

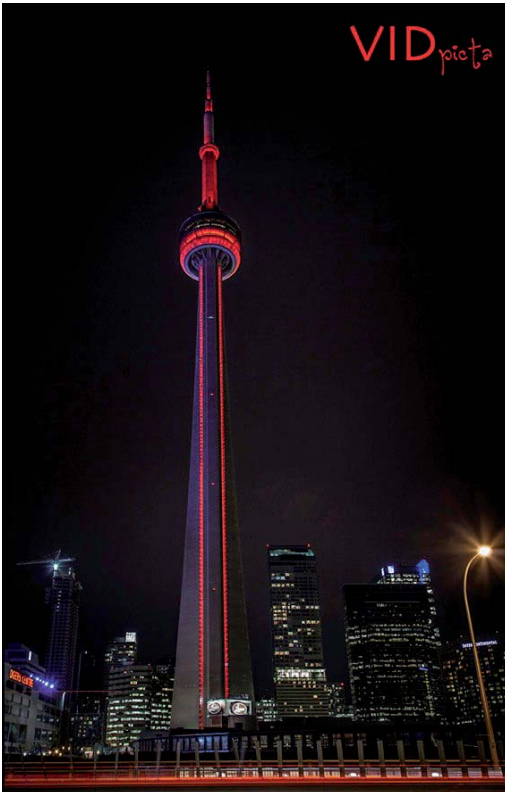
ANNUAL COMMUNITY REPORT

2013



Hemophilia Ontario

**COMMITMENT
to COMMUNITY**



WORLD HEMOPHILIA DAY Toronto CN Tower lit up in red
photo by – Athirayan Kandasamiar



BUSKERFEST 2013

REPORT COVER PHOTO
Amy Bondy and son Noah



Hemophilia Ontario
Hémophilie Ontario

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Hemophilia Ontario

Our Values



Our Future

Hemophilia Ontario provides information, programs and services to:

- People with an inherited bleeding disorder including hemophilia, vonWillebrand Disease, rare factor deficiencies and platelet disorders
- Their families and friends
- The health care providers in the Canadian network of inherited bleeding disorder comprehensive care clinics
- The member's community (day care workers, teachers, employers)
- Health care providers (primary care physicians, dentists, specialist, etc) who may come into contact with those who remain undiagnosed

Mission

Our mission is to strive to improve the health and quality of life for all people with inherited bleeding disorders, and to find a cure.

Vision

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

Values

Hemophilia Ontario is committed to the following 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 accountably.

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.

President's Report

Paul Wilton 2013|2014

You should expect much more from Hemophilia Ontario.

Over the past three years, we have focused on reforming our organization to be prepared to overcome emerging obstacles and provide meaningful results.

We have challenged the status quo and come together to make changes some thought could never be achieved. These include:

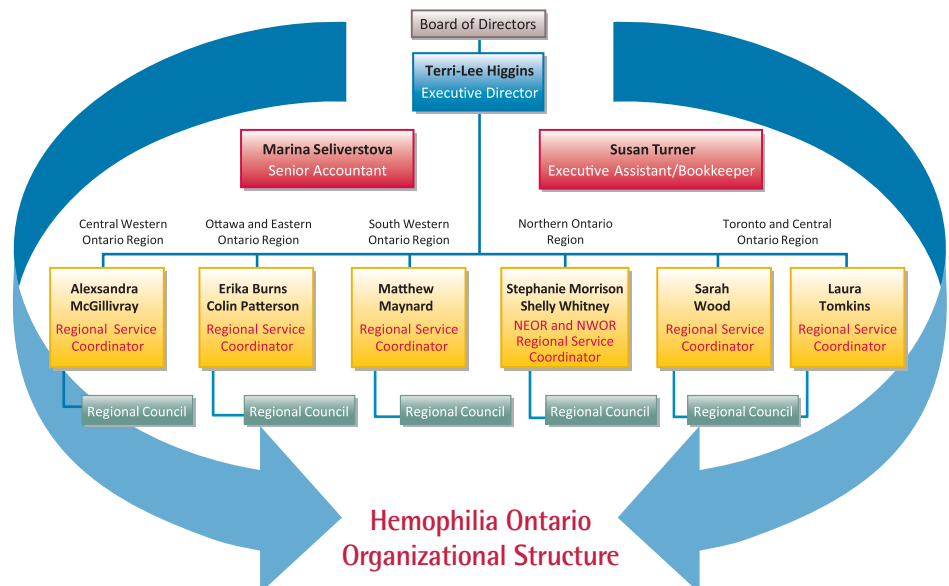
- Amalgamation of Hemophilia Ontario and Toronto and Central Ontario Regional Hemophilia Society;
- A consensus was reached on procedures governing our regions;
- An overhaul of our governance policies including a clear mission, vision, and desired outcomes;
- Development of an action plan which mobilizes staff and volunteers to accomplish these goals;
- Strong partnerships with our Regions, the Canadian Hemophilia Society, Hemophilia Treatment Centres, funders and external organizations;
- A more effective staffing structure;
- A successful transition between Interim Executive Director, David Page and current Executive Director, Terri Lee Higgins;
- 53.3% percent of our active Board Members are women;
- More young people are involved as leaders in each of our Regions and at the provincial level.

In a community in which historically women have been denied the treatment they need, and representation they deserve, we can be proud our Board is a leader in representation of women. Our Board's range of backgrounds, experiences and connections to the bleeding disorders community reflect the diversity of our stakeholders.

Our board is increasingly bright, engaged and energised. Moving forward, each of our leaders must have expertise in issues facing people with bleeding disorders or be dedicated to learning. Without this knowledge, our Board Members will not know the questions (and follow-up questions) to ask, to ensure we are actually meeting the needs of our members. You should test our leadership on key advocacy issues. If they don't know the answer, they should learn it and follow-up. Recruiting and developing informed leaders is essential to anticipating the challenges ahead.

Our future strength will come from our ability to demonstrate we involve an overwhelming number of people with bleeding disorders in Ontario. We need to focus on making sure we are engaging with the newly diagnosed and reconnecting with members we've lost touch with. This is a place our members can lead.

The two leading answers people give when asked why they haven't been involved with an organization is that they've never been asked or they didn't know how to. This coming year Hemophilia Ontario will do our part to ensure our members are aware of specific opportunities to get involved. However, I challenge you to help make us stronger by taking the Hemophilia Ontario 2 + 2 challenge. This year I ask you to commit to doing two things big or small, to make a difference for our community, and to find two people who may benefit from involvement in our community and ask them to get involved. If all of our stakeholders across Canada do this, the force we mobilize will ensure we meet each of our goals.



Our Goals

2014 | 2015

Care and Treatment for All:

Goal: Achieve comprehensive care for all people with inherited bleeding disorders.

Envisioned Outcomes 2014-2015

- 1.1 Nine Hemophilia Treatment Centres in Ontario will have been assessed to identify strengths and gaps in services as benchmarked with the national standards of care.
- 1.2 Nine Hemophilia Treatment Centres will have services for women with inherited bleeding disorders.
- 1.3 Ontario will have designated provincial funding for the Hemophilia Treatment Centres.
- 1.4 Those co-infected with HIV and Hepatitis C to have access to liver transplants.
- 1.5 Hemophilia Ontario will provide services to those living with Inherited Bleeding Disorders and/or HIV/AIDS and Hepatitis C and their families.
- 1.6 Access to care in less economically developed countries will be expanded.

Safe and Secure Supply:

Goal: Advocate for access to a secure supply of the safest and most efficacious therapies for the treatment of inherited bleeding disorders.

Envisioned Outcomes 2014-2015

- 2.1 Canadians with inherited bleeding disorders will continue to have access in a timely way to a safe and secure supply of the most advanced therapies with optimal quantities at no cost to the end-user.
- 2.2 Hemophilia Ontario will continue to have representation in the blood system in Canada.

A Strong and Cohesive Organization:

Goal: Build a strong and cohesive organization through the development of an engaged and informed Board and membership, while putting an emphasis on better collaboration between Hemophilia Ontario and the Canadian Hemophilia Society.

Envisioned Outcomes 2014-2015

- 3.1 Targeted sources of revenue will increase by 8% in 2014 and 13% in 2015.
- 3.2 Hemophilia Ontario's volunteer base will increase by 15% from 176 volunteers.
- 3.3 Hemophilia Ontario's membership base will increase by 100 stakeholders from 998 members. (National by-laws stipulate that members of chapters are members of the national organization).
- 3.4 25% of those stakeholders identified in outcome 3.3 will be people with von Willebrand disease, women with bleeding disorders or rare inherited bleeding disorders.

- 3.5 Young people aged 18-25 will be involved as leaders at the provincial level and in each of the five regions. Each Board and operational committee shall include at least one youth. Each Regional Council shall include at least two youths.
- 3.6 Two reviews will be completed to determine potential areas of collaboration, and to identify efforts that are unnecessarily duplicative. One review will be in partnership with the Canadian Hemophilia Society, the other with external organizations.
- 3.7 A Regional Council will be established in Northern Ontario which meets the requirements set out in the Regional Council mandate.

Research:

Goal: Promote and fund research to improve treatment and to ultimately find a cure.

Envisioned Outcomes 2014-2015

- 4.1 Hemophilia Ontario will contribute \$10,000 in 2014 and \$20,000 in 2015 to the Hemophilia Research Million Dollar Club.
- 4.2 Ontario researchers will have been able to recruit sufficient subjects to conduct their research in inherited bleeding disorders, HIV and HCV.

Awareness:

Goal: Raise awareness among people with inherited bleeding disorders, their immediate communities and health care partners.

Envisioned Outcomes 2014-2015

- 5.1 All people with inherited bleeding disorders in Ontario who are known to Hemophilia Treatment Centres will be entered in the Canadian Hemophilia Registry (CHR).
- 5.2 The number of women with inherited bleeding disorders in Ontario registered in Hemophilia Treatment Centres will increase by 5% from 1720.
- 5.3 The number of people with rare inherited bleeding disorders in Ontario registered in Hemophilia Treatment Centres will increase by 5% from 494.

Education and Support:

Goal: Provide effective delivery of information and support to patients and their families.

Envisioned Outcomes 2014-2015

- 6.1 A defined set of five core programs and services will be offered by Hemophilia Ontario annually.
- 6.2 Every person with an inherited bleeding disorder registered in a Hemophilia Treatment Centre in Ontario will be informed of the existence of Hemophilia Ontario and the Canadian Hemophilia Society and their programs and services.

Executive Director's Report

Through the commitment of our staff and volunteers and member engagement, we achieved the following highlights in 2013:

- We received a Volunteer Sector Reporting Award (VSRA) Nomination for transparency in financial reporting;
- We were recognized by the Canadian Hemophilia Society (CHS) with a Chapter Recognition Award for significant organizational and operational changes with the amalgamation of Toronto Central Ontario Region and Hemophilia Ontario;
- Staffing transitions resulted in the hiring of 4 new Regional Service Coordinators across the province;
- \$30,409 in financial assistance was provided to 100 Ontarians living with an inherited bleeding disorder;
- We partnered with the CHS on a membership drive resulting in a 21% membership increase;
- 176 volunteers contributed 4,008 hours of service (estimated value of \$88,737 based on USA independent sector volunteer values);
- New NEOR third party fundraisers raised over \$1,800 – thank you Alana Brassard;
- We distributed more than 3,300 condoms;
- 762 members were supported at provincial clinics;
- There were over 5,000 unique visitors to our website;
- 2,300 people participated in education and awareness opportunities across the province;
- Our Twinning initiative in Tanzania with Dar es Salaam was approved;
- Facebook fans increased 63% from previous year.

We looked at member needs and identified service gaps, thus allowing us to focus our time and efforts on key transformations. We also initiated a volunteer survey to identify strengths and where we could improve. Your feedback allowed us to critically evaluate and improve on the identified areas and for that we thank you. We will continue to capitalize on the past five decades of experience.

Risk management is at the forefront with Hemophilia Ontario. Training has provided staff with the necessary tools to ensure that day to day work, programs and events are reviewed and implemented with risk management in mind. This ensures the necessary oversights, controls and support are in place to provide continued accountability, transparency and financial responsibility. Staff and volunteers were diligent in preparation, planning and completing the assessment visit in Dar Es Salaam, including ensuring their personal safety by travelling only with

representatives of the Tanzania Society. In the past year, the Board has been actively engaged in blood safety issues. We will continue to have a voice in ensuring the health and safety of Ontarians through involvement in provincial and national blood safety committees.

We were honoured to receive Honourable Mention for a Volunteer Sector Reporting Award



Voluntary Sector Reporting Awards 2013
CPA-QUEEN'S CENTRE FOR GOVERNANCE

(VSRA) for transparency in financial reporting for our 2012 annual report. Transparency is key to promoting member and donor confidence. This prestigious award is judged by Queen's University School of Governance, The Chartered Professional Accountants Ontario and sponsored by Price Waterhouse Coopers and National Post. We are committed to the level of excellence represented by these awards.

Hemophilia Ontario's financial base is strong, and our revenues exceeded expenses for the year. We have put in place processes and tools throughout the organization to identify and analyse potential risks, and mitigate those risks. The full or partial loss of Ministry funding remains a very real concern. The ongoing economic downturn continues to pose challenges we cannot ignore. We must continue to pursue other funding opportunities with new partners and donors to ensure we can continue to provide programs and services to our bleeding disorder community.

We have established plans for the future and remain committed to helping members across the province. Our goal is to provide enriching experiences that will encourage our youth to continue their engagement for many years. The shared commitment in pursuing our mission, vision and goals with excellence, commitment and compassion will have a positive impact. We invest in our members so they can do great things. We look to our youth to lead and empower the community. We are committed to building a community of active citizens through engagement.

Thank you to our staff, Board members and volunteers for your support and countless hours of hard work. To our funders, partners, sponsors and every single donor we extend our sincere gratitude. We are humbled by your commitment to our community. Together we have accomplished much and I look forward to our continued efforts to build a positive future.

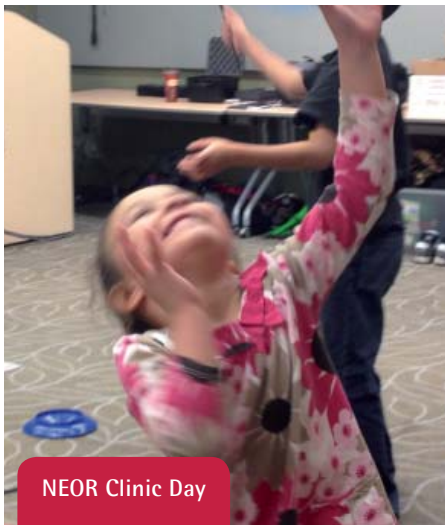
– Terri-Lee Higgins

Provincial Program Report

We are no longer living in an environment where programming is limited to what we can do in our own community.



Education gives us knowledge of the world around us and develops a perspective of looking at life. Hemophilia Ontario strives to implement programs that support and build confidence in individuals to manage their own personal care by networking with other affected individuals at camp, educational programs and member networking events. Our youth gather additional information by becoming engaged in Hemophilia Ontario Youth (HOY) where they learn not only about self-care but also enhance life skills that guide them as they mature. Adults, parents and seniors are amazing vaults of information for our children, youth and each other and our programs provide a conduit for this information sharing to occur. In the process of 'getting educated' members develop new connections and friendships that could last a lifetime.



Hemophilia Ontario provided strong, consistent programs to our members in the past year. Provincially, we offered *Blood Matters*, Just the Guys, Wellness for Women and the education sessions. Staff continues to be engaged in HIV / AIDS and Hepatitis C programs plus prevention awareness campaigns and developing new and creative partnerships. Our regional programs reflect the identified member needs within that region. What we have discovered however is that while each region is different there continues to be consistent member messaging around the education they want. We focused on program quality and innovation related to aging with a bleeding disorder, women's / men's and couples education and provided member networking opportunities. By utilising webinars for vWD education we expanded programming across the province.

We benefit from the support and partnership of working with nine provincial Hemophilia Treatment Centres. These individuals gave of their time and expertise throughout the year by participating as speakers in education sessions, writing article for *Blood Matters* or working with staff on local initiatives with the goal of providing strong and informative programs.

Everyone benefits by becoming better equipped to manage their own and their children's health. Hemophilia Ontario remains committed to doing our part to build a healthy community.



Programs | Events | Recognition



Commemorative
Event Speakers



Just the Guys



Supercrawl BBQ



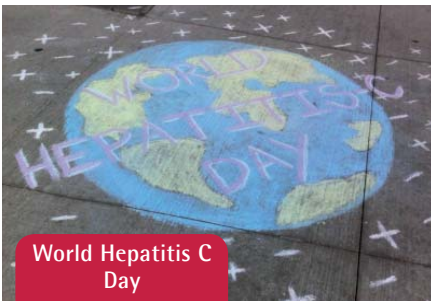
OEOR
Holiday Event



SWOR
Education Session



TCOR
Men's Event Fun



World Hepatitis C
Day



Polar Bear Dip



Pillar Partnership
Youth Recognition



SickKids Display



SD Golf OEOR



SWOR 2013
Myth Busters



Polar Bear Dip

Youth Report

“ *Hemophilia Ontario Youth, or HOY, is a community where I feel welcomed and comfortable hanging around and enjoying the company of friends, who just happen to be other individuals with inherited bleeding disorders. I think it is something unique where we are given this opportunity to meet up with each other and share the direction we would like to take our group.* ”

— 2013 HOY member



The youth who join HOY gain an outlet to share their experiences and hear how others cope with the same issues they are facing. Typically, these subjects are ones that youth with bleeding disorder have difficulty discussing with other non-affected peers. It's comforting to know that you are not alone in your seemingly individual personal issues, and there is in fact a network of friends and approachable regional staff who are inviting to meet in and outside of HOY. Through discussions and educational sessions in a safe and open community of established trust, youth are exposed to various character-building opportunities such as leadership development, independent outlets for growth, advocacy awareness and personal health initiatives. Even though growing up is a really intimidating and painful process, youth can find strength in themselves and lean on the support of others through HOY.

In January 2013, six HOY members were invited to take part in the North American Conference Camping Conference for Hemophilia Organizations, or modestly, NACCHO. The conference is the only camping conference of its kind, dedicated to summer camps that serve youth of the bleeding disorder community. Through organized "divide and conquer" strategies, youth were able to attend all sessions offered throughout the conference in an effort to educate all HOY members on the benefits of each session. Each HOY member brought back to Ontario valuable and applicable leadership development skills and new found character confidence to be used in all facets of their lives, in particular those youth involved at Hemophilia Ontario based camps, Wanakita and Pinecrest. One member was also the recipient of the 4th place NACCHO cup award, along with a \$250.00 cash prize to the camping initiative of their choosing.

Throughout the year, HOY members continued to contribute to the editions of *Blood Matters* magazine on various subject matter and issues surrounding living with a bleeding disorder. Every edition, a sound attempt was made to include new HOY members contributing to the Hemophilia Ontario Youth section of the magazine.

HOY was involved in the tentative planning of the year's events, a loose structure that was established through discussion and general consensus. Youth were strongly encouraged, if not urged, to be heavily involved in the planning process in order to take initiative and responsibility in the outcome of each planned HOY event. Along with this strong voice in planning also came the required justification for each event suggested. HOY was encouraged to explore why each event would be beneficial to the group, as well as how.

After the development of three core events to take place in 2013, it was established that HOY would need to conduct the majority of the group's fundraising themselves in order to ensure these events took place. Brainstorming sessions were facilitated, encouraged, and ongoing.

In June 2013, five HOY members took part in an eventful afternoon with Toronto Adventures, a city-based company providing adventure-based activities in urban settings. After undergoing a short but thorough basic canoeing lesson, together the youth and two regional staff took to the water and enjoyed hours paddling, chatting and above all else laughing (and some high volume, Disney-themed singing). Once back on dry land, the group shared lunch and took advantage of the rare opportunity to be sitting together to discuss fundraising opportunities, both in their local communities as well as at the provincial level.

During the fall of 2013, youth were made aware of an opportunity to view a showing of *Tainted*, a compressed oral history about the wrong doings and results of Canada's tainted blood supply in the 1980's, and what that felt like for one affected family. However, youth showed little to no interest and the event did not move forward.

In October 2013, it was announced that HOY would undergo a regional staffing change in early November. I believe that this transition will take time to settle amongst the HOY members, as a certain level of trust will need to be re-established in the newly appointed regional service coordinator(s).

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Ontario's NACCHO
Representatives

For the future success of HOY, we recommend the following:

1. Closing the generation gap between younger children and older youth by either establishing a younger, filter version of HOY for younger members, or decreasing the age limit for HOY altogether.
2. An increase in the base funding for HOY programs and committing to organized fundraising.
3. Strong promotion and awareness strategies for new HOY membership.
4. The establishment of a HOY Executive Team of existing members in order to ensure accountability and obligation between members.

— Amy Griffith

Programs ...in the spotlight

Twinning

Hemophilia Ontario representatives travelled to the United Republic of Tanzania to meet with The Hemophilia Society of Tanzania to assess the possibility of an organizational Twinning. While in Dar Es Salaam (a city of 3 million people) we met with affected families, Government and Hospital officials and National Blood Transfusion Services to determine the options for changing care for the better. The Hemophilia Society of Tanzania and Hemophilia Ontario were officially recognized as twinning partners in October of 2013 and now the real work begins.



Members shared
their stories



Tanzania
Medical Team

Looking back on the 2013 year in review, even after the best efforts of regional staff and a select few HOY leaders, HOY found itself at an overall standstill. The biggest obstacle that HOY was unsuccessful in overcoming was the mobilization of its members. Given that HOY members are scattered geographically throughout the province, HOY's greatest challenge is communication between youth. HOY relies on the voices of its members in order to create programming, establish communication and plan events. This also requires a certain level of responsibility and commitment that was missed in 2013. As a result, planning events and get together activities became next to impossible.

In order to properly plan and execute all desired events, which included an out of province trip, it became clear that HOY would need to fundraise 70% more than the allocated program budget. Although a few fundraising strategies were successful, the majority of HOY members were not committed to this initiative, bringing me back to my point above.



Amy and Michelle



CODERouge is a national program initiated by the Canadian Hemophilia Society. Its main purpose is to raise awareness and education amongst women across Canada, as well as health care providers and the public as a whole about women and bleeding disorders. It is important to identify undiagnosed women with

bleeding disorders so they can receive the appropriate medical care and obtain the support and information needed to lead a healthy lifestyle. Our goal is to increase diagnosis and access to care for women and girls with inherited bleeding disorders.

As a **CODERouge** ambassador I, as well as my counter parts across Canada, will play a critical role in raising awareness about the symptoms of bleeding disorders and how to access appropriate medical care. Being a **CODERouge** ambassador is very important to me personally. Growing up with many bleeding issues myself, I was never diagnosed with a bleeding disorder, therefore never properly treated for issues that could have been handled so much better. But the awareness was not there. It wasn't until my son was diagnosed with severe Hemophilia that I was finally given an answer to all my unanswered questions, at age 28. I am a symptomatic carrier of Hemophilia A.

As a **CODERouge** ambassador I represent CHS with the integrity and compassion needed to make a difference in the lives of affected women. If I can help girls and women become more empowered with their bleeding disorders, I will feel fulfilled with my part of being a **CODERouge** ambassador!

— Michelle Lepera

Making A Difference

Fiona Miletic



Finding out that your beautiful newborn baby has hemophilia truly plays with your emotions. In my case, the first emotion was denial. My firstborn son Callum, was beautiful and perfect and not at all affected by hemophilia. So my natural thought was that my second baby would not have a diagnosis either. When Luka was born, healthy and beautiful, I was instantly in love. When we were given Luka's diagnosis of severe hemophilia, he was only 5 days old. I looked down at him and every inch of his perfectness and I thought surely they must have made a mistake. Maybe the lab switched the results with another baby. Maybe his factor levels were read wrong, maybe he had mild hemophilia and not severe. To this day I am not sure at all why I was in so much denial about being a carrier and the risk of having a baby with hemophilia. I have never in my life had any bleeding problems. My brother has severe hemophilia, but my mother is the only person in her family with the disorder. None of her siblings or any member of her family has hemophilia. I guess I thought that my chances were higher for having a baby not affected rather than affected.

My denial quickly turned to a range of emotions daily, namely fear; fear for what this diagnosis would mean for Luka and our family, fear of not knowing exactly what our lives would look like. Sometimes I would experience moments of calm, thinking we can handle this, he is a sweet, beautiful and perfectly content baby. No matter the emotion, I quickly realized that facts are facts and I have a newborn son with severe hemophilia A. It is amazing how you can feel so alone at times like this as a parent.

Little did we know we had already met another family with a son with severe hemophilia. My husband and I took Luka to a baby car seat safety clinic and the gentleman who ran the program helped us on that day. Hard to explain what it was, but there was an instant connection and we felt that this man had really helped us. One month later we ran into him at the hemophilia clinic. My husband saw him and remembered him right away. After our clinic appointment we met with Alex from the Hemophilia Society and asked about the gentleman we saw, only to find out that the gentleman did live in the same city as us and had a child with hemophilia. Through The Hemophilia Society we were able to get in touch with this father and he was able to guide us and give us some great and much needed advice.

Through many events and seminars The Hemophilia Society has helped educate my husband and me on the disorder and learn what to expect as Luka gets older and of course learn about the new developments. That is not the only thing that the Society helped us with, by attending their events we connected with many families only to discover that two more hemophiliac families live in the same city. All the families have been so supportive and offer great advice to newbies like us. I appreciate The Hemophilia Society and all the people I have connected with because in turn they have taught me that there is nothing to be upset about, I have a beautiful healthy boy, that is still perfect in every way, he just needs a little extra tender, love and care!

The Hemophilia Society has helped educate my husband and me on the disorder and learn what to expect as Luka gets older.

Making A Difference

Adryanna and Nathaniel Cruse



Hello, our names are Adryanna (13 years old) and Nathaniel (12 years old) – and we both have vonWillebrand Disease Type 2B, which is the most common inherited bleeding disease. In my family our Poppa and Dad also have this bleeding disorder. This is a disease where a protein called vonWillebrand factor that is found in the blood that makes your blood sticky, and causes you to stop bleeding is low or not even there at all. Many people with vonWillebrand Disease have very mild signs and some people live for years with the disease and don't know they have it.

When we first found out that we had vWd, we didn't understand what it was all about. We have been very lucky to go to many different activities and camps sponsored by Hemophilia Ontario and have learned lots about vWd. Through these experiences we have made many friends who have the same or different bleeding disorders and it makes us feel like we are not the only ones dealing with this. It's nice to be able to be included in many different activities at camp that we normally wouldn't get a chance to do, and to feel like we belong and not be treated any differently just because we have a bleeding disorder. We understand that we really aren't that different from other kids except that we bruise easier and can bleed longer than a "normal" kid our age. We both wear Medic Alert bracelets in case of an emergency so that people will know how to help us.

We can play any sport we'd like; we have played baseball and soccer and we love to go swimming and ride our bikes, we just need to be a little extra careful.

Adryanna – "Now that I have started my cycle I need to take an iron pill each day to keep my levels within a good range and I take Tranexamic Acid to help with the bleeding monthly. Other than taking a few extra pills to help, I am no different than my friends."

Nathaniel – "I don't feel any different, except when I get a nose bleed, it can bleed for a long time which can suck but with what I have learned I know how to take care of my myself if my Mom and Dad aren't around."

It was a little scary at first not knowing what this disease was all about. Now that we have learned how to cope and have had some really awesome counsellors at all the camps we have attended. We both think it would be really cool when we get older to be that person for some other young kid just learning about their bleeding disorder and help them to understand what it is all about.

We have been very lucky to go to many different activities and camps sponsored by Hemophilia Ontario and have learned lots about vWd.

Making A Difference

Travis and Lindsay Hazelwood



We have been learning and growing in a life with Hemophilia since our sons Jake, Wyatt, and Luke were born. Both Jake, 7 years old and Wyatt, 6 have severe factor VIII deficiency and were not diagnosed until Wyatt was born, by the chance suggestion of an intern. They were referred to the Bleeding Disorders Program at London Health Sciences Centre. The support of the team at the Bleeding Disorders Program led by Lori Laudenbach and Dr. Jardine was important following that diagnosis but also meeting the Regional Service Coordinator for South Western Ontario Region. We needed at that point other families affected by hemophilia to talk to, but none were available at the time.

Both boys started on a prophylaxis treatment plan and through the RSC began to participate in the programs and services offered by Hemophilia Ontario in the region. Soon we found ourselves part of the community being both supported and offering support.

Now we are finding our own ways to be involved together to help new families through the Parents Empowering Parents, and I am involved with the Pinecrest Adventure Camp planning committee, and the school's Parent Teacher Association. Travis likes every opportunity to attend Just the Guys with the boys and finds ways to help on the SWOR Council and Chair the planning committee for the SWOR Annual Golf Tournament. He also sits on the LHSC Bleeding Disorders Advisory Council.

Being involved is about improving the lives of our kids and making a real difference for everyone with an inherited bleeding disorder.

After all, the more you know, the more you grow!

Hemophilia Ontario has helped us understand we aren't alone living with an inherited bleeding disorder.



Pinecrest Camp

Making A Difference

Anthony Obregon



My name is Anthony Obregon. I am 15 years old and was diagnosed with congenital Factor XIII Deficiency when I was one and a half years old. I was asked to write a bit about how Hemophilia Ontario has impacted my life. I agreed to do this since I feel like if it wasn't for Hemophilia Ontario, a lot of things in my life would be missing. They have so much to do with my care at Sick Kids and have been involved and a part of my life — and my younger sister's as well since she's also Factor XIII deficient. For those of you who don't know what Factor XIII is, it is basically a rare bleeding disorder that's passed on from parent to child at the time of conception and is caused by an abnormal gene. My sister and I are "bleeders" and to me that means our blood is missing that one factor that would make our blood clot. I think it's great that Hemophilia Ontario not only takes care of those who have Hemophilia A or B but they also help those very few children and adults with Factor XIII deficiency.

Another reason I am grateful for this organization is that they send me and my sister to Camp Wanakita every summer for two weeks (although this year I am going for a MONTH because I was lucky enough to make it as a first year Senior Counsellor!). Camp Wanakita has helped me to deal with my condition because I get to meet and make friends who also have bleeding disorders. I didn't know there were kids out there that have to infuse every other day. This made me realize that some kids have it really bad and I should be thankful that my condition only requires prophylaxis once a month.

The Polar Bear Dip is another big event that me, my mom and my sister have participated in. I'm kind of scared to do it this year because it's been a really bad winter but it feels good to do these sorts of things to bring awareness and to raise funds for Hemophilia Ontario.

Hemophilia Ontario has impacted my life and my family's life in a way that I can't put into words. I am very lucky and grateful that this organization was founded. I do consider myself a survivor in a way, because if it wasn't for Hemophilia Ontario and the research they have been doing from the beginning, I probably would never have been diagnosed and the outcome would have been entirely different. Together with Sick Kids, they have taught me many things and have helped me cope with my condition.

Thank you Hemophilia Ontario!

I feel like if it wasn't for Hemophilia Ontario, a lot of things in my life would be missing.

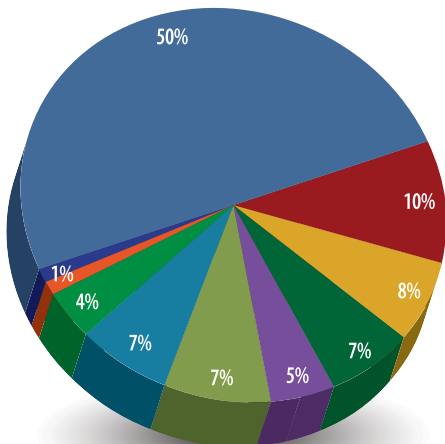
Supporting Hemophilia Ontario

2013 was a great year for Hemophilia Ontario! We completed the amalgamation with Toronto Central Ontario Region ("TCOR") mid-year, which unified our organizations, and will result in overall cost savings going forward. We are pleased with our 2013 financial results, with all the fundraising activities our volunteers took on, and with all the programs and services we provided to our community.

Due to various factors, our net income exceeded our expectations in 2013. In order to ensure a strong financial foundation, we continue to encourage participation by volunteers in fundraising and we are vigilant in controlling our operating costs. As always, our financial statements are presented in a manner consistent with the standards of the Canadian Institute of Chartered Accountants.

— Phyllis Gray, Treasurer

Who Has Given



MOH Grant
\$453,543 [50%]

Pharmaceutical Corporation
Contributions
\$89,200 [10%]

Federated Health Charity
\$76,945 [8%]

CHS National Revenue Sharing
\$60,399 [7%]

Events Revenue
\$67,368 [7%]

Donations
\$45,173 [5%]

Fundraising & Gaming Activities
\$59,819 [7%]

Other Contributions
\$40,685 [4%]

City of Toronto
\$59,819 [1%]

Other Revenue
\$11,310 [1%]

Revenue

A significant portion - 43% - of our revenue comes from provincial and municipal grants, 21% from fundraising and gaming activities and 23% from donations. Pharmaceutical corporations contributed 8%, down from 12% in 2012, but we offset this with increased donations and other contributions. In part due to our amalgamation with TCOR, donations increased by 27%, and events revenue by 66%. Bingo revenue remains consistent with prior years, and Nevada revenue increased slightly, by 2%. Hemophilia Ontario does not employ either staff or outside agencies to fundraise on our behalf - our continued success is dependent on volunteer involvement, and we thank all who contributed their time this past year.

Expenses

Hemophilia Ontario employs 6 full time and 3 part time staff to provide member services and support. Staff salaries are around the mid-range for equivalent positions, and are reviewed annually. Program expenses increased due to the amalgamation, and expenses were incurred for some necessary computer updates. Also due to the amalgamation, occupancy costs are not being shared with TCOR, so increased. Program and occupancy cost increases were offset by increased revenue.

Programs and Services

Hemophilia Ontario's purpose is to provide programs and services to educate and support those affected by bleeding disorders. 100% of the funds received through receipted charitable donations are used for member programs and financial assistance. Our programs were very successful this year, providing members with support and education, as well as lots of fun. As for financial assistance, we can give you statistics and percentages, but they do not show the real effect we have been able to have on the lives of the people in our community. We have provided funding for travel to clinics, orthotics, medication, and dental, just to name a few. Your generous donation of time and money in 2013 has made this positive impact possible, and is an investment in the future for our community. For this, we thank you, and we hope you continue to support our endeavours in 2014.

Our sincere thanks to our industry partners for their ongoing commitment to ensuring members can participate in educational programs that meet individual needs:



Condensed Statement of Financial Position

NOTE: The financial information in the following condensed statements is drawn from Hemophilia Ontario's audited financial statements. If you would like a copy of the complete audited financial statement, please contact us at: 416.972.0641 or visit www.hemophilia.on.ca

HEMOPHILIA ONTARIO

Statement of Operations and Changes in Net Assets

Year ended December 31, 2013

	General Program	TCOR	AIDS Bureau Program	2013 Total	2012 Total
REVENUES					
Grants:					
Ontario	\$ -	\$ -	\$ 453,543	\$ 453,543	\$ 400,793
Municipal		24,840		24,840	31,845
Programs and events	156,725	-		156,725	166,390
Donations:					
Federated Health Charities	76,945	-		76,945	79,897
Individuals and bequests	47,936	-		47,936	64,200
Other contributions	40,685	-		40,685	18,330
Fundraising and gaming activities:					
CHS national revenue sharing	60,399	-		60,399	58,361
Bingo and Provincial Nevada	68,422	-		68,422	73,941
Interest	5,925	-		5,925	5,478
Municipal property tax rebate	3,946	-		3,946	3,250
Other	799	-		799	378
	<u>461,782</u>	<u>24,840</u>	<u>453,543</u>	<u>940,165</u>	<u>902,863</u>
EXPENSES					
Staffing costs	91,390	-	319,203	410,593	423,046
Programs	196,465	24,840	55,922	277,227	272,137
Office supplies and expenses	61,318	-	28,550	89,868	57,646
Building occupancy (Note 6)	50,841	-	29,000	79,841	77,426
Staff and volunteer development	427	-	14,218	14,645	20,864
Travel	13,790	-	2,200	15,990	11,976
Insurance	10,954	-	3,000	13,954	10,779
Professional fees	11,165	-	1,450	12,615	11,279
Board and committee meetings	4,403	-		4,403	4,943
	<u>440,753</u>	<u>24,840</u>	<u>453,543</u>	<u>919,136</u>	<u>890,096</u>
EXCESS OF REVENUES OVER EXPENSES					
	21,029	-	-	21,029	12,767
NET ASSETS, beginning of year	<u>634,350</u>	<u>-</u>	<u>-</u>	<u>634,350</u>	<u>621,583</u>
NET ASSETS, end of year	<u>\$ 655,379</u>	<u>\$ -</u>	<u>\$ -</u>	<u>\$ 655,379</u>	<u>\$ 634,350</u>

Condensed Statement of Financial Position

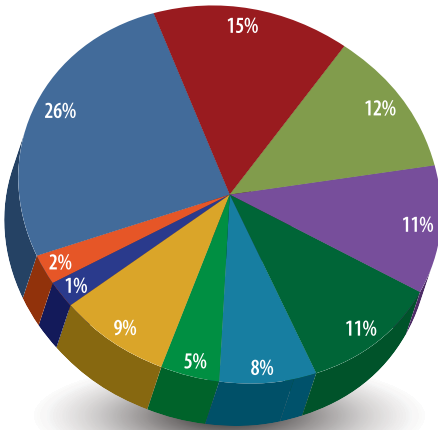
HEMOPHILIA ONTARIO

Statement of Cash Flows

Year ended December 31, 2013

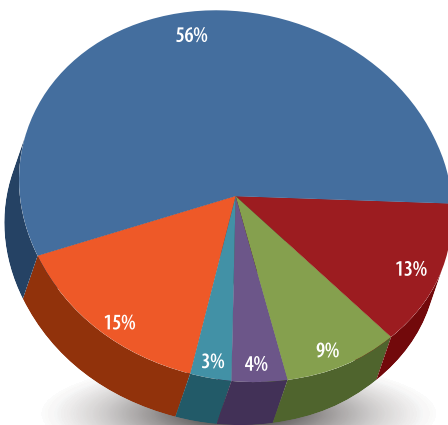
	2013	2012
Cash generated (used in)		
OPERATING ACTIVITIES:		
Excess of revenues over expenses	\$ 21,029	\$ 12,767
Impact on cash of changes in non-cash working capital items:		
Accounts receivable	5,247	7,853
Prepaid expenses and other assets	(8,296)	176
Accounts payable and accrued liabilities	7,133	5,881
Deferred contributions	<u>(26,296)</u>	<u>70,689</u>
	<u>(1,183)</u>	<u>97,366</u>
INCREASE (DECREASE) IN CASH	(1,183)	97,366
CASH, beginning of year	<u>757,369</u>	<u>660,003</u>
CASH, end of year	<u>\$ 756,186</u>	<u>\$ 757,369</u>

Where We Assisted



Dental	\$7,830	[26%]
St. Mike's Equipment	\$4,575	[15%]
Hospital Parking	\$3,824	[12%]
Medic Alert	\$3,436	[11%]
Clinic Travel	\$3,376	[11%]
Therapy	\$2,629	[9%]
Orthotics	\$2,453	[8%]
Medication	\$1,426	[5%]
Food Gift Cards	\$600	[2%]
Hospital Phone/TV	\$260	[1%]

Where You Have Given



Education, Support and Care Programs	\$506,316	[56%]
Administration	\$139,650	[15%]
Capacity Development	\$113,765	[13%]
Awareness Programs	\$83,677	[9%]
Community Programs	\$35,643	[4%]
Governance	\$25,713	[3%]

From Our Financial Assistance Recipients

“The financial support during my husband’s stays in London hospitals made a big difference for both of us.”

– Wife of affected member

“Having three young children with hemophilia creates a lot of worries on its own. Having financial assistance available helps to alleviate a lot of stress on how we’re going to afford to get to the next appointment, camp and so on. It really takes a tremendous load off of one’s shoulders.”

– Parent of affected children

“Two years ago our son was diagnosed with severe hemophilia A at six months old, when he had his first joint bleed. By the time he turned 13 months he had already had four joint bleeds, and was put on twice a week prophylaxis. This meant having to drive to Sick Kids twice a week for his infusions. Having decided to stay at home to take care of our son, finances were tight living on a single person income and the extra expense of close to \$40 a week plus gas was making things even tighter. About a year ago we were introduced to our Regional Service Coordinator who informed us that financial assistance was available to us through Hemophilia Ontario. We filled out a form and submitted some receipts and got reimbursed for some of our parking expenses, as well we were given multiple parking passes to help cover some future expenses. It is stressful enough having to bring our son to Sick Kids twice a week without having to worry about the added financial expense. The financial assistance we received from Hemophilia Ontario has helped lessen some of our stress over our finances. We are very grateful to Hemophilia Ontario for all their assistance.”

– Parent of affected child

“The financial assistance helped me not only financially but also physically. It has helped me to regain my confidence. The assistance given (for one year of hydrotherapy) helps. I thank each and every one for that. I would like the sponsors to look case by case and help those in need. I thank all the members for all the work and help given, and also to my sponsor’s.”

– Affected member

To Our Donors

A key part of our strategy is to build today for tomorrow. We recognize that our organization needs to be sustained into the future by smart responses to change, engaged staff and members and a strong organization. Whether from individuals, industry or other partners, we could not do the work we do without donor support. Every day, powered by the generosity of our donors, we work to improve the health and quality of life for individuals living with inherited bleeding disorders. Your support inspires our efforts and pushes us to continue our work. Although we cannot individually recognize every donor, we wish to thank our donors for their contributions in the past year.

Volunteers

Hemophilia Ontario has a long history of successful community and volunteer engagement. Our volunteers are the 'life blood' of our success and play a crucial role in governance, program support, fundraising and mentoring our youth.



Emily McCormack

I first went to Pinecrest Adventure Camp when I was six, I went with my brother Josh who has hemophilia. As a young camper and a carrier of hemophilia I was able to learn more about hemophilia, my brother had support from medical staff at camp and most importantly we spent time with other children with inherited bleeding disorders. Before going to camp Josh and I had not spent time with other children with inherited bleeding disorders. It helped us both to spend time with other people who understood what we dealt with on a daily basis. My brother and I returned as staff members to this camp in 2011 and although my brother is no longer able to volunteer, I have continued on as a staff member for the past four years. As a child I was always excited to attend camp and I think it's important to provide this opportunity to other children. It is important to me that I am able to be a part of the camp that provides support to families of children with inherited bleeding disorders, since the same opportunity was given to my brother and I.



David Neal

While enrolled in undergraduate studies at York University, I was approached by Karttik Shaw and asked if I was interested in participating in the Youth Committee with Hemophilia Ontario. Unfortunately, I had to decline at the time because I was focused on my studies. I did advise Karttik that I would consider volunteering once my studies were complete. So, upon graduation in the spring of 2003, I approached the Society to see what opportunities existed. At the time there was the opportunity to volunteer with a couple of committees and with Bingo. After a couple of years in these roles, I was approached in the spring of 2005 to join the TCOR Board of Directors. I felt that this would be a great way to gain exposure within the Society. Once elected, I was introduced to some members who had dedicated many hours (and years) of their spare time to ensure that TCOR (and Hemophilia Ontario and the Canadian Hemophilia Society) continued to reach out and help members of the bleeding disorder community. I was able to learn from these members, and as a result I have forged strong friendships that will last well into the future.

There are several reasons why I'm motivated to volunteer with TCOR and Hemophilia Ontario. My parents set a good example when I was younger and volunteered their time to causes they were, and still are, passionate about. So I looked for a cause that I could be passionate about – the Hemophilia Society was just such a cause. My parents volunteered with the Society when I was younger, so I was aware of the good work that the organization did. I thought I could make a difference when the time was right. I feel that with the work that I do for the Society, it is making a difference for the entire community. In addition, I feel that my professional and academic experiences have allowed me to make a difference at the Board level and at the grass roots level of the organization.

I was introduced to some great mentors in the organization, including John Plater, James Kreppner, Maury Drutz and Mike Beck, and I want to make a difference like they did. They set a great example for my generation of hemophiliacs, and I want to pass along their knowledge and experience, as well as what I have learned, to younger members so they can move the organization forward. By passing along this knowledge and mentoring younger hemophiliacs, I know that the organization will be strong and vibrant in the future.



Julia Lepera

Hello, my name is Julia and I am 19 years old. My brother, Johnny, has severe hemophilia. I have attended Pinecrest Adventures Camp since I was seven, starting as a camper, moving to a leader in training and this upcoming summer will be my fourth year as a staff member. Every year I continue to look forward to being at camp, it's always been the highlight of my summer. Camp has always been a huge part of my life because it was a time that Johnny and I could have away from our parents and have fun for an entire week. I always loved that I was able to be included in Johnny's health care and camp really brought us even closer together. My parents always included me in his check-ups, infusions and teaching me about his disorder. Since I am older, I've always had the responsibility of looking out for him and being a part of his care made that easier in case I was needed. The Hemophilia Society, and Pinecrest has done so much to help my family and it has made me a better person. I think I am a more caring and compassionate person because of Pinecrest and it's definitely taught me how to become a leader and step out of my comfort zone. I continue to volunteer at camp because I want to give back to the community as much as I can, and I love doing it! Without Pinecrest, my summers would be pretty boring. As I grow up and try new things, I know that camp will always be an experience that I will love sharing with people that I meet, and I will continue volunteering as long as I can.



Ashwani Kurichh

I have been an active member and volunteer with the Ontario Hemophilia Society, Ottawa and Eastern Ontario Region, for the past 5 years. I have been fortunate to have the opportunity to volunteer for such a wonderful organization that is committed to making a difference in the lives of its members by funding research and development and providing educational and family oriented programs and events for its members.

Volunteering has helped me realize that by donating a little bit of my time, I can make a difference in the lives of individuals in need. From lending a hand at OEOR's bowl-a-thon, helping organize and run the Shawn Duford Golf Tournament or dressing up as Santa for OEOR's annual holiday party, it is rewarding to see the smiles on the faces of the adults and children.

Volunteering is what makes a community because it brings people together to work on a goal. Whether it is a fundraiser for the research to cure a disease that affects the whole world, or to help a local family who has fallen in a time of calamity, volunteers make a difference and make it happen.

Member's Quote – The Impact of Programs Offered

In November of 2013, myself and my children attended our HTC and our fall clinic. Following this there was a dinner and learning session planned for adults as well as a fun activity for my children. With my children being entertained in the next room, I was able to relax and enjoy the talk about the importance of home infusion. The circus performer hired to entertain the children put on a good show and taught juggling tricks to all the kids. Events for the entire family allows siblings to learn about bleeding disorders and help them feel included. It also helps with preventing jealousy issues over time spent with the affected sibling while the non-affected sibling is being left out. Thank-you for your continued efforts!

– Shawn Morrison

Appendices

Board of Directors/ Governance

Hemophilia Ontario's Board of Directors consists of up to 18 volunteer members who are responsible for governance and strategic leadership, and ensuring the legal purpose of the organization is achieved.

The following individuals were elected at the 2013 Annual General Meeting to the Ontario Board of Directors:

Paul Wilton
President

Julia Sek
Vice President, Chair of Care and Treatment Committee

David Neal
Vice President, Chair of Board Development Committee

Mike Beck,
Chair of Nominations Committee

Rob Dinsdale
Secretary

Phyllis Gray
Treasurer

Directors:

Raja Ammoury

Mike Beck

Maury Drutz

Amy Griffith

Victoria Kinniburgh

Ashwani Kurichh

Kristen Luszka

Monica Mamut

Mary Pedersen

Igor Ristevski



Back row – Paul, Raja, Mary, Igor, Mojtaba, Mike, Jeff, Kevin
Seated – Phyllis, Victoria, Amy, Ash, Dave

The Board of Directors meets 4 times annually or more often, as required.

Jeff Beck, Kevin Cruse and Mojtaba Khezry served partial years.

CHS Delegate – as a result of a change in bylaws, Ontario has the opportunity to send a member as a delegate to the Canadian Hemophilia Society. For 2013 – 2014, that delegate was Paul Wilton.

Aligning with the key functions and priorities of the organization, the Board maintains committees allowing the Board to interact and guide the organization through these committees.

The following committees fall under the responsibility of the Ontario Board of Directors:

Board Development Committee
Nominations Committee

Provincial Operational Committees include:

Care and Treatment Committee

Program – to review submitted programs for the next budget year and provide recommendations to the Board [3 meetings annually]

Awards – review and select nominations to determine winners [2 meetings annually]

Planning Groups – Community Camp / Wellness for Women / Just The Guys (North, Ottawa and Southern Ontario) To plan and implement provincial programs with volunteer regional representation. [approximately 6 planning meetings annually per committee]

Financial Assistance Review – to review and approve (if appropriate) submitted financial assistance claims greater than \$1,000 providing funding is available [as required]

Each region develops and utilizes committees as required.

In 2013 these included:

3 Golf Tournament Committees

8 Program Planning Committees

Our Staff

Our greatest strength is in the team of people who work daily in various roles, from staff to volunteers. We rely on their voices to make positive change.

Whether working in a regional office, implementing a provincial program, raising awareness, or fundraising our staff and volunteers share a common goal – they are committed to making a difference in the bleeding disorders community. Hemophilia Ontario benefits from the time and effort of our 9 paid staff and over 300 volunteers working across the province.



Back row – Stephanie, Shelly, Matthew, Sarah, Susan, Laura
Seated – Erika, Terri-Lee, Alex

Terri-Lee Higgins
Executive Director

Susan Turner
Executive Assistant / Bookkeeper

Marina Seliverstova
Accountant

Erika Burns
Regional Service Coordinator OEOR

Jeenetha Kulasingam
Regional Service Coordinator TCOR

Matthew Maynard
Regional Service Coordinator SWOR

Alexandra McGillivray
Regional Service Coordinator CWOR

Stephanie Morrison
Regional Service Coordinator NEOR

Colin Patterson
Regional Service Coordinator OEOR

Laura Tomkins
Regional Service Coordinator TCOR

Shelly Whitney
Regional Service Coordinator NWOR

Sarah Wood
Regional Service Coordinator TCOR

Staff Profile | 2013 Staff Leadership Recipient

As a recent university graduate, I began applying to various positions without really knowing what field or type of job I wanted. I didn't have any real idea of what it would be like to work for a non-profit organization, or more importantly, I didn't have any understanding about what inherited bleeding disorders were. I became the Regional Service Coordinator in the Hamilton region (CWOR) in October, 2006. Since that time, my knowledge of inherited bleeding disorders and the needs of this community have grown exponentially, but there are always new things to learn and explore each day.

Over the past seven and half years, this community has become my family. I have shared in the joys of many families as their children learn to self-infuse, or head to camp for the first time. I have many fond memories of bonding with staff, families and volunteers at one of my favourite programs, Just the Guys, and some of my most treasured memories come from working with the Hemophilia Ontario Youth. There are also memories of harder times, and working hard to help families overcome their issues, and all of these memories, both good and bad, have instilled a great sense of love for this community and its people.

As a result of a wealth of opportunities, I have developed into a better person. There aren't many jobs in this world where you can go home at night and feel a sense of pride for helping someone overcome a fear, or giving someone confidence. There aren't many jobs where you find comfort in the team you work with, or the volunteers that work tirelessly alongside you as you work together to deliver the organization's mission. There aren't many jobs out there that let you do all this while still having fun. As much as there were difficult times along my RSC journey, it has, and always will be my love for this community that keeps me here. No matter where my future takes me, I know this community will forever be a part of me. Thank you !

– Alex McGillivray

Partnerships

Hemophilia Ontario and its regions rely on the power of collaborative partnerships as the best way to effectively reach the greatest number of people. Our staff, volunteers and members are involved in a number of organizations and coalitions that facilitate knowledge sharing across various channels. Formal and informal partnerships across the province allow us all to reach a higher level of learning and, ultimately, a higher level of service to our members.

Some of these partners include: The Ontario AIDS Network, PILLAR, Ontario Non-Profit Network, Ontario Organizational Development Program, various Volunteer Associations and Fundraising groups.

How to Get Involved:




Hemophilia Ontario
Hémophilie Ontario

Hemophilia Ontario welcomes the interest of individuals in our organization. The Board of Directors is elected at our Annual General meetings for a 1 year term. Each region elects a Regional Council at their Regional General Meeting.

For further information please contact:

Hemophilia Ontario, 65 Wellesley Street East, Suite 501, Toronto, ON M4Y 1G7

 info@hemophilia.on.ca

 [/Hemophilia-Ontario](https://www.facebook.com/Hemophilia-Ontario)

 [@HemoOntario](https://twitter.com/HemoOntario)

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

Make a donation, please visit:

<http://www.hemophilia.ca/en/provincial-chapters/ontario/to-donate/>

Donate monthly through direct debit or on your credit card

If your employer has a charitable donation program, have an amount taken off each pay cheque

Leave a bequest in your will



FUNDRAISE

Volunteer at a fundraising event, such as bingo

Join an event, such as the Polar Bear Dip, and obtain sponsors

Nominate Hemophilia Ontario as your company's charity of the year



CAMPAIGN

Become a Hemophilia Ontario campaigner. Tell your family, friends and colleagues about our work



VOLUNTEER

Become a Hemophilia Ontario volunteer. Each and every one of our nine regions across Ontario are always looking for volunteers to become active and involved. Give a little bit of time, or give a lot. Whatever time you can give will be greatly appreciated.

Head Office

65 Wellesley Street East, Suite 501, Toronto, Ontario M4Y 1G7

www.hemophilia.on.ca