

ANNUAL COMMUNITY REPORT

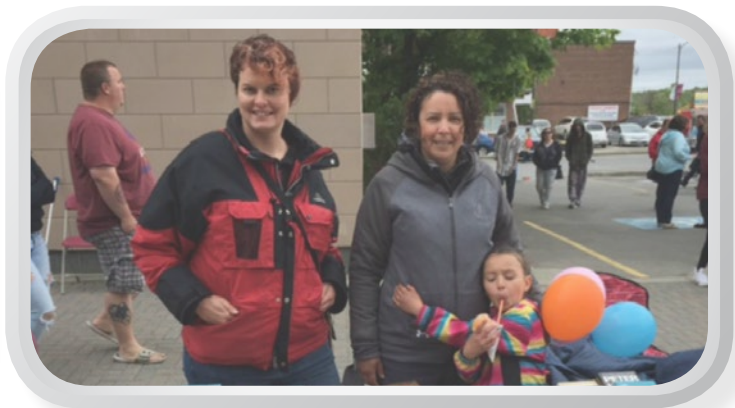
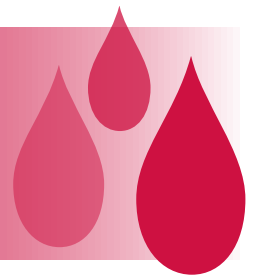
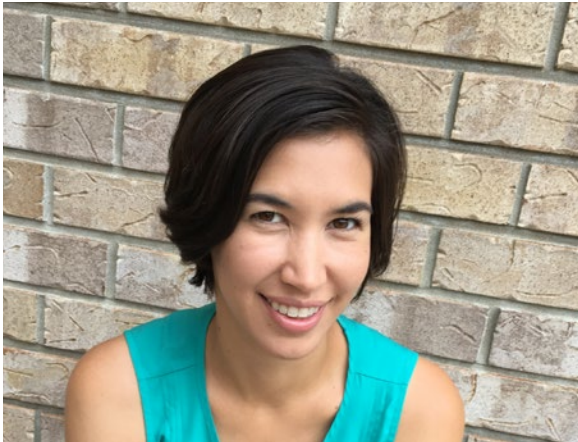




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2016 was a busy year for Hemophilia Ontario, as most of you would know better than I. When I joined the organization in December, it became clear that it had been a year of change at every level. It is impressive, and indicative of the organization's resilience, to look back now on all that was accomplished.

From traditional programs to new initiatives, support for patients through product changes, assistance navigating the 86-90 settlement and product recalls/withdrawals, Hemophilia Ontario was actively involved and making a difference throughout the year. Community Camp, in particular, was a tremendous success this year, with over 100 participants filling the program to capacity within days of registration opening. We were able to send one of

our largest contingents ever to Camp Wanakita in 2016, and Pinecrest Adventures Camp had a successful year thanks to the very hard work of the Camp Committee.

Particularly in this space, the Executive Director Report, I think it is important to recognize the hard work of Matthew Maynard, who for most of 2016 pulled double-duty, working both in his capacity as Provincial Coordinator of Adult Services and Interim Executive Director. He served as Executive Director for most of the year and was responsible for keeping the staff focused on service delivery and achieving the goals of the 2016 Program Plan.

We also had a change in leadership at the Board level in 2016, as Paul Wilton moved into the Past-President role to welcome Maia Meier as the new President. Maia is a strong leader, passionate and energetic, with a lot of ideas to bring to the table. But as we welcome Maia, we need to recognize and thank Paul for the profound impact he has had at Hemophilia Ontario. Paul has stepped up to the plate repeatedly to give his time, expertise, and insight when times were tough. The organization grew stronger under his leadership.



But above all, the successes of 2016 are thanks to you – the Regional Councils, the volunteers, the members, the stakeholders. Your continued involvement and dedication to this organization are why we continue today. Although we operate in a constantly changing environment, the needs of the community are always a #1 priority. By being involved, you show us what is important. Thank you for continuing to lead the way.

Jenna Foley, Executive Director 



DESIRED OUTCOMES



CARE & TREATMENT FOR ALL

GOAL: Achieve standards and evidence-based comprehensive care for all people with inherited bleeding disorders throughout their lifespans.

- 1.1** An action plan will be developed and implemented to address gaps in care identified through the most recent Ontario Comprehensive Care Assessments.
- 1.2** One-third of the Comprehensive Care Clinics in Ontario will be evaluated for accreditation each year using updated Comprehensive Care standards beginning in 2019.
- 1.3** Hemophilia Ontario will maintain strong representation on all key national/provincial/territorial blood committees to ensure safe, innovative therapies that have been shown to improve health outcomes or quality of life are accessible to users no more than six months after their approval.
- 1.4** The number of people who use clotting factor therapy at home and use MyCBDR in Ontario will increase from 80 at the end of 2015 to 300 by the end of 2018.
- 1.5** Women with bleeding disorders will have the opportunity to attend a women's bleeding disorder clinic either at their own centre or at a neighbouring one.
- 1.6** Hemophilia Ontario will continue to provide services to those affected by HIV and Hepatitis C.
- 1.7** All people registered in an Ontario Comprehensive Care Clinic infected with Hepatitis C will be offered the opportunity to undergo therapy with direct-acting antiviral therapy by the end of 2017.
- 1.8** Hemophilia Ontario will be involved in at least one active twinning partnership over the 2016-2020 period to ensure care and treatment for all.

EDUCATION & SUPPORT

GOAL: Deliver evidence-based information and support to patients, their families, health care providers and the general public across Ontario.

- 2.1** Hemophilia Ontario will provide support programs and activities to people with bleeding disorders and their families throughout the lifespan to help them cope with their chronic conditions and reach their full potential.
- 2.2** In collaboration with inherited bleeding disorder programs, 100% of people registered in these centres will be informed of Hemophilia Ontario and CHS programs and services every two years, starting in 2018.

RESEARCH

GOAL: Promote, fund, facilitate and conduct fundamental, clinical and quality of life research to improve health and quality of life and ultimately find cures.

- 3.1** Hemophilia Ontario will regularly advertise opportunities for members to donate to the Hemophilia Research Million Dollar Club.
- 3.2** Hemophilia Ontario will increase member participation in the Patient Reported Outcomes Burden and Experience Study (PROBE) each year the study is conducted by 10%.
- 3.3** Hemophilia Ontario will publicize opportunities for patients to participate in research and clinical trials of innovative therapies.

A STRONG & COHESIVE ORGANIZATION

GOAL: Build a cohesive organization through good governance, member engagement, effective communications, and fundraising to support our strategic goals.

- 4.1** Membership will increase from 1230 in 2016 to 1420 by 2020.
- 4.2** Two individuals aged 18-25 will sit on each regional council. One individual aged 18-25 will sit on each operational committee to ensure Hemophilia Ontario is developing future leaders and that youth are included in the operations of the organization.
- 4.3** In collaboration with the other Chapters, Hemophilia Ontario will develop a fundraising strategy which will be established to develop an internal case for support and increase fundraising capacity by June 2017.
- 4.4** Hemophilia Ontario will develop a communication framework to improve communication between the Board, Staff, Members, and Key Partners by June 2017.



OUR MISSION

Hemophilia Ontario strives to improve the health and quality of life for all people with inherited bleeding disorders, and to find a cure.

TARGET POPULATIONS: Who We Serve

- People with hemophilia, von Willebrand disease, rare factor deficiencies and inherited platelet disorders;
- Carriers of these conditions;
- Their families;
- The patients' communities (friends, co-workers, daycare workers, teachers, employers, etc);
- Health care providers in the Ontario network of inherited bleeding disorder comprehensive care clinics;
- Other health care providers (primary care practitioners, dentists, specialists...) who may provide care for people with inherited bleeding disorders.

OUR VISION



A world free from the pain and suffering of inherited bleeding disorders.

OUR VALUES

INCLUSIVENESS

By providing information, programs and services to all people with inherited bleeding disorders of all ages and their families.

CONNECTEDNESS

By being well connected to our grassroots community.

ADVOCACY

By actively representing people with inherited bleeding disorders to improve their quality of life while working towards a cure.

EXCELLENCE

By achieving quality, efficiency, and innovation while remaining open to change.

INTEGRITY

By acting honestly, responsibly, openly, and with accountability.

RESPECT

By treating the people with whom we interact with dignity, fairness, and compassion.

COLLABORATION

By fostering meaningful and collegial relations, and strong partnerships among our diverse stakeholders.



Hemophilia Ontario

Hémophilie Ontario

Since, 1956 Hemophilia Ontario has been a trusted voice in the Inherited Bleeding Disorders (IBD) community. We have helped people affected by IBD through influencing public policy, providing support programs to those in greatest need, supporting the best research, and engaging more people in our work. We build relationships that reassure people with IBD they are not alone. Our work is important to Ontarians with IBD, including the children and youth with IBD we send to camps, and the adults affected by the tainted blood tragedy for whom we continue to provide HIV/AIDS services. Together we continue to work to improve the health and quality of life of all people with inherited bleeding disorders and to find cures.

Hemophilia's Ontario's successes are due to our volunteers, donors, fundraisers, community leaders, members, government, health-care and corporate partners as well as our Hemophilia Ontario staff. We thank our individual donors and partner institutions whose generosity helps those we serve live fuller lives.

This past year your support helped us refocus on advocacy. A workshop taught new leaders advocacy skills to support our clinic partners in achieving evidence-based standards of care. Working with our clinic partners we have educated our members about the new Canadian Bleeding Disorders Registry and the importance of accurate and timely infusion records. We have partnered with the Canadian Hemophilia Society to complete the Patient Reported Outcomes Burdens and Experiences (PROBE) research study on quality of life for people with IBD. We are proud of Candace Terpstra and the Twinning Committee which has been awarded the World Federation of Hemophilia Twins of the Year award in recognition of their work with Tanzania. Exciting challenges lie ahead including ensuring people with inherited bleeding disorders have access to longer-lasting factor products and gene therapy. Our commitment to good governance and using resources as effectively and efficiently as possible to achieve results for our community remain strong. In 2017, we are preparing for the Imagine Canada accreditation process which recognizes excellence in board governance, financial accountability and transparency, fundraising, staff management and volunteer involvement.

This year we welcomed Jenna Foley as our new Executive Director. The Board and staff team are looking forward to community consultations this year in which we strive to learn how we can best engage you in our work. We are eager to hear your best ideas. We would like to thank Matthew Maynard for his dedication serving dual roles as Interim Executive Director and Adult Services Coordinator this year. In closing we wish to acknowledge our retiring Board Members Rob Dinsdale, Phyllis Gray, Monica Mamut and Paul Wilton for their years of service to Hemophilia Ontario. We appreciate their commitment to continuing to support our organization's future leaders in training, mentoring and support roles.

Hemophilia Ontario Board of Directors, 2016-2017 

Hemophilia Ontario

2016 PROGRAMS

Numbers can be boring or overwhelming, but they play an important role in identifying the impact we have. This chart makes it as simple as A - B - C!

A IS FOR ANIMALS

The ZooWalk grew even larger in 2016, with 75 people coming out to share a fun day at the zoo, raise money and experience an education session.

B IS FOR BALL (GOLF BALL)

The TCOR golf tournament had 64 golfers and raised \$12,685!



40 brave souls participated in the Polar Bear Dip raising more than \$5,500 in SWOR.

C IS FOR COMMUNITY CAMP

This bi-annual program provides education sessions for adults, couples, and children while participating in fun outdoor activities.

100 people attended Community Camp this year, our maximum capacity!



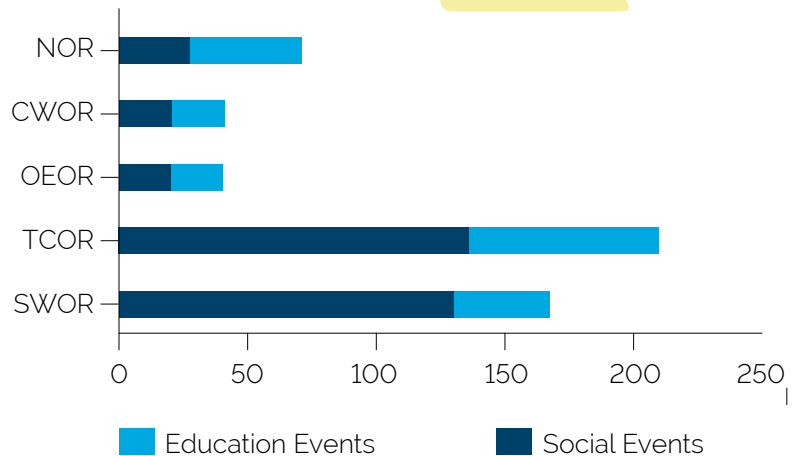
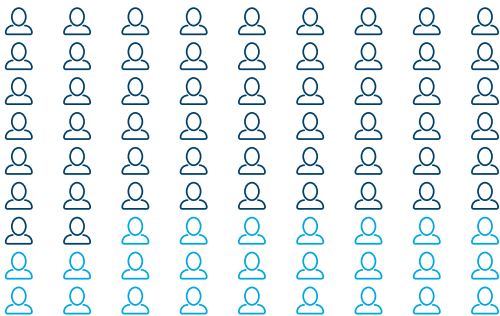
127 individuals attended Regional General Meetings held across the province.

Participation Statistics

Camp Attendance

2016

Dark Blue = Wanakita campers
Light Blue = Pinecrest campers



None of this would have been possible without the 137 volunteers we had this year! Thank you all so much.



NACCHO Article,

originally published in Blood Matters, Spring 2016

Hemophilia Ontario, through the support of Pfizer, provides the opportunity for up to four individuals to attend the North American Camp Conference for Hemophilia Organizations (NACCHO). This conference brings together individuals from around the world to share their best practices, successes and challenges as a means of helping those involved in camp type programs keep their programs vibrant and engaging. This year's attendees represented Community Camp, Just the Guys and Pinecrest Adventures Camp.

We are thrilled to share that Pinecrest finished fourth in the NACCHO Cup earning \$750 for their program this summer! We asked each attendee to share their overview of the conference, here are their stories:

Emily M.

This year I had the amazing opportunity to attend NACCHO. When applying to NACCHO my goals were to be able to continue to develop as a staff member so I can help make camp an even better experience for the children attending. By attending NACCHO I gained new skills and information that will help me do just that. At NACCHO I attended sessions on "Songs, Skits and Other Silly Things" and "Story Warriors". In these sessions I learned new songs to bring to camp and the art of telling stories. I can't wait to bring the information I gained from these sessions to the position of Spirit Leader. In other sessions I learned the importance of validating emotions, how to explain the importance of camp to others, and the importance of positive behavior in supporting campers. This was all mixed in with exciting ice breakers, a next level game of Simon Says and a mind teaser using two corks. One of the things I enjoyed most from NACCHO was meeting new people who have a similar passion in working at camps and planning activities for those with bleeding disorders. But most of all I enjoyed spending time and becoming closer with my fellow staff members. I can't wait till Pinecrest 2016!

Johnny L.


This year was my second year at NACCHO, and it did not fail to meet my expectations for the second year in a row. NACCHO has given me the opportunity to share aspects from my volunteering experience, as well as learn from everyone else who attended the conference. Being that I went on behalf of Just The Guys, it was enlightening for me to share what Just The Guys is all about. One group was so fascinated by the concept that they were going to propose the idea to their Hemophilia

community! NACCHO is a great experience because you get to learn about other communities, ideas, and programs that they have been a part of. It is the perfect place to learn, and personally, I have grown substantially as a leader and a person from attending the conference and learning ways to make my community that much better. NACCHO is an experience that I will never forget, and I look forward to bringing back what I learned to Camp Pinecrest, Just the Guys, and anywhere else that I volunteer in.

Hannah H.

As I continue to expand my volunteer involvement with 2016's Community Camp (a family camp that occurs every other year and is scheduled for October 14-16, 2016) I focused my NACCHO session on finding ways to engage new families that are not sure how to take the leap into camp. What I found most enjoyable about NACCHO this year was that it was a refreshing look on how the present is affecting the future of our camps. Taking this approach through the theme of Tomorrowland, the sessions provided us the tools to build strong programs today that will carry on into the future and strengthen the legacy of our camps and organization. One of the messages that stuck with me the most was from Travis Jon Allison. In both his breakout and key note session, Travis inspired us to use our own personal camp stories as a method to demonstrate just how important and transformative camp can be for a child, their siblings, or a family as a whole. Story telling allows you to give families a taste of what opportunities and memories camp can provide for them by sharing your own experiences. If you are a volunteer, I would strongly encourage you to apply for the opportunity to attend NACCHO – it's an amazing weekend.

Tyse B.

Being a camp staff for a while now, I've heard stories about NACCHO, and on countless occasions, ideas that came from it. I remember stories from there, but couldn't fully grasp how a bunch of bleeding disorders camps would run a conference. I now understand; NACCHO was an unbelievable and unforgettable experience. It was really hard to comprehend a community of that size all committed to bleeding disorders camps, but I can safely say every single person there was after the same goal as me. As the director of Pinecrest, I've taken away so many ideas to help with staff and leadership training, program development and working with children to name a few. This was a great opportunity to look at how we can improve our camp and as the theme "Tomorrowland" suggests, plan for the future. That weekend is something I will not soon (if ever) forget. 

Community Camp Article,

originally published in Blood Matters, Fall 2016

Our fourth Community Camp took place October 14 to 16th at the beautiful Camp Wanakita in Haliburton. One hundred community members attended from across Ontario!

Our keynote speaker was John Schmitke, Vice President CHS Manitoba Chapter. John spoke on engaging in your own health care and maintaining an active lifestyle.

Vanessa Bouskill MN, RN, provided us with an excellent update on the advances in treatment over the next 10 years.

Samantha Stuart, a child life specialist at Sick Kids Hospital spoke on the stages of coping for parents and patients with chronic conditions.

Theresa Almonte, Program Assistant at the Hamilton-Niagara Regional Hemophilia Program presented on the MyCBDR app, a new app which is to be used on a daily basis by members of the bleeding disorders community.


Ann Marie Stain & Liz Sagerman provided the group with information on the BE Program, which aims to increase workplace engagement by introducing participants to potential careers before they embark on post-secondary education.

The panel discussion was led by a diverse group of adults including those living with HIV and hepatitis, new to Canada, a couple, and a Board member. The conversation and candid discussion ranged from care to advocacy to the needs now and in the future.

While the adults were participating in the educational workshops, the children and youth were participating in lots of outdoor activities with the YMCA staff!

There was lots of positive feedback at the end of the weekend and the community really appreciated the opportunity to spend time with their families and other members of the community in the beautiful fall setting of Camp Wanakita.

Thank you to our sponsors for making this weekend possible: Bayer, Biogen, Octapharma and Pfizer!

A special thank you to our planning committee for helping plan and guide this weekend: Betty Ann Paradis, Tammy Bourque, Diane Bissonnette, Stephen Perry, Matthew Maynard, Alex McGillivray, Stephanie Morrison and Susan Turner. 

Article by Phyllis Gray,


originally written in October 2016

I'm the very proud grandmother of Benjamin and Nathan (age 9 and 7) who have severe Hemophilia A.

This summer was the first time Ben and Nathan attended camp at Wanakita, and I was so happy they had that opportunity. From what the boys said when they got back, it was a fun time - with maybe just a touch of homesickness. Just before Ben and Nathan's camp, I was able to attend the tea hosted by Betty Ann at Wanakita, where I met some of the pharmaceutical representatives, we all had a tour of the camp, and we got to chat in an informal and relaxing setting. I was also fortunate to be able to spend the weekend at community camp at Wanakita recently - as a kid I'd always wanted to go to camp, and I finally got my wish. What a beautiful setting.

Because of the treatments developed, Ben and Nathan have a quality of life probably never imagined 30, 40 or 50 years ago. When I watch the boys doing track and field, playing soccer, basketball, swimming and generally just being kids, I am so grateful for the research that's been done, the progress that's been made in treatments, and for the support provided by all of our stakeholders.

I've been on the Board of Directors, and volunteered at various events, for Hemophilia Ontario for a few years now, and during that time have met so many dedicated, caring and committed members of the community. I've learned much about bleeding disorders, and about new treatments already developed, and more coming in the future. These are exciting times for us.

My term on the Board will be over in the spring and I'll be stepping aside to give someone else the opportunity to grow, learn and contribute as I have. I'm confident that Hemophilia Ontario will continue to provide excellent programs, events, and resources to the bleeding disorder community - so those who are newly diagnosed and their families have the same support as our family had when Ben and Nathan were diagnosed. 



There were a number of accomplishments this year which built on the activities of the first two years of this HOT Twinning partnership. The Haemophilia Society of Tanzania (HST) was initially formed in the year 2009 and registered as a society under the Home Affairs Office. Prior to the Twinning, which began in 2014, patients and their families relied on the use of Fresh Frozen Plasma (FFP) for treatment of hemophilia regardless of their bleeding condition which for many was undiagnosed.



Two very significant developments during the Twinning included the provision of Factor which was life changing for patients and the availability of diagnosis. Factor concentrates were made available through the WFH Humanitarian Aid Program which began in 2014 and continues each year. Secondly, diagnosis of hemophilia, not initially available in Tanzania, is now done in - house at Muhimbili National Hospital in Dar Es Salaam. This hospital is effectively Tanzania's "Hemophilia Treatment Centre". A patient registry is in use at the hospital and this registry will form the basis of planning for future care. There are now approximately 100 patients on the registry.

Perhaps the most exciting development in 2016 for the Hemophilia Society of Tanzania (HST) was the formation of a support group for parents and youth using the free telephone "What's Up" App. Approximately 30 members participate in this group where they provide support to one another and share their positive experiences. Dr. Stella Rwezaula, Hematologist, at Muhimbili National Hospital intermittently participates in group calls to advise patients from a medical perspective. The HST also provides educational opportunities. In May 2016, a small group of parents and youth received a presentation by Dr. Rwezaula and a group of 20 Mothers met for a day in August to receive presentations on genetically inherited diseases, organizing groups and generating additional income to help with providing food for their families. Dr. Rwezaula also gave a presentation at the 2016 AGM.



Also notable this year - the Western Pennsylvania Hemophilia Treatment Centre and Muhimbili National Hospital, as HTC Twins, sponsored the first ever Medical Symposium on Hemophilia to be held in Tanzania. With 71 participants representing hospitals from 10 regions, the implications of this event will go a long way toward developing a network of treaters across the country. The HOT Twinning partners were instrumental in facilitating this educational event and a panel of patients and parents were included in the symposium program. The HST Booklet, providing basic facts about hemophilia and its care and treatment, as well as important aspects of living with hemophilia, was circulated to medical professionals at this event. An educational outreach presentation was also provided to medical professionals in Bugando which is located in the northern most region of the country.

At the organization level, in October 2016, the Executive Board received training in a number of areas based on the WFH model of steps for developing a strong patient driven society capable of education and advocacy. This included a review of governance issues: the authority of the Executive Board as determined by the Membership at

the AGM, the roles of the various officers- bearers, as well as a review of the organizational structure and suggested key committees to address the education and support needs of patients, parents, and youth as well as to address the further development of the organization's capacity. Time was also taken to set out the the action plan for 2017.

The HST Executive Board was initially comprised of three doctors and the brother of a patient with hemophilia. Over the past two AGM's, the composition of the Executive Board has shifted to include parents, family members and patients. Dr. Rwezaula now serves as the medical advisor. The election at this year's AGM was successful in filling all of the office bearer positions on the Executive, thus creating a stronger more patient and family driven organization. Revisions to the Constitution in 2014 and 2015 were recommended to facilitate the creation of regions as well as to clarify some of the issues around membership, registration and the authority of the Executive.



Two meetings with Ministry of Health officials (2013 & 2015) have produced opportunities to discuss hemophilia, and the required care and treatment of this condition. A concept paper was requested by the Ministry and subsequently submitted in July of 2016. Hemophilia is a fairly recent "discovery" in the Tanzanian population (first patient identified in 2007 by a visiting physician) and just this past month the Ministry, in response to the concept paper, has recognized hemophilia as a treatable condition. However, Hemophilia remains classified as non – curable. This is a distinct disadvantage for the patients who would otherwise receive free or lower cost treatment if hemophilia was to be re- classified as a "chronic" condition.

The Haemophilia Society of Tanzania is to be congratulated on their efforts considering the challenges they face, given and political and economic reality of this developing African Nation. Progress is relatively slow and resources are lacking at the individual, organizational and government levels. This shows up in the form of transportation issues, communication issues and the lack of personal and community resources that would allow parents, patients and youth to fully participate in a voluntary organization that seeks to engage them in strongly advocating for their own needs as a patient population.

In this final year of the project, the main focus will be on developing a plan for a sustainable future so that the HST can continue to meet the needs of its members over time, as well as advocate for improved care and treatment in major centres across the country, the possible purchase of limited factor by government, the reclassification of hemophilia as a chronic condition and pursuing accreditation as a full member of the WFH federation.

We are thrilled to announce that the Tanzania Hemophilia Ontario Twinning has recently been selected as Twins of the Year for 2016 !! Our thanks to all who have supported this ambitious endeavor over the years. Respectfully submitted on behalf of the Hemophilia Ontario Twinning Team.

Candace Terpstra 



In 2016 we continued to transition as a result of reduced funding from the Ministry of Health and Long Term Care ("MOHLTC"), and the many resulting changes to our organization. We appreciate all the support and help we received from staff and volunteers during this time, as we have moved our office to a new location, and as we have gone through the process of hiring a new Executive Director.

Even with an almost 20% reduction in funding from MOHLTC in 2016, we were able to adjust our operations in such a way as to end the year with less of a deficit than had been anticipated. The anticipated deficit was as a result of some one-time costs related to reorganization of staffing.

We are grateful and want to thank MOHLTC, pharmaceutical corporations, employees who donate through Federated Health Charity, CHS who support us in many ways, our staff, and all of the individuals in the hemophilia community and their friends and families. Without all of your most generous contributions and support, we would be unable to provide the much needed education and services for our members.

Our financial statements are presented in a manner consistent with the standards of the Chartered Professional Accountants of Canada.

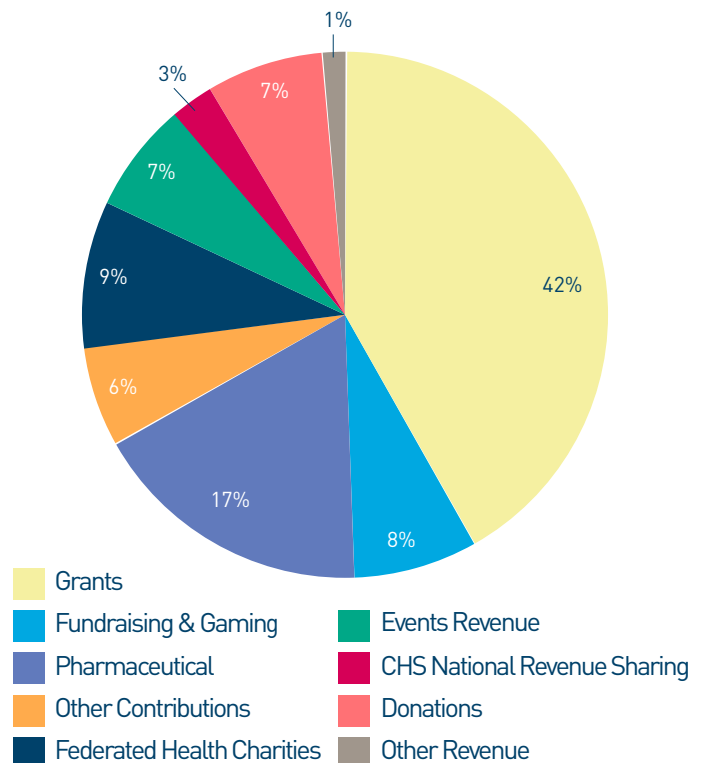
Revenue

As you can see from the attached chart, a significant portion (42%) of our revenue continued to come from grants from MOHLTC (39%) and the City of Toronto (3%). Pharmaceutical corporation contributions are critical funding for our programs, and accounted for 17%. Donations, including those received through Federated Health, contributed 17% to our revenue. If revenue that must be used for specific purposes is not used in a particular year, it is deferred and recognized when the funds are spent on those specific purposes. Typically, those funds would be used in the following year, unless specified otherwise. In 2016, there was a reduction of some \$25,000 in deferred revenue, as can be seen on the Balance Sheet, indicating a use of funds received in a prior year. Those funds were used to cover the expenses of a portion of the programs, education and services. Hemophilia Ontario does not employ staff or outside agencies to fundraise – we rely solely on our volunteers, and we thank all of our contributors and volunteers for their continued support in giving – either monetarily or of their time - in 2016.

Expenses

As of December 31, 2016, Hemophilia Ontario employed 4 full time and 1 part time staff to provide programs, support and education to our inherited bleeding disorder members and their families. Staff and volunteers work diligently to provide these services in a cost-effective manner. Employee salaries are around the mid-range for equivalent positions, and are reviewed annually. As referred to above, there were some one-time costs related to staffing reorganization, thus our costs increased year over year. Programming costs were reduced, as regions and staff worked to prioritize their needs and wants, and eliminate events and programs that were not meeting the needs of the community. Occupancy costs were reduced significantly, by more than 60%, due to the relocation of the Toronto office, and the closing of one of the regional offices. The net result was a total reduction in expenses of some \$76,000.

2016 REVENUE



Programs and Services

Hemophilia Ontario's purpose is to provide programs and services to support and educate those affected by inherited bleeding disorders. 100% of the funds received through receipted charitable donations are used to support member programs and provide financial assistance. Our programs this year, as always, were both educational and fun, helping to bring newly diagnosed and affected families together with others who can provide them with hope, support and encouragement. Our programs also give members and their families an opportunity to spend time together in a positive, caring environment (for example our very popular Community Camp in the fall). We also provide financial assistance for travel/parking for clinics, therapy, medication, orthotics and dental work. Once again, we offer a big thank you to our staff, volunteers, donors, supporters and other stakeholders for so generously supporting us in our endeavours in 2016.

Phyllis Gray, CPA, CGA - Vice-President, Finance 

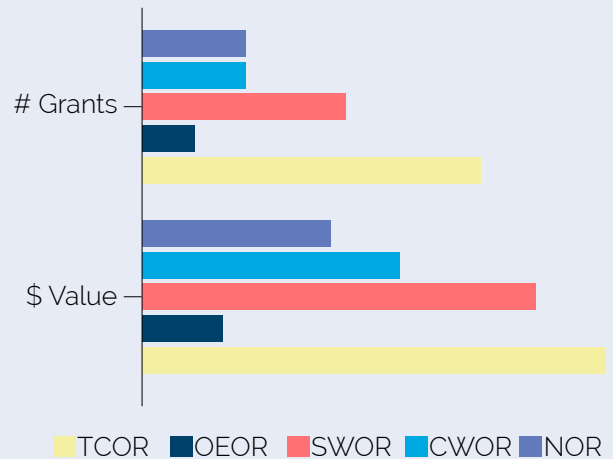
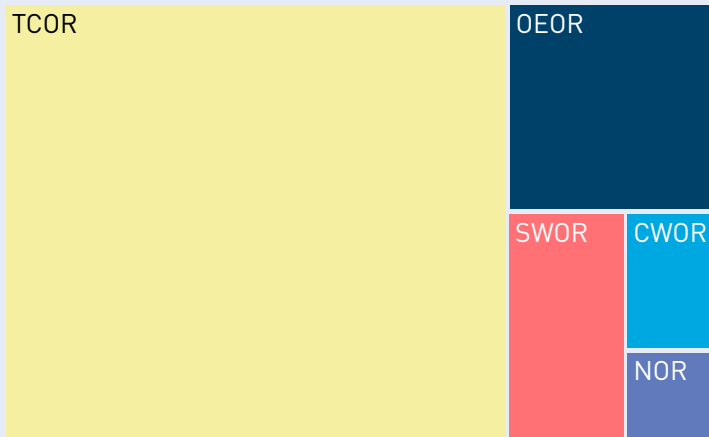
HEMOPHILIA ONTARIO

Financial Assistance

SUPPORTING OUR MEMBERS

Where did it go?

This graph identifies the amount of Financial Assistance funding received by region. TCOR has bingo fundraising to support some of its Financial Assistance requests.



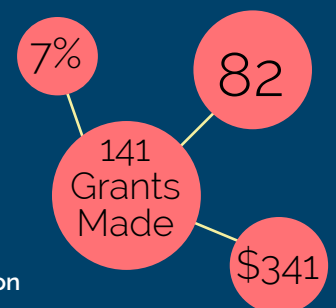
NEW Program

This graph illustrates the distribution of Now Experience Wellness (NEW) funding across regions, to support children with inherited bleeding disorders and promote healthy lifestyles.

\$27,953

Every year, Hemophilia Ontario commits a significant amount of money to its Financial Assistance program. This program receives no pharmaceutical contributions and is supported 100% by the membership.

- 7% of members impacted
- 82 individuals assisted
- \$341 average grant per person



What was it for?

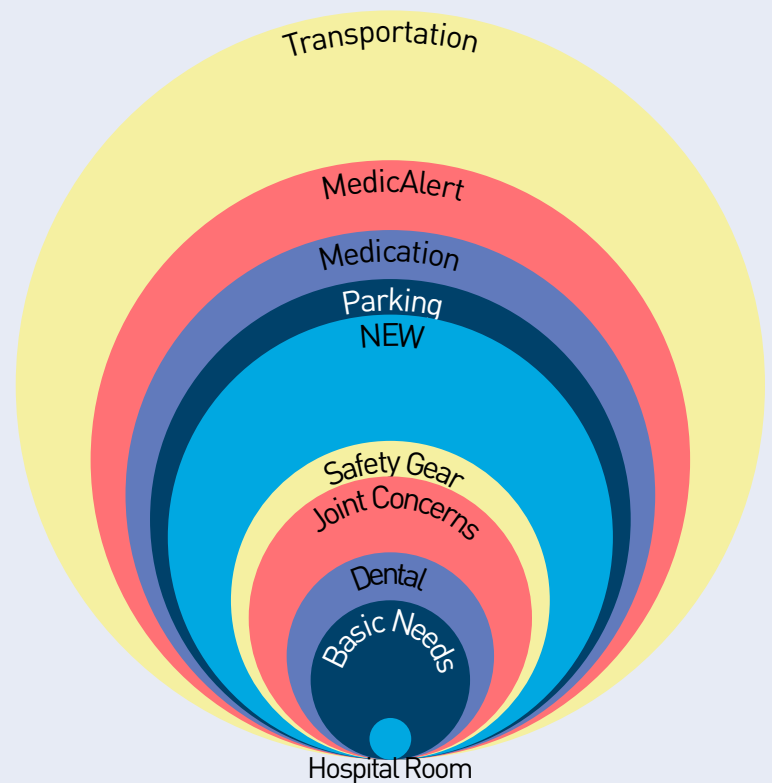
This graph represents the amount of funding received per request category.

The highest amount of funding received was \$6,303 to support transport requests.

The smallest amount was \$233 to pay for semi-private hospital accommodations.

Other amounts include:

- \$4,610 for MedicAlert bracelets
- \$4,086 for uninsured medication costs
- \$3,524 for hospital parking
- \$3,251 for Now Experience Wellness (NEW)
- \$2,006 for helmets and bumper pads
- \$1,712 for orthotics, physiotherapy, and braces
- \$1,133 for uninsured dental work
- \$1,090 for basic needs (i.e. food, shelter)



Thank you to all those who contributed to funds in 2016!

To make a donation to the Financial Assistance program, please visit: <http://events.hemophilia.on.ca/payments.php> or call Susan Turner at **888.838.8846 x 11**

HEMOPHILIA ONTARIO

Financial Assistance

SUPPORTING OUR MEMBERS



2016 YEAR IN REVIEW

VOLUNTEER CONTRIBUTIONS

Total Volunteer Hours

Fundraising



463

Education



128

Events



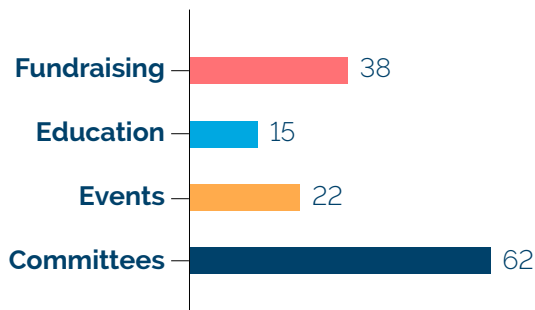
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Committees



665

Breaking it Down

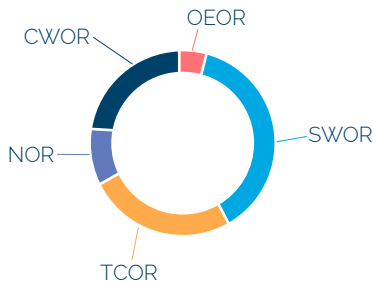


Noteworthy

Hemophilia Ontario was supported by 137 volunteers in 2016. Their commitment and generosity was a major contributing factor to our success this year. Volunteers are essential to seeing events and activities in your area.

If you would like to volunteer, please contact Jenna Foley at 888.838.8846 x 17.

Volunteer Distribution



"Alone we can do so little; together we can do so much."

~ Helen Keller

THANK YOU TO ALL VOLUNTEERS



DONORS, SPONSORSHIP & PARTNERS

TEAM: Together Everyone Achieves More

Hemophilia Ontario exists thanks to the strength of its partnerships. These partners include funders, like the Ministry of Health and Long-Term Care, other non-profit organizations, like Federated Health Charities, and individual donors, like you.

As the landscape surrounding our organization continues to shift, support from our member base becomes increasingly important. If you would like to make a contribution to Hemophilia Ontario, please visit <http://events.hemophilia.on.ca/payments.php> or contact **Jenna Foley at 888-838-8846 x 17**.

To everyone who donated in 2016, thank you most sincerely for demonstrating your commitment to the organization and the ongoing support of our members.

2016 SPONSORS





Hemophilia Ontario employs a very hard-working group of individuals across the province to deliver programs and services for the benefit of our members. Their flexibility and dedication to the community in 2016 was greatly appreciated. The following list contains staff members and job titles as of December 31, 2016.

Jenna Foley, Executive Director
Susan Turner, Administration & Program Supports
Matthew Maynard, Provincial Coordinator – Adult Services
Alexandra McGillivray, Provincial Coordinator – Programs & Communications
Stephanie Morrison, Provincial Coordinator – Northern Programs & Services
Marina Seliverstova, Manager of Finance

2016 Staff Leadership Award – Matthew Maynard

The Hemophilia Ontario Staff Leadership Award celebrates, promotes and encourages quality service that reflects the values of our organization. The award recognizes exceptional staff service through:

- Support for members and their families
- Support for other staff
- Innovation and Responsiveness
- Ethics and Courage
- Professionalism and Competence
- Commitment and Enthusiasm
- Administrative and Corporate services

Matthew Maynard worked very hard in 2016, in his dual role as Provincial Coordinator for Adult Services and Interim Executive Director. His leadership and commitment have been recognized by his coworkers as a key component of successfully navigating a challenging time within the organization.

BOARD OF DIRECTORS

The following individuals were elected at the 2016 Annual General Meeting to serve on the Hemophilia Ontario Board of Directors for 2016-2017. This was a challenging year that demanded a lot from the Board, and this team continually demonstrated their level of commitment, dedication, and leadership.

President

Maia Meier

Vice-President Finance

Phyllis Gray

Past-President

Paul Wilton

Secretary

Shelley Hewett

Directors

Kwadwo (Michael) Bosompra
Amy Griffith

Julia Sek
Ashwani Kurichh

Rob Dinsdale
*Monica Mamut

Delegate to the CHS

Maia Meier

Nominations Committee

Rob Dinsdale, Chair
Paul Wilton
Victoria Kinniburgh
Ash Kurichh



HOW TO GET INVOLVED

Hemophilia Ontario welcomes the interest of individuals in our organization. The Board of Directors is elected at our Annual General meetings for a one year term. Each region elects a Regional Council at their Regional General Meeting.

**For further information please contact:
Hemophilia Ontario,**

4711 Yonge Street, 10th Floor, Suite 10100, Toronto, ON M2N 6K8

 info@hemophilia.on.ca

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 [/HemophiliaON](https://www.pinterest.com/HemophiliaON)

Your generosity is the key to providing programs and services to individuals with inherited bleeding disorders. No other organization in Ontario offers these supports to those living with and / or affected by inherited bleeding disorders. With your passion, commitment and dedication we know we can make a difference.

HERE ARE SOME OF THE WAYS YOU CAN HELP:

-  **DONATE**
-  **FUNDRAISE**
-  **CAMPAIGN**
-  **VOLUNTEER**



Hemophilia Ontario
Hémophilie Ontario

HEAD OFFICE

4711 Yonge Street, 10th Floor, Suite 10100, Toronto, ON M2N 6K8

www.hemophilia.on.ca