

Ever Onwards



MANITOBA
NEUROFIBROMATOSIS
SUPPORT GROUP
"New Friends Make The Difference"
mbnf.ca

This newsletter is dedicated to bringing new friends together to improve the quality of life for those living with NF and coming together in hope of finding a cure.

Voice of the Manitoba Neurofibromatosis Support Group

Fall 2014

We will face each new challenge together as a family

A Mother's Point of View
By SHANNON GOODALL-GEORGE

Our son Dane is 9 years old and he has been diagnosed with Type 1 Neurofibromatosis (NF). We had a confirmed diagnosis the day before his second birthday.

It had been suspected since shortly after his birth that he may have NF, as he had multiple café-au-lait marks on his body, but it was only confirmed after he had a bad fall. He had a CT Scan because of the fall, the scan was clear for the bump on his forehead, but did show something suspicious behind his right eye.

Our family doctor ordered an MRI and it confirmed he had an Optical Glioma behind his right eye. Meeting two of the eight criteria provided a positive diagnosis of Type 1 NF.

The news of his diagnosis felt like someone had just hit us with a baseball bat. It sunk in very quickly how this was going to affect our lives once we started re-



NINE-YEAR-OLD DANE GOODALL-GEORGE is the one diagnosed with NF, but he is facing the genetic disorder with the dedicated support of his sister, Kennedy, and parents Shannon and Ian.

ceiving appointment notices from doctor after doctor. From neurologists, to geneticist, to oncologists and child psychologists – we have had contact with almost every

type of doctor we knew existed.

Every step of the way we have received the best care we could have asked for Dane.

NF is a genetic disorder that affects one in 3,000 people and its affects can vary from very mild to quite severe and life altering.

For Dane, the majority of his symptoms have been mild to moderate.

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Help end Neurofibromatosis by joining the confidential NF Registry. To learn more and participate, please click here or go to www.nfregistry.org

Mission Statement

The Manitoba Neurofibromatosis Support Group is committed to improving the lives of individuals and families affected by NF.

MBNF provides support, promotes awareness by educating the public and helps fund research to improve treatment and find a cure.

Vision Statement

MBNF envisions lives freed of physical and emotional pain caused by Neurofibromatosis.

What Is MBNF?

The Manitoba Neurofibromatosis Support Group was formed in 2005. It is a registered non-profit voluntary organization. The group provides an opportunity for families and individuals affected by NF to connect and develop friendships while sharing resources on this largely unheard of, yet common disorder.

Majority of Dane's symptoms mild to moderate

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He has Optic Gliomas behind both eyes and multiple other non-cancerous tumours in his brain that so far are not dangerous, but have affected his physical growth, his balance and have created some learning impairments. As Dane has gotten older he has added the freckling to the list along with absentee seizures and headaches.

It has just been recently that we are really starting to feel the effects of Dane's diagnosis: His mood has changed dramatically; he is becoming more emotional with everything; he is struggling more at school than ever before; and has started to regress in some areas, especially his speech.

He just wants to be at home where he feels safe. Previously he was extremely outgoing and never worried about meeting new people or making new friends. His never ending smile has disappeared and the twinkle in his eyes has faded.



We don't know what the future holds for Dane, but one thing will always remain true and that is, we will face each new challenge together as a family as it maybe Dane who has this diagnosis, but it affects all of us in our family.

Being an active part of the Manitoba Neurofibromatosis Support Group has provided support and education to the whole family. We are just trying to learn how to deal with this lifelong diagnosis that doesn't necessarily have to be as hard to deal with as it is to say or spell. "NF" - New Friends really do make a difference!

Taking steps to improve lives of friends living with NF

MBNF provides confidential support and distributes information about NF to members, families, health care professionals, and various organizations.

We publish an annual newsletter and hold two Support Group Meetings each year.

We host an up-to-date website with a members Forum.

We host a variety of fundraising events and group get-togethers to support those living with neurofibromatosis.





We continually look for ways to advance the awareness of NF.

Contact:

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<http://www.mbnf.ca>

   
<http://www.youtube.com/user/mbnfca>
<https://twitter.com/MBNFSupport>
<http://mbnf.ca/feed/>
<https://www.facebook.com/pages/MBNF-Manitoba-Neurofibromatosis-Support-Group/111326038882795>

Coming Events

Benefit Fundraiser Oct. 24

Fall Meeting Oct. 25

Santa Photos Dec. 6

Visit our website, check us out on social media or call the contacts to learn more about these and other activities.

Connect With Us <http://www.mbnf.ca>





Run 4 NF events were held in Manitoba this summer, including Minnedosa (above collage) and Winnipeg (below). Both enjoyed wide support and brought together many of the Manitoba families dealing with Neurofibromatosis.

2 Run 4 NF events

This year marked our first annual Run 4 NF in Winnipeg and the return of our Run 4 NF in Minnedosa, which started in 2006.

The weather was fantastic for both events and the turn out was great, with between 80-100 participants. We are thankful to Eddie and Brenda for organizing the Winnipeg Run, for continued support from the Menard Family, and for all our wonderful volunteers and generous sponsors. We look forward to seeing you at next year's events.



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December 14, 2013

Winnipeg Goldeyes Baseball Club
Field of Dreams Foundation
One Portage Avenue East
Winnipeg, Manitoba R3B 3N3



To whom it may concern,

Thank you for your generous donation to Manitoba Neurofibromatosis Support Group. Because of your donation, I was able to attend the Children's Tumor Foundation NF camp this summer. It was a great experience!

I especially enjoyed the high ropes course, horse back riding, the water slides, the arcade, and making new friends. I hope to go again another year, because it was really fun. It is also great to meet other people who have NF.

Sincerely,
Isaak Lendroy

September 19, 2014

To the Winnipeg Goldeyes:



Thank you for letting me go to camp this year it was awesome we went to a water park and many more exciting places!

It was fun to go to Salt Lake City and I was privileged to have the opportunity to meet other people that have NF.

Thank you so much for your donation to MBNF to help me go.

From:
Kiara DeGagne

A Heartfelt Hello!



Dear friends,

I have had the privilege to work alongside many of you in past years, but am thrilled for the opportunity to work as your executive director. I am passionate and eager to create awareness about Neurofibromatosis and our support group. I believe it is vitally important to empower our friends living with NF to be the best possible advocates for this disorder.

We learned about Neurofibromatosis when our youngest son Seth was diagnosed 14 years ago, at only three months of age. Prior to that, neither Troy nor I had ever heard of NF. Many of you will understand that all too well! In reality, not many people HAVE heard of Neurofibromatosis before their initial diagnosis. So when we learned that the disorder affects one in every 3,000 people, we were both surprised and frustrated. The doctor handed us a little piece of paper with one big word scribbled on it. No information at all about the word that was about to change our entire world, and no one to turn to for help.

Thankfully today, that does not have to be the case! MBNF is working to make the diagnosis easier by providing some much-needed support. We have many goals, hosting our first NF Forum and the creation of a monthly NF Clinic just to name a few. I truly believe that together we are stronger, and that together, we will conquer the NF battles we need to face.

Wishing you hope, health and happiness,
Tracy Gregorash
Executive Director
tracy@mbnf.ca

#getwhipped4NF challenge set to raise funds, awareness

It was bound to happen: The ALS ice challenge is an amazing viral phenomenon to create awareness and funds for a very worthy cause! Now we have a similar type of challenge started for NF – #getwhipped4NF.

We take a whipping for our friends...no not a beating, unless you are using beaters to whip your cream! We take a face wash with whipped cream. It's really quite tasty! Barely fair, considering our friends with NF go through so many painful surgeries,

live with disfigurement, loss of sight, hearing and continued monitoring of their tumors. We just want to sweeten up their lives with a little fun and a lot of support. A cure is desperately needed. Please start up your own #getwhipped4NF challenge and nominate some family members. Let's swamp Manitoba with NF Awareness and raise some funds for #mbNF along the way. It's easy to donate online at www.mbnf.ca for those that do not want to #getwhipped4NF.



Connect With Us <http://www.mbnf.ca>



The Neurofibromatosis Awareness Month Act

(Submitted by Annette Lissenberg)

Earlier this summer, after a lengthy process and with the support of MLA Leanne Rowat, Bill 214 declaring every May **'Neurofibromatosis Awareness Month'** was successfully passed!

A group of individuals from MBNF were present in the legislature on June 9 for the third and final reading and motion to pass the Bill. It was an exciting day for everyone involved and various news/media were present to interview several of us and report on the bill passing, as well as to hear some of our personal stories. The final part of the process took place the week after Bill 214 was approved, where six or seven MBNF members shared their personal stories in a private session with a group of MLAs.

Tracy Gregorash, Executive Di-

rector of the MBNF, and Leanne Rowat, MLA (Riding Mountain) worked together tirelessly to ensure this Bill was passed. May 2015 will be the first official NF Awareness Month in Manitoba!

As it appears on the Provincial Website (<http://web2.gov.mb.ca/laws/statutes/2014/c04014e.php>), the *The Neurofibromatosis Awareness Month Act* reads as follows:

(Assented to June 12, 2014)

WHEREAS neurofibromatosis (NF) is a neurological disorder affecting one in every 3,500 births, and for which there is no preventative treatment or cure;

AND WHEREAS NF causes tumours to form on nerves anywhere in the body, resulting in disfigurement, blindness, deafness, learning disabilities, abnormal growth, epilepsy and cancer;

AND WHEREAS there is a need to

promote awareness, education and discussion about NF to ensure that the needs of NF patients are acknowledged, and to support research that may bring hope to patients and their families;

THEREFORE HER MAJESTY, by and with the advice and consent of the Legislative Assembly of Manitoba, enacts as follows:

Neurofibromatosis (NF) Awareness Month

1 The month of May in each year is to be known throughout Manitoba as Neurofibromatosis (NF) Awareness Month.

C.C.S.M. reference

2 This Act may be referred to as chapter N83 of the Continuing Consolidation of the Statutes of Manitoba.

Coming into force

3 This Act comes into force on the day it receives royal assent.



ON HAND FOR THE AUSPICIOUS OCCASION at the Legislature, June 9, were Kari Goodall (standing, from left), Jeff Nykoliati, Doreen Loewen, Kennedy Goodall-George, Shannon Goodall-George, Becky Penner, Carol Philip, Margaret Hay, Kathleen Demers, Lyndon Demeres, Leanne Rowat (front), Nancy Anderson and Tracy Gregorash.

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Lindsay Willms
(Treasurer)

Lindsay is married to Arron and has two young boys, Connor, 9 and Mason, 7. Lindsay enjoys camping and being outside. If she can find time, she enjoys a good book. Lindsay works at Raynor Bookkeeping Services in Brandon.



Brenda Marion-Gerula

Brenda is married to Eddie, they have four children, Ethan and Julian 6, Aidan 5 and Abigail 2. Brenda and her husband love running together. Brenda loves to run long distance and by October will have completed 23 half marathons. She also runs a home daycare.



Shannon Goodall-George

Shannon is married to Ian and they have two children, Kennedy, 12 and Dane, 9. They live in Oakbank with their three pets. "I love scrapbooking, history of Winnipeg, reading, water sports, watching my kids play sports and the Winnipeg Goldeyes."

Meet the MBNF Board of Directors



Christa DeGagne
(President)

Christa is married to Corey and they have two daughters, Kiara, 12 and Kaylee, 6. Christa works at the University of Manitoba and in her spare time likes staying active and having fun with family.



Troy Gregorash

Troy is married to Tracy and they have two children, Levi, 16 and Seth, 14. They live in Minnedosa where Troy works for Manitoba Hydro. Troy loves watching and playing hockey and flying.



Lyndon Demers

Lyndon lives in Winnipeg and works for Skybridge Americas and Walmart. He enjoys spending quality time with family and friends. He also enjoys playing and watching hockey, watching football and playing video games, and he also enjoys some water sports and camping.



Nancy Anderson
(Vice-President)

Nancy is married to Blair and they have an adult son, Neal. She works at The Manitoba Museum and volunteers with the Manitoba Crafts Museum and Library, the Winnipeg Fringe and as a staff representative on The Manitoba Museum board. In her spare time she enjoys quilting, knitting and biking with their dog, Chloe.



Jeff Nykoliati

Jeff lives in Brandon and works for Meyers Norris Penny Limited. He enjoys curling, travelling and watching hockey, baseball and football.



Doreen Loewen

Doreen moved to Brandon to be closer to her two children, son-in-law and two grandchildren. She runs a bookkeeping business for small businesses. When not spending time with her grandchildren, she enjoys dancing, golfing and hanging out with friends. Introduced to kayaking, she's totally hooked and will be at it again next summer.



Appreciation Award

MBNF DELIVERS ITS FIRST Appreciation Award to Charlie Rimbault of Brandon. She was honoured for her many years of devotion towards those living with NF. Charlie started raising funds for MBNF at 14 years of age. She has been a race director in the run for NF; she created a Christmas Traditions fundraiser in Minnedosa; and has acted as the group's secretary for seven years. We consider her an honorary MBNF member, even though she has no NF within her family.

Fantastic fundraiser at Walmart

September 21st turned out to be a fantastic day for our Walmart BBQ Fundraiser despite the weather teasing the volunteers throughout the day.

The Manitoba NF awareness fundraiser is spearheaded by director, Lyndon Demers and was held at the Regent Ave. location. This BBQ was the most successful to date, with more people inquiring about NF and a total of \$680 raised and generously matched by Walmart.

Second annual Let's Dance for NF a rousing success!

By Doreen Loewen, MBNF Director,
Dance coordinator

The second annual "Let's Dance for NF!" was held on May 3, 2014. The evening began with an address from our Executive Director, Tracy Gregorash, which included a showing of MBNF's Public Service Announcement.

By a show of hands we determined that about 35 per cent of those in attendance had never heard of NF until they attended our Dance Benefit Social – we knew right then and there that we had accomplished one of our goals: to raise awareness of NF. Len Isleifson, Brandon's Deputy Mayor, also acknowledged this date as proclaimed by the City of Brandon as "NF Awareness Day."

The dance showcase included the Datura Belly Dance Troup and dancers from the Brandon and Westman area as well as 2 guest couples from Shirley's Dance Studio in Winnipeg. They entertained the audience with renditions of the tango, the Lindy hop, a two-step and some cabaret-style belly dancing.

The music man kept the dance floor hopping all evening and thanks to our many generous sponsors we were able to keep the dance prizes



GUESTS ARE INVITED by MCs, Trent Bartley and Amber Vandale (Star FM) to the dance floor to learn fun and creative dance moves.

flowing all night long. For extra kicks and giggles, Studio 78 sponsored a photo booth. This added the opportunity for anyone to choose to put on a little attitude with the available props and their best smile, and come away with a memorable photo!

Thanks to a generous business community and a group of hard-working and dedicated volunteers it was a wonderful evening. Good time had by all!

The 3rd Annual Let's Dance for NF will be held on April 25, 2015.

Mark your calendars and re-sole your dancing shoes!



DANA AND DUSTIN MAXWELL demonstrate the tango.



DANCE VOLUNTEERS (above) are dressed up having a well-deserved break at the photo booth, while soaking up the success of the evening. Trent Bratley (left) of Star FM, shows some of his moves.

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Thanks for making our work possible!

A&L Get Active
All that painting and Decorating
Avon
Beef and Barrel Restaurant
Black Tie Event
Bladeworx Barber/Salon (NEW 2014)
Booster Juice
Brandon Business Interiors
Brandon Jean's Day for Charity
Brandon School of Dance
Brandon Wheat Kings
Canada Safeway
Canadian Tire
Cando Rail Services
Centric Productions
Copy Cat Bags (Darian & Jordan Tratch)
Cranberry's Restaurant
Dari Isle Drive Inn
Demers, Kathleen
Derksen Mechanical Services Inc.
Dundee Designs
Dynamic Physiotherapy and Sports Injury Clinic
Elkhorn Resort
EnJoy Salon and Spa
Fabutan
Glacier Wash
Grower Direct Fresh Cut Flowers
Henuset, Tera (Evolve Salon)
Heritage Co-op
Home Hardware
Howling the Night Away
Kim's Chinese Restaurant
Kuipers Family Bakery
Landmark Theatres
Little Caesar's Pizza
Little Chief's
Longscape Design
M & M Meat Shops
Manitoba Harvest c/o Harvey Chippendale
Manitoba Hydro Employees
Mercedes-Benz
Minnedosa Chiropractic Centre
Minnedosa Credit Union
Minnedosa Pharmacy
MNP LLP
Modern Looks
Murray Auto Centre Brandon
National Bank Financial

Nykoliation, Jeff & Jeanette
Olive Garden
Photography by Dale
Planet Kia
Precision Toyota
Provincial Exhibition of Manitoba
Running Room
Shallako Acres - Shannon McKenzie
Smitty's
Sportsman's Park
Staples Business Depot
Star FM
Starbuck Credit Union
Steppin' Time Dance Studio
Subway
Sunrise Credit Union Ltd.
Sunset Gourmet/ It Works! - Donna Gerlinger
Super Thrifty Drugs Canada Ltd.
The Green Spot Home & Garden
The Minnedosa Tribune
Victoria Inn
Walmart
Westoba Credit Union Ltd.
Wheat City Cowtown
Wildflower Café
Winnipeg Goldeyes Field of Dreams Foundation
Words Work Brandon
YMCA

With so many terrific individuals, businesses and organizations helping us, we may have missed this opportunity to acknowledge everyone and so, to those whom we may have missed in this list, please accept our most sincere apology and know that any omission is entirely our fault and the public recognition you are due will be included in next year's newsletter.

Requesting Your Support

We are a volunteer-driven charitable organization and rely on the kind support of members, sponsors and the public at large to deliver our services. To learn how you can help, please visit our website, www.mbnf.ca, join our mailing list or link to our Facebook, Youtube and Twitter accounts. Stay connected and informed on our events and discussions. We count on the generosity of our friends and members to help us operate.

Connect With Us <http://www.mbnf.ca>

