG OR WALK WITH US NEXT YEAR AT THE
2019 SCOTIABANK HALF MARATHON AND
5KM CHARITY CHALLENGE**

SUNDAY, JUNE 23RD 2019

WHEN AND WHERE

7:30am

Half-Marathon Start at UBC Thunderbird Arena

9:30am

5k Fun Run/Walk Start
at Stanley Park Fish House

HOW

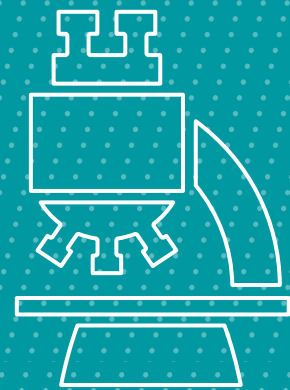
To register go to: vancouverhalf.com

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!

COMMIT TO RAISING A MINIMUM OF \$200 AND WE'LL PAY YOUR REGISTRATION FEE.
That means no cost to you to participate in this fun event and you get two free t-shirts!

BRITISH COLUMBIAN FAMILIES' CONTRIBUTIONS TO NF RESEARCH



PATRICIA BIRCH, MANAGER, FRIEDMAN LAB, UNIVERSITY OF BC

About 28 years ago, the gene that causes NF1 was discovered and later that same year, the Friedman Lab was awarded a contract by the US National Neurofibromatosis Foundation (now Children's Tumor Foundation) to develop an international database to study the signs and symptoms (the "phenotype") of all types of neurofibromatosis. Within a few years, we had amassed data from many countries and had begun a research program that centred on analysis of these data. We had a number of wonderfully bright and enthusiastic graduate students to help out. But importantly, at the same time, the British Columbia Neurofibromatosis Foundation (BCNF, now the Tumour Foundation of BC) was blossoming, members were asking questions, demanding answers, and becoming interested in learning about and contributing to research.

At the beginning of 2018, we looked back on the contributions of BC families to the world's understanding of NF and the many ways the Tumour Foundation of BC facilitated this.

In the early 1990s, there were just a handful of researchers studying NF and so it was important for us to work together. The Tumour Foundation of BC brought key researchers to speak at the annual NF conferences. In doing so, it gave our lab the opportunity to collaborate with some of the best NF minds to try to understand

the clinical picture of both NF1 and NF2. Many of the top names in NF: Gareth Evans, Pierre Wolkenstein, Vic Riccardi, Dave Viskochil, Victor Mautner, and others all visited Vancouver to speak to families and to collaborate with Dr. Jan Friedman and his research team.

These collaborations enabled us to develop a more thorough understanding of NF. For example, our findings enabled us to reassure parents that optic gliomas rarely develop after early childhood, and that certain types of scoliosis or pseudarthrosis are unlikely to develop after the end of elementary school. On the other hand, we discovered that a specific type of congenital heart problem is ten times more common in people with NF1. These seem like small details but each one helps to put together the jigsaw puzzle of information about NF. We were also able to develop growth charts for NF1 so that people the world over may now use appropriate height, weight, and head circumference charts for their children with NF1.

**THESE COLLABORATIONS
ENABLED US TO DEVELOP
A MORE THOROUGH
UNDERSTANDING OF NF.**

We worked with data from people with NF2 and developed models of tumour formation that helped to understand the progression of this condition. With Gareth Evans and others, we demonstrated that NF2 tends to be similar in related individuals, which ultimately led to the current understanding of effect of the type of NF2 mutation on disease severity and tumour progression. This is particularly important when people are evaluating the effect of experimental drugs on tumour growth.

BC families with NF listened as we explained new findings at each annual NF symposium. There is always the opportunity for questions and on one occasion at a meeting in Burnaby, some parents asked why their children with NF1 had more dental cavities than those without NF1. We had no idea that this was even an issue, but you told us, in no uncertain terms, that it is a significant problem. Together with Tumour Foundation of BC, we designed a study to evaluate this, and many of you may remember receiving dental mirrors in the mail along with a request to count caries and fillings. We published this, and then the whole world knew that dental health was something to be extra careful of, particularly in children with NF1.

The sudden onset of cardio-vascular disease in an otherwise healthy British Columbian man with NF1 prompted our lab to explore vascular disease in NF – a concern that was previously under-appreciated. Many of you came to Vancouver for special testing – including blood work, ECG, and an ultrasound of the artery in the neck. It was quite a commitment. But from these studies, we developed an understanding of the risk of vascular disease in adults with NF1.

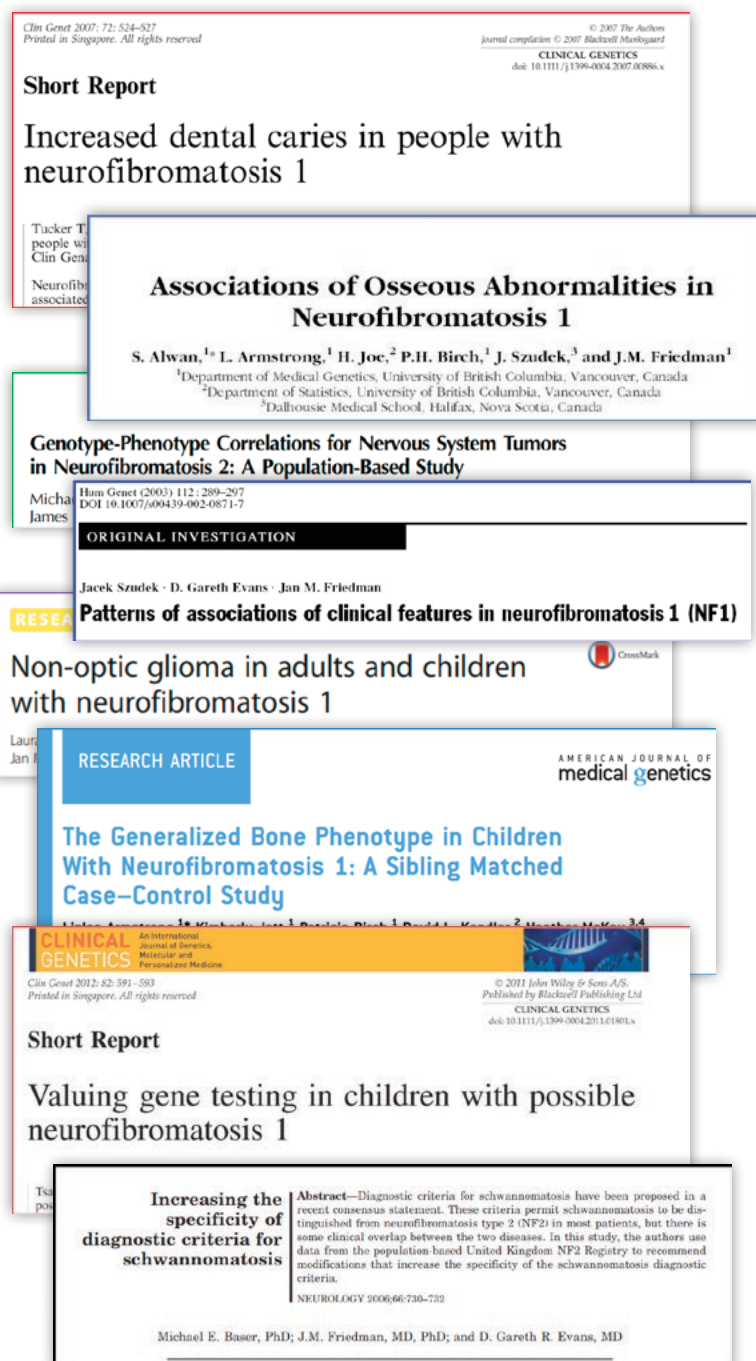
Similarly, we became aware of lower vitamin D levels in some people with NF1. BC families contributed to two studies to help us better understand possible links between this and low bone mineral density in children and in older adults with NF1. The results of these two studies help to drive an international project, now underway, to try to prevent bone loss by supplementing people's diets with vitamin D and calcium. Yes... some of you are involved in that now too.

Much of this detailed work in both NF1 and NF2 was assisted by graduate students or summer students who were often partially funded by grants from the Tumour Foundation. Many of these students have since taken their expertise in NF1 and NF2 to become researchers

and clinicians in areas such as family medicine, otolaryngology, obstetrics, cytogenetics and a variety of other areas.

This page mentions just a few of the studies where BC families or the Tumour Foundation of BC, has been central to world-leading research. Of over 60 publications on NF1 and NF2 that have involved our lab, you, or your organization facilitated over two-thirds of them.

THANK YOU, AGAIN!



MY HEALTH AND ESSENTIAL OILS

A PERSONAL EXPERIENCE

BY BRANDY MEISNER, NF PARENT

I was first introduced to essential oils at a class hosted by my son Tyler's Educational Assistant. I didn't know much about using essential oils to improve my health, or my family's well-being, but I was curious. When you are on the NF journey there aren't a lot of treatment options so you have to get curious.

At this event I won my first bottle of essential oils. The name of this particular blend was Serenity, which made me happy because this oil was known to support sleep. (Tyler at the age of seven was still not sleeping through the night.) I needed that oil!

When I got home, I mixed two drops of Serenity oil in with solid coconut oil and massaged it onto the bottom of his feet. I wasn't sure what to expect, but he fell asleep within 15 minutes and then slept through the night!

This had never happened before and I immediately knew I had to get more of these wonderful oils.

I loved the benefits we were experiencing so much that I immersed myself in learning more about these oils and then became a wellness advocate for the company.

I started to get creative with the oils and made a rollerball for Tyler to use at night which had blend of oils including Serenity (sleep), Juniper Berry (nightmares) and Vetiver (anxiety). With this blend Tyler's anxiety has decreased, his nightmares are gone and he has continued to sleep really well. This impacted all aspects of his life and our family's, for which I am so grateful for.

I have also been able to help my mom with her sciatic pain. I made her a pain rollerball which didn't give her the relief she needed, so we tried something else, and deep blue rub and deep blue oil was what worked for her. It took time (a couple of months), but it worked and now when the pain comes on, she uses a little bit of it and it she gets quick relief.

In our house, we now use OnGuard for our foaming hand soap. This provides great help with immune support and protection against environmental threats. When we do get sick, I use a combination of Tea Tree, Oregano, Frankincense, Lemon and OnGuard. For the kids, I put this in a rollerball diluted with fractionated coconut oil and for the adults, I put a few drops in a veggie cap and within a few day the cold/flu is relieved.



A LITTLE OIL INFORMATION

The thing with these oils is they are 100% pure oil with no additives or synthetics. DoTERRA prides themselves on making sure you are getting the purest oil as this gives the best efficacy. They can reach the brain through the limbic system within 22 seconds of inhaling, 2 minutes and they will be found in your bloodstream and 20 minutes they will affect every cell in the body. Again, this isn't a cure for NF, but the improved health has been amazing for our family!

DoTERRA oils do not take the place of your prescription drugs, but they may work in combination with them. I have seen many people improve their overall health and wellness with these oils.

If you are curious about how essential oils can support your over well-being please get in touch with Brandy.

Brandy Meisner is a mom of a child with NF and a DoTERRA Wellness Advocate. Brandy is passionate about helping families live a healthier lifestyle by providing them with natural and safe products.

You can reach Brandy by email:
Buterfli_2@hotmail.com

Facebook:
facebook.com/groups/462558097472849/

Website:
mydoterra.com/essentiallyexpresedoils/#/

SOMETHING TO LEAVE YOU WITH

By incorporating these oils into your life on a daily basis you are reducing your toxic load, balancing your emotions and providing your body with the nutrients and support it needs. Whether or not you live with NF they make a difference!

This is still the beginning of my journey with DoTERRA essential oils and I am looking forward to helping as many people as I can to improve their overall health and wellbeing.





***WE CAN'T ALWAYS CONTROL
WHAT HAPPENS TO US, BUT
WE CAN ALWAYS CONTROL
HOW WE RESPOND.***

Change is hard. Most of us resist it. Our brains like the familiar. We want things to stay the same.

Yet, the one thing I know for certain is that life changes. Relationships breakdown. Jobs end. Finances shift. And when you live with NF, symptoms can change, often without warning.

How much we struggle and suffer through life's twists and turns all depends on our willingness to accept the changes as they come.

After my car accident a few years ago I resisted accepting that the injuries had sidelined my running career. I was a runner. Period. I became angry and frustrated as I struggled to accept my new reality of being a walker. I wanted to run. Eventually I had no choice but to accept this as my truth as I physically could not run. I look back now and realize how tight I had been holding on to my

identity as a runner. I fought my new reality so hard that I lived with resentment and frustration.

Try this quick exercise. Hold on to something with both hands. It can be anything. Now try to reach for something else while still holding the original object. What did you experience? You can't reach for anything new when you are still holding on tightly to something else.

Hanging on to an image of how we think life should be is what keeps us stuck. When we flow with the changes, we struggle less, and reclaim our happiness and peace much more quickly.

Here are a few tips I learned to navigating change with greater ease and less suffering:

STOP RESISTING

Take a deep breath and accept what is happening right now. Resisting change is where the pain comes from.

1

ACKNOWLEDGE THAT CHANGE FEELS UNCOMFORTABLE

2

Take another deep breath and become aware of what you are feeling. Maybe you feel sadness, frustration, anger or something else. Honour your feelings by making space to feel them. Then let them go. Don't get stuck here. Change will happen anyway and you will end up bitter and resentful if you don't let your emotions pass through you.

FOCUS ON THE GOOD

3

Looking for the positives when life throws you a curve ball can challenge even the most optimistic souls. (Our brains are programmed to look for the negative. It was a survival mechanism back in caveman times when our ancestors had to stay aware of evil lurking to avoid being eaten by sabre-tooth tigers.) It takes energy and intention to find the good in a tough spot, but there is always something small you can focus on when you look hard enough.

CREATE A NEW DREAM

4

It's often not the relationship or job loss that we grieve but our dream of how we thought our life will unfold. Grieve that story you wrote in your mind, and then create a new and empowered vision. You are the creator of your life! Don't let circumstances turn you into a victim.

TRUST

5

Sometimes the only thing we can do in navigating change is to trust all be ok, and that the path will appear as you take that first step in a new direction.

Navigating change is rarely easy, but it is possible. Don't let your life be controlled by what was, when there are new gifts to discover in what will be.

COCKTAILS 2018 FOR A CURE



Thanks to a team of amazing volunteers, led by our board member, Candace McGuire, our second annual fundraiser, Cocktails for a Cure, was a bigger success than last year! The event sold out and the room was packed with donated auction items. Thanks to our auctioneer Marco Iannuzzi, from the BC Lions, who did a sweet job of encouraging our guests to open their hearts and their wallets, we are able to reignite our research micro-grant program.

Keep your eye on our website and our Facebook page for next year's date – coming soon!



Shine a Light



This year's *Shine a Light* campaign which ran during May Awareness Month reached over 200 buildings, bridges, and architectural icons in eleven countries. We were so pleased that we can continue to increase the awareness of NF throughout the world. Check out some of the iconic buildings that lit up in BC.





Health Mentors Program

The UBC Health Mentors program is looking for Health Mentors to share their medical expertise with our health-care students.

The UBC Health Mentors Program is a 16-month volunteer program in which adult mentors and/or caregivers meet with a small team of UBC students twice each semester.

Health Mentors are experts in their health and want to share their experiences living with a chronic condition. Students are new healthcare professionals who learn about patient-centered care and how providers can better support people with chronic conditions.

By being a Health Mentor you will be part of a pioneering program that is contributing to the education of the health professionals of tomorrow. Health Mentors should live in the Metro Vancouver area and be comfortable talking about their health condition.

The program starts in September 2018 and runs to December 2019.



Apply Today!

For more information and to apply to be a Health Mentor, visit their website or email the Program Coordinator:

pcpe.health.ubc.ca/healthmentors

jen.macdonald@ubc.ca



NF RESEARCH PROGRAM

Thanks to the amazing fundraising efforts of our board and recent donations from our donors, we are relaunching our research program this fall!

Funding research isn't cheap by any means. Scientists and support staff need salaries, facilities, equipment, and a pile of other things that are part of the process of having an idea, researching it, and then developing a chemical mechanism that can do what they want it to. While at this point we don't have huge funds for huge projects we will provide microgrants to stimulate NF research. It's a step in the right direction.

MICROGRANTS

As we go to press on this issue of the magazine the staff at the Tumour Foundation are exploring a pathway to partner with the Rare Disease Foundation to offer our microgrant research dollars to scientists in the NF community.

We are really excited at this opportunity as the Rare Disease Foundation has a deep commitment to research which improves the care of patients living with rare diseases. Additionally, lay people from the community take part in the review process, making sure that the priorities of the community are placed front and centre.

DO YOU HAVE A LOVE OF MONEY?



If you enjoy working with money, and have experience with financial statements and financial forecasting, we invite you to volunteer your passion and expertise with the Board of the Tumour Foundation. We are seeking a volunteer with financial experience to guide and support the Board in their fiscal responsibilities. We meet via video conferencing on the first Wednesday of the month. The Treasurer role requires 2-4 hours a month and is supported by professional staff.

Interested? Please get in touch with the Executive Director to learn more: desiree@tumourfoundation.ca

MICROGRANTS

VERSUS

TRADITIONAL GRANTS

COMPARING THE 2 TYPES OF FUNDING



Microgrants are small. And small is beautiful!

Their purpose is to solve problems for today's patients.

Microgrants are judged by a panel of patients, parents, doctors, ethicists and scientists.

How they work: Submit one page and get your answer and your funds released in 15 days.



Traditional grants are large.

Their purpose is to deepen knowledge in a particular area by intensively studying specific questions.

Traditional grants are judged by a panel of scientific peers.

How they work: Submit 25 to 100 pages, receive your answer in 9 months and your funds released in 1 year.

Graphic courtesy Rare Disease Foundation

THE POWER OF VOLUNTEERING

While sharing your time and skills with our charity benefits our community, did you know that volunteering is the secret power of happy, successful people? The Tumour Foundation relies on volunteers to carry out its mission. From board governance, to fundraising, to raising awareness, there are a variety of ways you can get involved in our charity.

While sharing your time and skills with our charity benefits our community, did you know that volunteering is the secret power of happy, successful people?

Research has repeatedly shown that working in the service of others enhances physical, mental and emotional well-being.

Studies have shown that volunteering helps people who donate their time feel more socially connected, thus warding off loneliness and depression. And there is a growing body of evidence that suggests people who give their time to others are also rewarded with better physical health – including lower blood pressure and a longer lifespan.

Evidence of volunteerism's physical effects can be found in a recent study from Carnegie Mellon University. Adults over age 50 who volunteered on a regular basis were less likely to develop high blood pressure than non-volunteers. High blood pressure is an important indicator of health because it contributes to heart disease, stroke, and premature death.

If you are inspired to start volunteering, I invite you to take a moment to pause and reflect on these seven questions below, as one kind of volunteer experience will not fit everyone.

1. *What are my interests?*
2. *What are my skills?*
3. *What do I want to gain from the experience?*
4. *How much time do I have to give?*
5. *Do I want an ongoing position, a short-term position, or a one-day special event?*
6. *Do I want to work alone or with a group?*
7. *How will my volunteering affect my other commitments?*

At the Tumour Foundation we will work with you to find just the right position that fits your lifestyle and your goals. Check out our website for volunteer opportunities at tumourfoundation.ca/volunteer

MARK YOUR PLACE WINNERS



We were honoured to receive the submissions to the recent Mark Your Place Art Contest. This contest was open to youth living with neurofibromatosis. The purpose of this initiative was to engage our young community, and have them share creatively what it meant to have a diagnosis of neurofibromatosis.

Here are the winning creations that will be turned into promotional postcards and bookmarks this summer as we continue to raise awareness for the disorder.

WHAT IS NEUROFIBROMATOSIS?

Neurofibromatosis (NF) is a rare genetic disorder that causes tumours to grow on nerves throughout the body

NF affects
**ONE IN
3000
BIRTHS**

50%
of all NF cases
occur in families
with no
history
of NF



**3 TYPES
OF NF:**
NF1, NF2, and
Schwannomatosis

NF IS NOT CONTAGIOUS

You are
born
with it



NF IS NOT PICKY

It affects all
genders and
races equally



NF IS NOT CONSISTENT

Its symptoms can be
wildly different from
person to person

THERE IS NO CURE YET

Find out more and get involved at
TUMOURFOUNDATION.CA

