



iNFormation

Winter/Spring 2016 - Newsletter

NFON

Neurofibromatosis Society of Ontario

Upcoming Events

May 1st, 2016

Semi-Annual Meeting
Board of Directors Election

May 17th, 2016

NF Awareness Day

Summer 2016

Taste of Lawrence
Summer Picnic

October 16th, 2016

Scotiabank Marathon

30th Anniversary Celebration

Neurofibromatosis Ontario kicked off our 30th anniversary celebration on Saturday, October 3rd, 2015 at the Holiday Inn in Toronto-Yorkdale. We were happy to have over 75 members in attendance, along with founding member, Mary Harris, and Dr. Brill from the new adult Neurofibromatosis clinic.

During the celebration, NFON President, John Huynh, proudly revealed our official new logo and the progressive changes the charity has undergone over the past year including our rebranding, new fundraising initiatives, and strategic plans. With a full board of directors, NFON has been able to focus on rebuilding our charity to meet the needs of our members, identify ourselves as a resource for those affected by NF, and increase our fundraising to support research.

Inspirational humorist, David Roche, brought the NFON audience to tears with his honest, humorous, and humbling presentation about his struggles with his own disability. David instilled a sense of community within the group by inspiring a positive outlook to the every-day struggles of life, regardless of whether you are a person challenged with a disability, illness, or disorder. As stated on his website, David is “guaranteed to open hearts and minds to inspiration, courage

and laughter,” and his presentation at the 30th Anniversary did not disappoint.

Following this, Mary Harris’ story of founding Neurofibromatosis Society of Ontario was shared. Mary’s story was filled with honesty and heartache, as we learned of the hard work and challenges NFON faced in the earlier years of its identity. As a continually growing charity, it was humbling to learn how far we have come, and it inspired confidence that we will continue to grow and support those affected by NF.

After 30 years, Neurofibromatosis Ontario is thriving and continuing to grow, and we have a lot to be proud of as a charity. Thank you to all those who were able to make it to the celebration and those who made it a success. We depend on the generosity of our speakers and volunteers to make these events happen, and we are forever grateful to these individuals. Cheers to another 30 years!



Key Note Speaker David Roche



Above: Our 30th Anniversary Cake

Bottom: Wide angle photo of 30th anniversary attendees





President's Message

Neurofibromatosis Ontario (NFON) has had quite the journey this past year. We celebrated our 30th anniversary, held several events to reinvigorate our charity. Starting with the launch our new logo, we kicked off May with the city of Barrie officially proclaiming May as NF Awareness Month, We gathered in front of the CN Tower to watch it light up in blue and green, and raised NF awareness at the Taste of Lawrence. Our members also gathered together for a summer picnic, ran local awareness events and some even ran like the wind at the Scotiabank Toronto Waterfront Marathon. All of this work would not have been possible without the help of my fellow board of directors, our volunteers, donors and especially our members in the NF Community. It is also with mixed emotions and a heavy heart for me to announce that I will be stepping down as President and from the Board of Directors at the conclusion of our Semi-Annual meeting this spring.

Elections will be held at our upcoming general meeting this spring which means that NFON is looking for new individuals to join our charity's Board of Directors. The board plays a key role in the work that our charity does. We encourage that board members are represented from across Ontario. The next couple of years promise to be both challenging and exciting for NF Ontario as we continue to grow. Those who join the board will have the opportunity to affect change during this period of growth and development. If you would like to positively affect the NF community, and have the time, I encourage you to apply.

The charity has made great strides and improvements over the past 18 months. I am proud to have the opportunity to be part of this board and the work that was accomplished. I have the utmost confidence that in the next chapter, the combined skillsets, passion and enthusiasm of our charity's new and returning directors have the capability to lead NFON onwards and upwards.

Sincerely,

John Huynh

NF Ontario donates \$3,500 towards Neurofibromatosis Research

NF Ontario recently made a donation of \$3,500 through the Toronto General and Western Hospital Foundation to the Elizabeth Raab Neurofibromatosis Clinic to support NF Research.



May is NF Awareness Month

NF Ontario will once again be working to raise the profile and awareness of Neurofibromatosis during the month of May. Last year we celebrated this month by having the CN Tower light up in blue & green on May 17th. We are happy to announce that the CN Tower and other landmarks across North America will be lighting up this year thanks to the work spearheaded by the Children's Tumor Foundation. We are also working towards getting more municipalities across the province to recognise May as Neurofibromatosis month in 2016.



If you would like to help us assist you in getting NF officially recognised in your own community please e-mail us at info@nfon.ca with attention to John Daly, Media Relations Director & put 'May Awareness' in the subject line.

Remember, the entire month of May is NF Awareness Month and a great time to connect with and educate others about Neurofibromatosis. A local event run by you is a great way to unite NF families, and meet new ones too.

Here are some ideas that are based on events our members have done themselves in the past to raise awareness and funds for NFON.

NFON can also help provide you with guidance if you want to run an event of your own

- **Yard Sale**
- **Pancake Breakfast & Silent Auction**
- **'Coffee Talk' at work to teach others about NF**
- **Bake Sale**
- **Casual / Jeans day at work**
- **Lemonade Stand**



When: Sunday May 1st, 2016 **Spring Semi-Annual Meeting**

Time: 10:00 am - 3:30 pm (Registration starts 9:30 am)

Where: Holiday Inn Yorkdale. 3450 Dufferin Street, Toronto, ON M6A 2V1

Our Semi-Annual meeting is a full day event. Included in the registration fee is: A buffet lunch, Personal Development Workshop, guest speakers from the medical community and more.

- Take part in the Personality Dimensions® development workshop
- Hear from Medical Professionals
- Meet other individuals NF in a safe environment
- The agenda and full list of speakers will be posted on our website and Facebook page in the coming weeks.

**Cost: \$10 for Adults
\$5 for Children & Teens**

Please **Register** and **Pay** online before **April 15th, 2016** at www.nfon.ca/events/SpringMeeting2016

You may also register over the phone by calling us toll-free at: (866) 843-6376

The registration fee is a fraction of the true cost to the charity to hold this meeting and helps us ensure adequate food and seating for our attendees. If you are not able to afford the registration fee, please contact us in advance. We have set aside a small budget to assist members who would like to attend but cannot afford to.

If you would like to book a hotel room, please contact the Hotel directly at: 1-800-291-9434 or online at: www.hiyorkdale.com

American Sign Language (ASL) and captioning will be provided upon request. In order for us to book an ASL interpreter or captionist, please advise us if you require either of these before March 31st, 2016.

NF Ontario promotes a scent-free environment. We request that you refrain from wearing fragrances or colognes at our meeting.

Seeking Applications to join our Board of Directors **Application Deadline: April 15, 2016**



NF Ontario is currently seeking individuals to serve as board members. Joining the board of directors is a 2 year commitment, with possibility for extension and leadership opportunities. We encourage applications from all people whether or not they live with Neurofibromatosis. We also encourage applications from outside the Greater Toronto Area, as our mandate is provincial in scope.

REQUIREMENTS AND DUTIES:

While we are interested in a variety of skills and experiences, we seek individuals with one or more of the following:

- Work experience in the private/corporate sector
- Experience working on non-profit boards
- Knowledge and skills in one or more areas of Board governance: policy, accounting (Not-for-profit preferred), programs, and/or personnel
- Skills and interest in philanthropy and sponsorship
- Connections to leadership organizations (e.g. business associations, media)
- Actively participate in the charity (5 to 10 hours per month)
- Attendance of board meetings, and general membership meetings
- Prepare for and participate in the discussions and the deliberations of the Board
- Establish overall short and long-term goals, objectives and priorities for NF Ontario
- Monitor and evaluate the effectiveness of NF Ontario through a regular review of programs and services
- Foster a positive working relationship with other Board members, volunteers and the NF community.
- Accountability to our donors for the services provided and funds expended
- Be aware of and abstain from any conflict of interest

If you are interested in applying to join the board, please send an e-mail to elections@nfon.ca with the following:

- Your resume,
- A short statement that describes your motivation for joining the board and how you can meet the skills we are seeking

Board position would take effect as of the next semi-annual meeting in May 2016.

A son's journey, a mother's struggle

As a parent like all others, I've always wished nothing but the best for my children. You grow with them, dream with them, you cheer for them, and you laugh and cry with them. I had already had a beautiful son that I was extremely proud of. I had thought of having another child but no plans at the time. Well, someone higher up had other plans for me. At the age of 35, I was blessed with another beautiful healthy baby boy, Patrick.

I had concerns that I had brought forward to the doctor at his 3 month checkup and continued to voice many more as time went on, constantly receiving reassurance that he was fine. At the age of 14 Patrick was diagnosed with scoliosis. At the age of 15, after many visits with doctors and specialists we were referred to Sick Kids where we received a diagnosis that my son has Neurofibromatosis (NF-1). This was devastating news to my son and family as we knew absolutely nothing about this disorder or what to expect. I can only relate my experience with Neurofibromatosis to a quote by Tom Hanks in the movie Forest Gump, "Life is like a box of chocolates, you never know what you're going to get".

Due to complications from NF-1, tumors developed over my son's torso and along his spine which I much later learned was the cause of the scoliosis. At the age of 14 years, his spine was at a 34 degree curvature. He was molded into a body brace that he wore for approximately 4 months, 12 hours a day, until we were finally advised by the orthopaedic surgeon that the brace was not going to correct his spine and the only other alternative was surgery. At the original diagnosis the curvature was at a 34 degree curve, within two years it escalated to a 93 degree curve.

After viewing and discussing the dangers of the curvature and the results of the x-rays and MRI's with the specialist, I went home and cried to myself knowing there was no other alternative, yet trying to stay strong and trying to keep my sons life as normal as possible.



Image of Patrick's spine

Elaine Samways, NF Ontario board member and mother of a child with NF shares a personal story on her experience with NF this past year.

Surgery was finally scheduled. My son would be turning 17 shortly thereafter. As the days grew closer to the surgery date my nerves were boiling over. Silently, I was terrified for him. I was obsessed with the surgery and every terrifying thought kept running wild through my mind. The "what ifs" and "should haves" took over, at the same time I had to remain calm and strong to keep everything as normal as possible for him. I kept searching for reasons to blame myself for what he was about to go through. Somehow I felt it was my fault. All I kept thinking was how he would never live his dream of being a police officer, it tore me apart.... but yet when I looked at him... wow ... he was a trooper! Amazing to watch actually, his spirit remained high and carefree, he showed no real signs of anxiety or fear. In hindsight, I believe he was being strong for us. Now I know where "NF Warrior" comes from. The strongest group I've ever had the pleasure to meet.

Finally, the morning of surgery, March 2, 2015, 8:00 am, prepped and ready to go. Suddenly it was almost cancelled due to lack of beds in the ICU. I couldn't imagine going through this waiting game of the unknown again so soon. An emergency meeting was held and the surgeon fought for my son as he believed he was at a critical state that at any time he could he could become a paraplegic on his very own, and we couldn't take a chance and wait another 4 months. At 10:00 am my son was called up for surgery.

"I couldn't eat and I was completely exhausted and terrified."

I can't describe my feelings as I watched him walk through the doors to the operating room. Due to the dangers and degree of his curvature, my first thought was, will he "walk" out of this hospital? I hadn't slept for two days, I couldn't eat and I was completely exhausted and terrified. It was the longest day of our lives, and I never prayed so hard in my life as I did that day. Family and friends came and went, supporting us. Thank God for them! The surgery lasted for 9 hours and he was in ICU for another 2 before we could see him. It was 11:00 pm, my family and I were sitting in the waiting room waiting for news when I saw the doctor walk in, and for a quick second I thought I was going to actually have

a heart attack until I saw the smile on his face as he greeted us. He brought us in a little room and explained the surgery to us and how pleased he was with the outcome. I was elated! Thrilled! I couldn't wait to see my son. Part of me was still afraid of the consequences and complications after surgery. My family and I went into ICU to see him. He was lying flat on his back sleeping. We each took our time alone with him and then everyone left but me. He woke up in pain and cried, repeating what he was told before surgery, they had promised that he would feel no pain when he woke up. I comforted him and spoke with the nurses and he soon had his meds and was sleeping comfortable. I finally decided to try and get in a nap. I went to a waiting area, curled up in a tub chair where a sweet nurse brought me a warm sheet to cover with. I dozed off for 20 minutes and during that time I kept feeling a vibration, I first thought it was just my body vibrating from the lack of sleep then quickly realized that it was my phone. It was ICU calling not once but twice. I rushed in to find him asleep again. I asked the nurse if everything was okay, she said she didn't know if this was normal but he wanted her to call me because he wanted his phone, he wants to check the stats? I was so relieved! I couldn't help but laugh and cry at the same time. I was thrilled as my heart skipped a few beats, because it was the NHL trade deadline day, his favorite game! From then on, I just knew he was going to be okay. He was transferred to his own room later the next day.

I stayed with him for the remainder of his five day stay at Sick Kids. He did amazing! He walked the day after surgery, gained an inch and a half in height, he was nicknamed Hercules by the nurses because he was so strong and so far advanced. He was very determined to get well and go home. He had many visitors from family and friends which made him feel the love, and a special visit from Morgan Riley, defenceman for Toronto Maple Leafs. His favorite player. He was stoked! That was a great day!

I can't say enough about Sick Kids other than they are the best of the best. The nurses and doctors were amazing, they explained and answered every question we had, I felt safe and blessed that my son was in their care. They are all cut from a special cloth.

We left for home on the fifth day, feeling nervous of the drive and how we were going to get my son in the car comfortably. Questions running through my head, how was I going to care for him, I'm not a nurse, can I do this? I felt alone and afraid that something terrible would happen. Once home he went

straight to his room where he remained it seemed for many long days and nights. Slowly, day by day he was improving and his recovery actually went better than expected. He was soon off all medication and almost back to normal. He continued to have family and friends visit, lifting his spirits. He was back in school 8 weeks later and continued into summer school.

He is now doing extremely well, graduating high school in a few months, going on a grad trip to Dominican, and looking forward to a future in Sports Management. I am so very proud of the courage and strength he has shown, how far he has come and how well he is doing physically and mentally and the young man he has become.

Soon we will be revisiting Sick Kids for his one year follow up post-surgery, and praying for a great outcome. I feel confident he will do well. I believe everything happens for a reason. I also believe as my mother always told me, when one door closes

another one opens. There is opportunity everywhere, take it and run with it. Keep your faith and spirits high and you can conquer your fears. I've learned from this experience that fear and worry is the worst obstacles in life, conquer that and all there is left is wonderment and joy. Just something to think about.

Will my son live the dream of being a police officer? Most likely not. Do we know what his future holds? No, but I do believe he will do great things with his life? Absolutely, confidently 100%. He has a powerful will to overcome any obstacles in his life and do wonderful things. He has already taught me a lot from this experience without even realizing it. To me, that is an amazing start.

- Elaine Samways

“He was very determined to get well and go home.”



Patrick Samways, Age 17

“There is opportunity everywhere, take it and run with it. Keep your faith and spirits high and you can conquer your fears.”

- Elaine Samways

1st Annual Holiday Party

NF Ontario held its first annual Holiday Party at the Earl Bales Community Centre in Toronto on Sunday, January 10th 2016.



Fun in the Photo Booth!

Over 50 members, including a number of families new to the NFON community, came out to beat the post holidays blues and celebrate the season all over again with the NFON family. We had music, games, prizes, arts and crafts, raffles and a secret Santa gift exchange for the kids! Lots of yummy treats and pizza were served and everyone enjoyed a lunch and visit together. The photo booth, with props and costumes, provided by Chris MacDonald was a big hit for kids and adults alike. More pictures of the event can be found on the nfon.ca in the pictures tab. With such a successful first event we will be having an Annual Holiday Party so stay tuned for the

date for next year's party which will be posting in the fall. Hopefully we will have double the turn out and can have double the fun for year 2!



Our party goes smiling for the camera



On Sunday October 18th, 2015, members, families, and friends of NF Ontario participated in the Scotiabank Toronto Waterfront Marathon as part of Team NF WARRIORS!. Collectively our team of walkers and runners helped raise over \$8,547 for NFON.



L to R: John, Julian and Kathy

The 2016 marathon is scheduled for Sunday October 16th, and NF Ontario looks forward to participating again. More information on how you can participate will be available this summer.



Some of our NF WARRIORS at the finish line

Pictures from our 30th Anniversary Celebration



Volunteers recognised for their contribution to NFON



Keynote Speaker, David Roche and NFON founder, Mary Harris



One lucky member was the winner of an Toronto Raptor's Jersey autographed by DeMar DeRozan



NFON Members: Nicole, Sue, Kathy & Dariusz



Vice-President, Sonya Corson and President, John Huynh



Taking part in our ice-breaker activity

NF Ontario would like to say thank you to all our members, friends and donors for your support in 2015. Your help, donations, and participation has allowed our charity to help raise awareness about Neurofibromatosis and bring people with NF together from across the province. Thank you also to the professionals in the medical community for your tireless work in improving treatment and care of individuals with NF.



Franca Agosta	John Daly	John A Heddle	Rhonda Nasby	Peter Takeda
Giuseppina Amato	Jim D'Amico	Pat & JP Holenski	Betty Nelson	Susan Tastula
Antoinetta Aprile	Jill Davies	Lori Hull	Harold O'Brien	Frances Therrien
Carolyn Basso	Rita Dermott	Shawn Hull	Elaine Oram	Cec & Lee Thorsby
Colleen Beattie	Alejandra Galvan	Giovanna Infantino	Harvey & Joan Pinkerton	Marilyn Totten
Al & Mary Beaucage	Anne Downing	Carol Ireland	Helen Pleadwell	Marcela Uribe
Craig Bentley	Debbie Dumaresq	Judith Johnson	Bailey Powell	Jodi Van Damme
Vera Bentley	Katherine Farnell	Tom Johnson	Edith Preston	Willy Vander Wielen
Warren Biback	Josephine Foley	Mike Johnston	N Razeena Fernando	Marlene & Eric VanDyne
Robert Bingham	Rod Foley	Darlene Klassen	Doug Reith	Frank & Anna Vecchio
Arelene Bolliger	Shirley Foley	Denys Kowlessar	Eddie Ribble	Quintino Volpe
Laura Bonavota	Ruth Fountain	PJ Kursell	Helen Ribble	Joseph W Venne
Vincenzo Bonavota	Francis Gabriel	Sheila Lawson	Lucie & Dooley Ricci	Sigmund White
Rosario Bonomo	Ines Gabriel	Heather Lenz	Rod Rye	Doris Whitehead
Mary-Jane Bowyer	Nancy Gardiner	Paul Lohnes	Doris & Marshall Sands	Dave Wong
Lawrence Boyes	James Gardner	Geraldine M Deveau	Bruce Sargeant	Don Wright
Rocco Cacciola	Rose Garofalo	Margaret MacCallum	Lynda Sargeant	Inta Zvagulis
Theresa Carey	Donna Gascho	Orazio Macri	Betty Schmidt	
Candy Chan	Marilyn Georgiou	David McCarthy	Teresa Seeley	Desjardins General Insurance Group Inc
Louise Chow	Natalie Gould	Edna McFarlane	Dave Sharbrook	Pembroke Petawawa Lions Club Inc.
Mary Cogan	Jane Groom	Norman Meunier	Mary Slingerland	Stayner Lions Club Inc.
Arlene Corbett	Sharon Guillemette	Len Milligan	Linda Smith	
Rob Cornish	Ann Haran/Larry Alpin	Mike Mitchell	Tom Smith	
Tamara Curtis	Mary Harris	Luis Munoz	Paul Staveren	
Andrew Dalakoudis	Judy Harvey	Janet Nancarrow	Yvonne Tai	All anonymous donors

We would also like to thank those who donated anonymously, through their charitable giving programs at their place of work, and the many donors who sponsored our walkers and runners in the Scotiabank Toronto Waterfront Marathon.

While we make every attempt to ensure the accuracy of our public acknowledgement. We do apologise if we have accidentally omitted your name.

Contact us:

Neurofibromatosis Society of Ontario

PO Box 91119, Bayview Village
Willowdale, ON M2K 2Y6

Phone: (905) 638-0811
Toll-free: (866) 843-6376
E-Mail: info@nfon.ca
Website: www.nfon.ca



Neurofibromatosis Society of Ontario is a registered charity run entirely by volunteers. We are not funded by the government and rely on donations and fundraising to financially sustain our activities which include newsletters, toll free help line, literature, support meetings and calls, family events and more.
(Charitable # 11905 3775 RR0001)

Our current Board of Directors are:

- | | |
|---|--|
| John Huynh - <i>President</i> | Tory Johnston - <i>Events Coordinator</i> |
| Sonya Corson - <i>Vice President</i> | Claire McDonald - <i>Volunteer Coordinator</i> |
| Annamaria Grassa - <i>Treasurer</i> | Sharon Caunan - <i>Membership Coordinator</i> |
| Elaine Samways - <i>Secretary</i> | Lynne Leyland - <i>Medical Liaison</i> |
| John Daly - <i>Media Relations</i> | Chris McDonald - <i>Technology Coordinator</i> |
| Sue Corson - <i>Fundraising Coordinator</i> | Birgit Grimberger - <i>General Director</i> |

NFON provides information to educate the community about issues and information related to Neurofibromatosis. Unless specifically indicated, we do not endorse any treatment, program, product, or service.

NF Registry

The NF Registry created by the Children’s Tumor Foundation in 2012 is an attempt to create the largest worldwide database of individuals with NF so that together we can speed the development of promising new treatments. The NF Registry seeks to match patients with trials and make it easier for people living with NF to find opportunities to get involved with research. It is a way to better understand the "natural history" of the disorder, and why the symptoms of NF can be so different from person to person. It also lets patients see the "big picture" of the group as a whole by viewing Registry charts and graphs. All information is confidential and no names are attached to these charts and graphs.

If you would like to take part in the NF registry and for more information visit:

www.nfregistry.org

Membership

A reminder that a membership with NFON is now just **\$10 a year.**

Your membership can be purchased or renewed by mail, phone and online.

To download a form or renew online, visit our website at:

www.nfon.ca/membership

Donate Online

Did you know you can also donate online at **www.nfon.ca/donate**

#NFWarrior



Jaimelee, Age 9

Perseverance with a smile best describes 10 year old Jaimelee, who was diagnosed with NF1 at 15mths old. It is a smile that lights up her face and brightens those around her. Jaimelee has an optic glioma brain tumour.

She had chemotherapy from January 2012 to June 2013. Unfortunately the tumor still grew, so chemo again from Nov 2014 to Dec 2015. She just began another round of chemo in Feb 2016.

Jaimelee has made many friends on her journey and participated in some great activities and camp. She has been an awareness ambassador and also raised money for the hospital. And through it all, her smile shines on.

Her tumour has taken most of her vision in the right eye, early puberty, balance issues and many days off of school. Yet despite everything, Jaimelee usually has her smile on, laughs a lot and is a good friend to others.

She looks forward to making many more friends through out this journey. She is what "hero" means to her mother.