MBNF

New Friends Make the Difference!

March 2009, First Edition

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Board of Directors

Tracy Gregorash
Christa DeGagne
Troy Gregorash
Charlie Menard
Kent Minshull
Nola Bowering
Jennifer Dawson

A Word from MBNF's President

Along with the board members, I would like to wish everyone a **late** Happy New Year. I am very excited with the approach of each New Year, because it is time to focus on a new goal or accomplishment. I am proud to say that the progress we have made during our first full year as a registered charity is something we should all be proud of. As the President, it is my goal to continue to improve our organization. It seems only fitting to start 2009 with our first annual Newsletter.

The Manitoba Neurofibromatosis Support Group continues to grow in number and spirit. We have a very active, encouraging and dedicated group of people who keep our growing number of events fun and organized. The participation from our members is what makes these events so special. Thanks to everyone who makes the effort to attend and/or help at any event they can! We love the opportunity to get together and enjoy each other's company.

I will briefly list the events which have developed into annual fundraisers or get-togethers. I would like to personally thank each person who has taken on the responsibility for these events, it is their dedication which makes our support group so special.

Summer Picnic-Stephanie Weselak

Run for NF-Charlie Menard/Tracy and Troy Gregorash

Wal-Mart BBQ-Lyndon Demers/Rhea and Steph

Spud and Steak-Christa DeGagne

Christmas Traditions-Charlie Menard

This was our first year to recognize a full year of donors with tax-exempt receipts. I would like to thank all of our donors who contributed to the growth of MBNF. I would also like to thank our treasurer, Troy, for the countless hours he worked through our new donation program.

We have numerous ideas evolving for our group. We are updating our website, resources and new library. An NF Summer Camp is in the works thanks to one of our members and we hope to initiate the purchase of MRI goggles for the Health Science Centre.

May this year bring health, prosperity and new advancements in our NF community.

Blessings to you and yours,

Tracy Gregorash

MBNF Picnic - Submitted by Stephanie Weselak

The Second annual MBNF BBQ in the park was held on August 16th 2008, in Assiniboine park. The weather was perfect and the turn out was spectacular. Thank you to all, that could make it out.

The afternoon was filled with laughter and fun and games. Some of which included a water fight, soccer game, and an attempt to break the piñata which was a little harder to break than expected.

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Jackson breaking the piñata

We had great food, organized by Christa and Cory and it was an all out great opportunity to meet new members and catch up with the old ones. I would like to extend a warm welcome to Helen and her son Bill from Winnipeg and Jeff from Brandon, whom we met in the park that day. It was great to meet you and I hope to see you and our other friends at many of the MBNF events in the near future.

Special thanks to Lyndon and Rhea for their help in filling the 200 water balloons and for helping set up for the day. Thanks also to those who came into the city for this event.

Please stay tuned for news on the 2009 picnic, and if you want to have any input on location, games, food please e-mail Stephanie at Littlecalgarycowgirl@gmail.com

Summer Camp - Submitted by Mike Gardner

I am proud to announce the Gardner family is building a camp/campground about 30 minutes outside of Winnipeg. We plan to host a part of each summer exclusively for children and families with NF! The projected grand opening is scheduled for the summer of 2010.

We have decided to build this camp in support of Floyd who will be working towards managing the camp. Some of you already know Floyd from the MBNF meetings.

There is still lots of work to be done and we plan to get busy on it as soon as the snow starts melting this spring. As well, this is being funded by our family so it's a bit slow (but steady). We hope to get government and other funding soon to help speed up the process. Our goal is to add things like a swimming pool, washrooms, several cabins and a dining hall over the long term.

Once we get everything in place we hope to open a full summer camp in the near future for our kids with NF as well as our other special needs children.

We are hoping to be able to host an MBNF meeting/weekend camp this summer 2009! We will keep you informed.

Calendar of Events

Support Group Meetings:

March 7th 3:30-5:00 PM
Westhaven, Portage Ave, Winnipeg

September-Possibly Portage again

Run 4 NF:

June 6th 10:00 AM
Minnedosa Beach

MBNF Picnic:

July-TBA

Summer Camp:

August-TBA

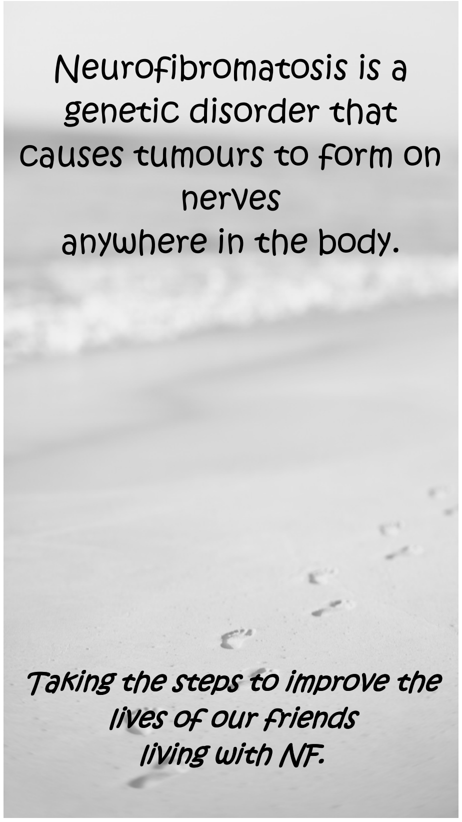
Wal-Mart BBQ:

TBA

Spud and Steak:
October or November-TBA

Christmas Traditions:

November or December-TBA



Neurofibromatosis is a genetic disorder that causes tumours to form on nerves anywhere in the body.

Taking the steps to improve the lives of our friends living with NF.

Run 4 NF - Submitted by Tracy Gregorash

Our third annual "Run With ME...4NF" event rose $5000 for our Support Group. This run has been started to help spread awareness about neurofibromatosis and our group. This past year was the first year our support group benefitted from the funds. In the past we have donated to the Rehabilitation Centre for Children and the Ronald McDonald House in Winnipeg.

The 5k and 10k race starts at the scenic Minnedosa Beach area and takes route through the town of Minnedosa finishing with a run across the Dam. We provide entertainment and refreshments after the run at the Pavilion on the beach. Prizes are also provided to top fundraisers and top runners in many categories.

This year's event will be held on June 6th and will start at 10:00 am. Please visit the Manitoba Neurofibromatosis Support Group at **www.mbnf.ca** to learn more about this event and Neurofibromatosis.

Spud and Steak- Submitted by Christa DeGagne

For the past two years MBNF has held a Spud and Steak fundraiser at Cowboys in the Windsor Park Canad Inn. The $12 ticket cost included a steak and potato meal and MBNF received half the proceeds from all the tickets sold. We were also fortunate to have arranged a 50/50 draw and a silent auction thanks to the generosity of many friends, family and businesses who donated prizes. On both occasions the event was attended by approximately 75 people and MBNF raised over $1000 both years. A special thank you to all who volunteered at the event.
The evenings concluded with Lyndon surprising Tracy with a donation cheque from the Wal-Mart Barbecue.
We hope to arrange another Spud and Steak fundraiser this year (in late October or November) and I look forward to your ongoing support. We will post further information on the website when available and hope to see many new faces there this year!!

Christmas Traditions - Submitted by Charlie Menard

For the past three years I have hosted a festive evening in early December at St. Mark's Anglican Church Hall in Minnedosa. My friends and family generously volunteer their time and effort to transform the facility into an awesome winter wonderland. Guests take part in an evening filled with local musical entertainment, traditional desserts and fellowship. This venue is a perfect example of how a community can be educated and come together in support of a cause that touches many of our hearts.

Those in attendance are given the opportunity to give a monetary donation to the MBNF Support Group. This event has always been a huge success and generous contributions this past winter totalled $1,400.00 for MBNF.

This annual event has become a very significant tradition for me and my family. I hope that Christmas Traditions continues to grow so that as a community we are able to show our appreciation for the difference that this support group is making in the lives of those living with Neurofibromatosis.

Meet Our Friends

Hi, My name is Cheryl McClelland. I'm 31 years old. My husband and I don't have any children, but we do have a very lovable dog named Storm. I worked as an optometric technician until 2 years ago when my pain level got so bad that I couldn't tolerate work anymore. I was diagnosed with NF at the age of 10 and have had numerous surgeries since then. I live with various levels of pain every day and am very emotional when talking about my struggles. It scares me not knowing what the future will bring and where the next tumour will grow. I've always tried to have a positive attitude which has helped me deal with it, but lately it's been getting harder to find the positive. Finding this support group and meeting others with NF has helped since I always thought I was alone in this struggle. I find it very frustrating that the doctors I have been to know very little about this condition, especially since it affects so many people.

MBNF gave me the opportunity to attend The NF Symposium in B.C. and it was a very emotional experience for me. It made me more aware of my daily struggles and the emotional pain involved in day to day living. I met many nice people during the conference and learned much more about NF. There was so much information to take in, in just one day that I found it very overwhelming. Some of the information that we received was very depressing, like the number of people that are affected with NF and the different faces to this disease. The fact that there are no rules or any one way that it affects people brought many questions forward. The speakers tried their best to answer all the questions but at the end they ran out of time and had to leave. I was encouraged by the research being done, it sounded like they are making some progress. The biggest goal is to make others aware about this condition, especially the medical professionals.

I found that the speakers that spoke on the psychological and physical effects of this disease had very interesting information. The psychological effects of this disease stuck with me the most, due to the fact that I've felt so alone in dealing with this disease for so long. I've had NF for 21 years and only recently found out about the support group right here in Manitoba so when the speakers talked about the depression, anxiety, pain and frustration that most people with NF experience, it really helped put things in prospective for me. I now know that living with NF is real and feeling bad is just part of dealing with it. Going to the symposium gave me a new confidence. Understanding that I'm not alone and knowing that there are people committed to finding a cure made me feel better.

Submitted by Cheryl McClelland

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MBNF
New Friends Make the Difference!

We're on the Web!

How You Can Help

Donations: We now have Registered Charity Status and are able to issue Tax-Exempt receipts for any donation of $10.00 or more.

Lanyards: We have lanyards to purchase for $3 each.
Email Tracy@mbnf.ca to have them sent to you.

Attend or hold a Fundraiser.

Neurofibromatosis is an umbrella name for three distinct complex genetic disorders (NF1, NF2 and Schwannomatosis) that share a common manifestation: tumour growth in tissues that surround nerves.

While most of these tumours are benign, they can occasionally become malignant. NF can also cause disfigurement, bone deformities and learning disabilities. NF affects all men, women and ethnic groups equally.

Approximately 10,000 Canadians have NF making it more prevalent than Cystic Fibrosis, Duchenne's Muscular Dystrophy, Huntington's Disease and Tay Sach's combined.

The disorder results from a spontaneous genetic alteration (50% of cases) or is inherited.

There is no cure and treatment strategies are still in the trial stages.

Mission Statement:

The Manitoba Neurofibromatosis Support Group is committed to improving the lives of individuals and families affected by Neurofibromatosis. MBNF provides information and support, promotes awareness and works to fund research to improve treatment and aid in finding a cure.

Vision Statement:

Bringing new friends together to improve the quality of life for those living with NF and coming together in hope of finding a cure.

Contact Information across Canada

BCNF Foundation
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Alberta NF1 & NF2 Association
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