Manitoba Neurofibromatosis Support Group

ANNUAL REPORT

2016

About Manitoba Neurofibromatosis Support Group

Mission and Vision

The Manitoba Neurofibromatosis Support Group was formed in 2005. The group provides an opportunity for families and individuals affected by NF to share their stories and resources. MBNF received its charitable status in August 2007.

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 aids in funding research to improve treatment and ultimately find a cure.

Vision Statement

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

What We Do

MBNF provides confidential support and distributes information about NF to members, families, health care professionals, and various customessaywriter.co.uk organizations. We publish an annual newsletter and hold two Support Group Meetings each year. We host an up-to-date website and a discussion forum on Facebook. We host a variety of fundraising events and get-togethers in support of those living with neurofibromatosis and we continually look for ways to advance the awareness of NF.

The NF Team

Board of Directors

Nancy Anderson, Chair | Brenda Miller, Treasurer | Suzanne Lendvoy, Secretary|
Christa DeGagne, Past President| Lyndon Demers, Director | Brenda Marion-Gerula, Director |
Corrine Bobrowich, Director | Kathleen Demers, Director | Becky Penner, Director |
Kevin Bonazew, Director |

Staff

Connie Krahenbil, Managing Director | Doreen Lowen, Book Keeper |
Tracy Gregorash, Volunteer |

MESSAGE FROM THE PRESIDENT

Nancy Anderson, President of the Board of Directors

As I completed my first full year as President, 2016 continued to be a time a growth and change for MBNF. Our success in achieving our mission to support families and individuals affected by NF is possible because of the dedicated work of volunteers and those who support our cause.

Each year our organization takes steps to raise awareness about NF while raising the funds necessary to continue that work. And those steps are not only figurative, but literally involve a lot of feet pounding on the pavement for the cause. MBNF was a charity partner with the Manitoba Marathon. Some of our members and supporters participated in the run while others manned our Expo booth or joined the enthusiastic cheering squad along the route. In June, we marked the 10th Anniversary of the Minnedosa Run 4NF. This momentous event was marked with special participant medals, a cake and a band. And finally, runners were treated to a picture perfect fall morning for the annual NF run along the Red River at Lockport.

There was also some fancy footwork involved along the way as well when Doreen Loewen and her amazing crew hosted the Dance for NF in Brandon. It was a great event with an entertaining dance showcase followed by audience participation on the dance floor. And lots of great auction prizes as well.

Sometimes it is just as important to kick back, relax, and have some fun as the MBNF family. The annual picnic in August was well attended and participants enjoyed an afternoon of good food, games and fellowship.

Once again we were pleased to be able to send be able to support the participation of three of our younger members at the Children's Tumor Foundation NF Camp in Salt Lake City Utah. This would not be possible without the generous support of the Winnipeg Goldeyes Field of Dreams Foundation and MBNF supporters. NF Camp is not just about a week of fun filled activities. It also offered the three teens the opportunity to meet with others young people living with NF and to form lasting connections.

As the year ended, we faced a significant change as Tracy Gregorash decided that it was time to step away from her work with MBNF and devote more time to her family. Over twelve years ago, Tracy, along with Christa DeGagne, was one of the founders of the MBNF. In all those years she has played a key leadership role in the organization and served for many years as President as MBNF moved from a couple of moms sharing stories to an active group making a difference in our community. Over three years ago, she took some time away from her teaching career and helped us transition from a solely volunteer organization. She stepped into the role of Executive Director and continued to dedicate her time and talents to working with, and advocating for all of us who are affected by NF. The accomplishments during her time are numerous, but a few of the highlights include achieving charitable status, raising funds for MRI goggles for the Children's Hospital, the proclamation of NF Awareness month in Manitoba, and our first NF Symposium. Tracy will continue to be involved with MBNF in smaller ways and we wish her all the best in her future endeavours.

Respectfully Submitted,

Nancy Anderson
Chairperson

MESSAGE FROM THE TREASURER

Brenda Miller, Treasurer of the Board of Directors

It has been my pleasure serving on the board for my first half of my two-year term. I have met many hardworking and dedicated individuals and have been busy with the transitions made during this year.

I am happy to report that I deposited all funds in a timely manner and issued all cheques needed for the operations of MBNF financial business. I submitted a reporting to our Bookkeeper for entry in order for her to prepare our financial statements. I initiated the bank signing changes for the new executive and we went to 2 signature required signature.

I have attended most board meetings, attended nearly all other meetings and events and volunteered to assist where needed i.e. Manitoba Marathon. I assisted with the process of hiring our new managing director, attended and contributed to the strategic planning session (& arranged food for the day). I also made contacts with various related parties to ensure timely record keeping for our MBNF group and answered queries promptly. I have learned along the way the uniqueness of MBNF and have provided input as a board member to the best of my ability.

I assisted with the filing of the 2017 Annual Return of Information re: Corporation Act and Income Tax Return filing with Doreen's lead and expertise.

I worked with Doreen Loewen, our bookkeeper and the remaining board with the transition and still have more to learn in the coming year regarding Sumac, issuance of donation receipts for tax purposes and more overall features of MBNF.

I look forward to continuing in the role of Treasurer and future volunteer opportunities for MBNF as they present themselves.

Respectfully submitted,

Brenda L. Miller, CAIB, FCIP, C.I.M.
MBNF Treasurer

FINANCIAL REPORT

Income	2016	2015
Event Income	$20,171.92	$27,565
Gifts – not receipted	$12,328.53	$34,762
Gifts – receipted	$25,513.38	$5,165.00
Gifts from other Charities	$5,157.87	$8,230.08
Merchandise Sales	$626.50	$567.00
TOTAL INCOME	**$64,344.00**	**$76,2001.03**
Expense		
Advertising and Promotions	$1084.33	$5,750.00
Awards and Grants	$4,121.05	$5,938.01
Depreciation Expense	$0.00	$1,401.59
Equipment	$0.00	$878.78
Bank Service Charge	$15.00	$0.00
Equipment	$77.28	$0.00
Fundraising/Event Expenses	$8,945.94	$6,278.38
Honorariums and Gifts	$50.00	$450.89
Insurance	$1,304.92	$0.00
Meeting Expense	$1,091.61	$10,120.09
Membership and Association Fees		$25.00
Miscellaneous	$154.12	$190.95
Office Expense	$2,215.42	$4223.86
Operating Costs		
Admin Assistant	$360.00	$0.00
Book Keeping	$1,424.75	$0.00
Executive Director	$10,925.00	$13,000.00
Professional Fees	$0.00	$1,312.17
Program Support	$2,538.06	$5,366.89
Transaction Fees – Canada Helps	$4.76	$0.00
Transaction Fee – Mercury	$588.94	$0.00
Transaction Fee – Race Rooster	$252.45	$0.00
Transaction Fee – Running Room	$161.70	$0.00
Promotional Materials	$0.00	$995.29
Volunteer Appreciation	$96.92	$83.75
TOTAL EXPENSE	**$35,412.25**	**$56,061.46**
NET INCOME	**$28,931.95**	**$20,139.57**

Message from the Executive Director

"It takes a great team to build a great organization"

It is those words that struck me the most when trying to figure out how to start my report (always the hardest, starting). I am so honoured to be writing a report and to be a part of this organization. There were large shoes to fill, Tracy was an amazing champion for NF. Her support in this transition has been invaluable.

The Board of Directors are an amazing group of people; and have been very busy. We did a strategic planning session in June, and new sub committees will be implemented in November.

Thank you to the support of the Board and members during this transition year. I have been honoured to be a part of this organization; and I am really looking forward to what we are going to do next year.

Respectfully submitted,

Connie Krahenbil
Managing Director

The Board

(President) **Nancy Anderson** is married to Blair and they have an adult son Neal. Nancy works at The Manitoba Museum. She also 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.

(Past President) **Christa DeGagne** is married to Corey and they have 2 girls, Kiara is 13 and Kaylee is 7. Christa works at the University of Manitoba and in her spare time likes staying active and having fun with family.

(Treasurer) **Brenda Miller** Brenda Miller has been employed in the General Insurance Industry for over 33 years and has achieved 3 insurance designations and recently obtained her Certified In Management (C.I.M.) designation. Brenda has a “blended” family with her husband Dale including two adult daughters and three adult sons. Brenda has been a volunteer for many years for various groups and has joined the board to support those living with NF including her long-time family friendship with the Demers family.

(Secretary) **Suzanne Lendvoy** is married to Robin Lendvoy. They have two sons, Isaak(17) and Nikolas (20). Isaak was diagnosed with NF1 when he was 7 years old, although some of the signs were present much sooner. The Lendvoys live in Regina, where Suzanne works as an occupational therapist. Since there is no formal support network for those with NF in Saskatchewan, Suzanne reached out to neighbouring provinces, and feels lucky to have found the MBNF group.

(Director) Be**cky Penner** is the only one in her family who has NF. She has two older sisters and a dachshund named Oliver. She enjoys to cook, make cards and spend time with family. She is currently working in administration at Executive Nursing

(Co-President) **Lyndon Demers** lives in Winnipeg and where he works for Skybridge Americas and Wal-Mart. He enjoys spending quality time with family and friends. He enjoys playing and watching hockey, watching football and playing video games. He also enjoys some water sports and camping.

(Co-Vice-President) **Kathleen** Demers has been a member since 2007. Kathleen has enjoyed 10 years of activities and support thru MBNF. Kathleen has been married for 33 years, is the proud mother of 3 adult children, 1 daughter-in-law and 1 beautiful granddaughter. She keeps busy working full-time in an elementary school as the Assistant Administrative Secretary. In her spare time, Kathleen enjoys time with her family and friends, quilting for charity raffles and spending time participating in MBNF activities.

(Director) **Brenda Marion-Gerula** I am a mother of 4 children, Ethan, Julian (10) Aidan 8 years old, and Abigail 6 years old.

I run a home daycare and enjoy running with my husband, together we have ran many half marathons, marathons and a few ultra marathons including a 24 hour run where we achieved 100km. 3 of my Children have NF, and Aidan has been going through Chemotherapy for an Optic Nerve Glioma. We have an amazing oncologist who has a passion for NF and Aidan has shown huge success with his treatment. We enjoy camping, movies and board games.

(Director) **Corrine Bobrowich** is married to Brad and they have 2 children, Brady (10) and Brooke (7). They live in St. Andrews, MB. Her son, Brady has NF 1, being diagnosed at 5 months of age. She is a Physiotherapist and she and her husband own their own clinic (Steelcity Physiotherapy) in Selkirk, MB. In her spare time, she enjoys camping/ cottaging, playing volleyball, jogging and spending time outdoors.

COMMUNICATION

Website

MBNF is proud to have a very modern website where we post our mission, events and member stories for people to use as a reference. Our website is often a first point of contact for folks in search of support, so we work hard to keep our best foot forward here! The website also enables us to keep reference materials and event updates available 24/7! We value our members and want to keep everyone informed of our events and fundraising efforts. We also have a DONATION opportunity available on the website to help with fundraising.

Please see our website to learn more about Neurofibromatosis, our group's activities and member's stories. http://www.mbnf.ca

Facebook

This page is dedicated to those living with NF as well as their families and friends. It is a great way for everyone to participate in exchanging stories, ideas and information! It helps us reach a wider audience to create awareness about NF, our group and updates on the various events. Please check it out and be sure to 'like'!

MBNF also hosts a Virtual Coffee Group for its members. This is a private page reserved for those who have NF and their immediate family members. It is intended to be a safe place for people with NF to be comfortable to discuss their challenges, struggles and triumphs with other members. The Coffee Group is a lovely gathering of friends, and the discussion is lively and uplifting!

Database

MBNF has been working to establish a database for group members. This platform enables us to communicate more effectively with our group, integrate our events and fundraising with our website, and perhaps most importantly, create a credible, quantitative measure of the support services we offer. Ultimately, we envision a Patient Care Coordinator at the provincial level who will coordinate medical and other support services for those with NF, and in order to strengthen our voice, quantitative, empirical data must be available to substantiate our request. As MBNF group membership continues to grow, we are committed to gathering meaningful data that will be used to advocate for best patient care, and contribute to meaningful research.

EVENTS

Let's Dance for NF

The Let's Dance for NF event was May 14, 2016 at the Victoria Inn in Brandon, MB! The evening involved a Dance Showcase, talented MC's and DJ, plus great prizes and an auction!

Manitoba Marathon – Charity Partner

In 2016 we were honored to be a charity partner with the Manitoba Marathon held in Winnipeg! Approximately 208 participants gathered and participated in various events (including the Super Run, 10k, relay, half marathon, and full marathon) wearing the MBNF bib!

Congratulations to all those who participated in the event, including runners, volunteers at the NF booth at the Expo and of course, our wonderful cheer team!

NF Fundraiser

A HUGE thank you to everyone who came out to Nicole Rayy CD Release Party and NF Fundraiser!!

Thank you to everyone who helped make it possible. We could not have done it without you!! Special shout out to Kimberley Dawn, Now Country 104.7, Cowboys Roadhouse, Rhia Rae and the Rubies, Aaron Starr, and Tyler Del Pino for doing what they do so well and adding to the night!

Annual Picnic

Every August, MBNF group members meet on a Sunday afternoon at a park for an afternoon of food, games and fun. The 2016 Annual Picnic was a great success!

It is a wonderful opportunity to interact with other NF families and friends whose support is invaluable!

NF Camp

In partnership with the Children's Tumor Foundation, Camp Kostopulos hosts 2 weeks of specialized NF camp in Salt Lake City, UT. It boasts a variety of activities such as swimming, horseback riding, camp fires, rope course, climbing wall, fishing and day trips. Everyone attending the camp is affected by NF, which creates an atmosphere of compassion and understanding, and an opportunity to build friendships with those who live with similar issues. The camp is a fantastic opportunity for young people who are living with NF, not only for the physical adventure, but also for the social support and confidence they gain that lasts well beyond the duration of the camp. In 2016, the Winnipeg Goldeyes Field of Dreams Foundation awarded $2,000 to MBNF to provide a scholarship to attend this amazing camp. Our support group was able to help two other teens join them on this adventure.

Run with Me – Lockport River's Edge Run

The inaugural Lockport Run was held on September 19, 2015 and this year the 2016 had a total of 208 participants, all receiving a finisher medal and pancake breakfast. The run generated a total of $16,823 for MBNF. Much of this money is from business sponsors and online and in person donations. This event continues to grow and create awareness to MBNF and the cause that it serves.

May is Awareness Month

NF Awareness Month is May!

In 2014, Bill 214 was passed in the Manitoba Legislature (sponsored by Mrs. Leanne Rowat), which proclaims the month of May each year as Neurofibromatosis (NF) Awareness Month. In 2016, MBNF celebrated the event by holding a public education event, our trivia contest; a support group meeting, school presentations; and Employee Soup Fundraiser – thank you to Skybridge and its employees for supporting NF Awareness Month.

Thank you!

To everyone who supported us and helped us make the lives for those living with Neurofibromatosis just a little bit better.

For more information visit us at mbnf.ca/ or join us on Facebook at facebook.com/MBNFsupport/