



# Hemophilia Ontario

## 2015 ANNUAL Community Report



TOGETHER WE CAN

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Enjoying the Pig Roast Fundraiser



Emil & Darcy at the SWOR Winter Celebration



Animal Encounter at the SWOR Winter Celebration

# EXECUTIVE DIRECTOR'S SUMMARY

## CHANGING THE FACE OF THE ORGANIZATION | Terri - Lee Higgins

With a new plan and new direction, Hemophilia Ontario has begun the necessary changes to build the organization in a stronger and strategic manner. Our actions reflect our integrity and honesty whether it is choices everyone sees or the choices no one sees. At the heart of every decision is ensuring that what we do has value and meets our mission to improve the health and quality of life of people with inherited bleeding disorders. We must make the right choices, whether big or small, even if the choices are not easy and no one is watching.

Our top priority was ensuring that we continued to meet members needs, not just trim the bottom line. Our MOHLTCAB funding reduced by 21% (with further reductions of 17% in 2016 and 34% in 2017) resulting in changes to our staffing structure, relocation or closing of offices, replacing landlines with cellphones and closely monitoring the budget to ensure minimal impact on programs, supports and services. Once we determined our potential restructuring plan, we reached out for feedback and received frank and honest input that helped mold our forward path. Thank you! We spoke with key stakeholders to hear where we are excelling and where we are falling short. Staff analyzed existing programs, services and supports to determine what we needed to let go of, what we kept and then, we determined how we will proceed with those programs and activities that provide you, our members, with the most value. As an example, while smaller regional education programs are good, there can be many challenges with organizing how participants would attend whereas offering the same program as a webinar where people can participate from home was seen as a better option. Thank you to our members, Hemophilia Treatment Centre teams, local Councils, volunteers, funders and sponsors, for your patience. It was imperative that we properly evaluated our current staffing, programs, and future funding so that, as we considered how to move forward, we were doing so in an informed manner.



Terri - Lee receiving Staff Award

### The results?

I believe Hemophilia Ontario has acted with honesty and integrity throughout this process though it has not been without it's challenges. We have had to rethink our staffing structure with funding continuing to decrease over the next two years and how this will impact our capacity to provide quality programs. We have evaluated our programs to determine what and how to best deliver those with the best impact with fewer staff. We know that we will need your help to plan and implement programs, fundraisers and member events such as Holiday parties or summer BBQ's. This is the truth of the future of the organization. We have had to make hard decisions to change what needed to change and to have the courage to say no to continuing to offer programs and activities "just because" we have always done so. While they may not be popular decisions, the choices had to be made to ensure the organization remained strong. I believe we have achieved what we set out to do, and to have done the right things because they are right. Socrates said "The secret of change is to focus all of your energy not on fighting the old, but on building the new". 2016 is the beginning of our 'new'. We are excited to share the future with you.

# OUR IMPACT



OEOR thanks Didi as she retires



SWOR Scrapalicious fundraiser



Connected with  
over **700**  
members at  
regional clinics

**\$27,134** in financial assistance  
provided to **151** members  
(Average of **\$175.70** per person)



**24** Community  
Awareness  
presentations given to  
**3,411** people



**\$156**  
Average amount  
of individual  
donations

**1,682**  
Total number of  
requests for  
information



↑ **18%**  
(563 followers)



↑ **51%**  
(362 followers)



↑ **60%**  
(99 followers)



Wanakita - **199**  
Pinecrest - **17**

**216**  
Total number of  
self-infusions by youth  
at summer camps



Provincial Programs  
attended by  
**380** members



Regional Programs  
attended by  
**690** members



Physio Mary Jane checks out Jake



Fundraiser book sale in NOR

# HEMOPHILIA ONTARIO

## 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.

## OUR VISION

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

## OUR GOALS

### Care and Treatment

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

### Research

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

### Education and Support

Deliver evidence-based information and support to patients, their families, health care providers and the general public across Canada in both official languages, English and French.

### A Cohesive Organization

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

## OUR GLOBAL RESPONSIBILITY

While the primary mission of the Canadian Hemophilia Society and Hemophilia Ontario is to work within our own borders on behalf of Canadians, this strategic plan recognizes our responsibility to the global bleeding disorder community.

Canadians with inherited bleeding disorders enjoy access to advanced therapies. Our comprehensive care clinics provide a high standard of care. Such is not the case around the world where 75% of people with hemophilia do not have access to safe and efficacious treatments and highly trained health care providers. Life expectancy remains less than 20 years and these short lives are filled with pain and suffering.

The national organization and its chapters, as well-developed patient associations, acknowledge their responsibility to work with the World Federation of Hemophilia (WFH) to further its mission of

TREATMENT FOR ALL.

## 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 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.

## TARGET POPULATIONS: Who We Serve

Hemophilia Ontario and the Canadian Hemophilia Society provides

information, programs and services to ...

- 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...);
- 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.

# PRESIDENT'S MESSAGE

Paul Wilton



This year we finalized an agreement with our major funder the Ministry of Health and Long-Term Care AIDS Bureau. Thank you to our community for your patience as we have developed our new staffing structure that resulted from this agreement. Implementation of our funding strategy has put us on a path to a more sustainable future. I am certain the changes we have made to Hemophilia Ontario will make us stronger and more prepared to address the needs of our community.

Hemophilia Ontario played a leading role in the development of the Canadian Inherited Bleeding Disorders Strategy which has guided the development of our own local organizational goals. We completed an Engagement Strategy to increase participation and

developed a Regional Council Orientation to help give our grassroots volunteers the tools they need for further success. We amended our by-laws to create a more effective governing structure.

Moving forward, our organization needs to continue to focus on finding new ways to engage more of our community. We need to continue to adapt to the times in the ways we reach out and market our services to those who need them most. We should continue our focus on developing future leaders for the community. We should review our leadership development strategies on an on-going basis to ensure we are providing the support future leaders need. We need to continue focusing on ensuring all of our services align with our organizational goals which are developed from the input of our community.

Care and Treatment issues should continue to be the highest priority of the organization. Patients have a role to play in ensuring clinics are well resourced and provide evidence based standards of care. Patients can help ensure women with inherited bleeding disorders receive the treatment they need. Patients can help make the case to governments that providing access to innovative products is an investment in better health outcomes and lower long-term costs. Our community continues to be the watchdog of the blood system. There is still a need to support those affected by tainted blood. We can partner with developing countries to share our expertise and experiences to improve care and treatment for all people with inherited bleeding disorders.

I am proud of our Board of Directors team and the work they have completed this year. We have a diverse group of people with different areas of expertise and experiences with the inherited bleeding disorders community. This Board is bright, engaged, and collaborative. It has been a pleasure to work with them. This year we dug into financial projections, comparative analysis of similar sized not-for-profits, strategic planning, and issues involving engagement and leadership development. This experience helped develop new Board members who will be strong leaders for the organization in the future.

# MAKING A DIFFERENCE

## MEMBER'S STORIES

### THE WHOLE FAMILY | Michelle M.

For our family with 2 boys that have severe hemophilia, Hemophilia Ontario was introduced to us by being a familiar face at our quarterly clinic appointments. They helped us to navigate the resources available to us and were a place to easily send off a question to and then point us in the right direction for an answer. As we became more familiar with the community our chapter events were a way to network with others in similar situations. It was nice for the boys to meet other thriving kids. Chapter events for parents helped us to see other parents coping and viewing their kids' lives normally, without pity. As they grow, volunteer opportunities help the boys stay in touch with the community and see possibilities that having hemophilia opens up to them.



### WE KNOW WHERE TO TURN FOR KNOWLEDGE AND SUPPORT | Nadine & Serena B.

The nose bleeds began when she was an infant and we chalked up her innumerable bruises to the fact that she was a rough and tumble girl that played real hard but there was more to the story. After several doctor and ER visits for excessive and long-lasting nose bleeds, our local primary care provider began to suspect that our youngest daughter, 11 year old Serena, had an inherited bleeding disorder and referred us to the HTC in Hamilton for diagnosis and treatment. When we learned that Serena had Von Willebrand's Disease this winter we had so many questions and concerns. The HTC did their best to educate all of us about Serena's illness. They provided us with credible information and advised of available resources and supports. Most of all, they assured us that Serena's quality of life does not have to be impacted negatively by her diagnosis. She is beginning to learn about managing the physical activities she is so fond of and shifting some of her attention to other pursuits, like learning the violin. Serena is also very excited that she is attending YMCA Camp Wanakita this year with other kids like her. Our involvement with Hemophilia Ontario is just beginning but it brings us no small comfort that we have somewhere to turn for knowledge and support.



# PROVINCIAL PROGRAM REPORT

BUILDING STRONG COMMUNITIES | Provincial/ Regional/ Youth

NORTHERN GETAWAY WEEKEND | Amy B.



Just The Guys weekend getaway

Being able to participate in our regions Just the Guys/Member Weekend Getaway has been an invaluable experience. This year was not only the first time that my family attended the JTG/Member Weekend (my son just four years old) but it was also the first time our whole family had been to an event together. To be able to get away as a family and be given the opportunity to gain more education on inherited bleeding disorders is such a valuable experience since we need to be well versed on our disorder and there is so much to learn.

Like most kids, my son has those moments of struggling to understand why he needs injections and his friends back home do not, or why he cannot

participate in some activities. Being able to interact with other children at this event has helped him see that he is not alone. My son created close friendships with other children that, even though we may only see them a few times a year, he looks forward to the next time we get together and are able to pick up playing where they left off. Being able to interact and participate in activities with other families encourages us to share stories, create bonds, and create support systems through keeping in touch after these events. I was able to leave this event feeling like our whole family learned a few new things, became more prepared for the future, had a great time, made new friends, and became a stronger family unit. I look forward to attending more of these events in the future.



The gang's all here



At Just the Guys weekend

## WEBINARS | Venus R.

Webinars organized by Hemophilia Ontario have always been a popular option with our family. We registered for our first webinar in 2012 presented by Dr. Paula James about von Willebrand disease and have participated in a variety of other webinars since. The webinars have been easy to register for and connect to from the comfort of our home. There are opportunities to interact during the webinars by asking questions and we often receive follow up information afterwards. Whether it's a webinar focused on topics like von Willebrand disease, hemophilia, transitioning from pediatric to adult care, physiotherapy or new factor concentrates we always find something to take away from the presentations and they often trigger discussions about the material presented. We are definitely looking forward to future webinars!

## TWINNING | Candace Terpstra

### Progress Report on the Tanzania - Ontario Twinning 2015

Considerable progress has been made in this, the second year, of the Twinning with the Hemophilia Society of Tanzania (HST). Here are some of the key accomplishments from 2015:

- World Hemophilia Day, the President, and two HST members appeared on a popular community information program raising awareness in rural areas. As a result, four new patients were identified and diagnosed at Muhimbili National Hospital in Dar Es Salaam.
- The HST brochure was translated into Swahili and a one-page flyer focused on hemophilia and the need for treatment was provided in English and Swahili
- Diagnosis is completed at Muhimbili where there is a Patient Registry in development. To date 80 patients have been identified (an increase from 29). There are times patients are required to pay for testing and this is not affordable in the general population
- Patients can now attend regular clinics on Tuesday and Friday for treatment
- The Ministry of Health requested Dr. Rwezaula, Head of Hematology, draft a concept paper on Hemophilia Care so they can better understand the needs of these patients
- Over 40 families travelled across the country to attend an Education Workshop featuring Dr. Enrico Novelli speaking on the basics of hemophilia.
- A 2-year constitutional review was approved at the AGM where 2 youth were recruited to the Board.



Hemophilia Society of Tanzania AGM education with Dr. Novelli, Hemophilia 101



HST Board develops 2016 Action Plan

The progress in Tanzania has been significant this year and we are hopeful that this will continue into 2016. I sincerely appreciate the support and commitment of the Hemophilia Ontario Twinning Team – Dave Neal, Amy Griffith and Zach Adams with staff assistance from Terri-Lee Higgins. They have all been very generous with their time, interest and effort.

## PROGRAMS | EVENTS | RECOGNITION



W2 Youth Group



Self Infusion in the Bayer Den



Camp is all about lifelong friends



A Medieval affair at SWOR's Pinecrest



Animals abounded at the SWOR Polar Bear Dip

## HEMOPHILIA ONTARIO YOUTH (HOY)

**Stephan L.**



Brothers cheering on the Blue Jays

HOY allows youth living with hemophilia and other inherited bleeding disorders from all over Ontario to get together and enjoy an event. We often saw each other at organized sporting events like a Raptors game or a Toronto Marlies game. We bonded over lunch and sports, while learning valuable skills to manage hemophilia as a young adult. The educational presentations often focused on dealing with hemophilia socially. We were taught on how to disclose to other people. Since hemophilia is a rare disorder it is often difficult to meet others with this condition, but the best part of HOY is being able to meet and relate with others going through the same process of growing up with hemophilia and other inherited bleeding disorders. HOY also brought in presenters, some of them were older hemophilia patients that provided real world experiences on how they managed their hemophilia.

# SUPPORTING HEMOPHILIA ONTARIO

Phyllis Gray, CPA, CGA | VICE PRESIDENT, FINANCE

We are pleased to present our 2015 financial results, as we are making our way through the transition of reduced funding from the Ministry of Health and Long Term Care (“MOHLTC”), and the resultant changes to our organization. Our staff and volunteers have been most supportive during this process, and we are very appreciative of all.

Even with reduced funding from MOHLTC, our net income exceeded our expectations as we were able to offset the reduction in income by becoming more efficient in the provision of programs, and by a reduction in the number of staff. In 2016, we will see continued reduction in costs, including occupancy and staffing as we move further through these changes.

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.

Hemophilia Ontario Profit & Loss January through December 2015				
	Jan - Dec 15	Jan - Dec 14	\$ Change	% Change
<b>Ordinary Income/Expense</b>				
<b>Income</b>				
4100 · Grants	405,617.06	433,983.00	-28,365.94	-6.54%
4200 · Fundraising & Gaming activities	175,792.34	216,983.44	-41,191.10	-18.98%
4305 · Pharmaceutical Corp Contrib	150,850.00	156,095.00	-5,245.00	-3.36%
4310 · Other Contributions	28,050.58	53,634.72	-25,584.14	-47.7%
4316 · Federated Health Charity	68,249.49	77,190.04	-8,940.55	-11.58%
4320 · Events Revenue	60,395.01	70,386.06	-9,991.05	-14.2%
4321 · CHS national revenue sharing	55,780.00	55,416.00	364.00	0.66%
4400 · Donations	54,518.36	120,364.72	-65,846.36	-54.71%
4500 · Other Revenue	11,112.67	11,134.76	-22.09	-0.2%
<b>Total Income</b>	<b>1,010,365.51</b>	<b>1,195,187.74</b>	<b>-184,822.23</b>	<b>-15.46%</b>
<b>Gross Profit</b>	<b>1,010,365.51</b>	<b>1,195,187.74</b>	<b>-184,822.23</b>	<b>-15.46%</b>
<b>Expense</b>				
5100 · Staffing Costs	356,508.31	434,200.32	-77,692.01	-17.89%
5200 · Program Expenses	297,928.17	305,621.90	-7,693.73	-2.52%
5300 · Gaming Activities - Nevada	134,232.87	166,933.07	-32,700.20	-19.59%
5400 · Office & General Expenses	53,527.96	62,149.53	-8,621.57	-13.87%
5500 · Travel Expenses	14,465.34	14,196.03	269.31	1.9%
5560 · Occupancy Expenses	85,364.50	81,335.32	4,029.18	4.95%
5585 · Professional fees	9,846.60	9,492.50	354.10	3.73%
5590 · Insurance costs	13,617.27	13,377.77	239.50	1.79%
5600 · Staff and volunteers training	20,784.52	24,737.82	-3,953.30	-15.98%
5700 · Committees Expenses	7,418.47	6,608.62	809.85	12.25%
<b>Total Expense</b>	<b>993,694.01</b>	<b>1,118,652.88</b>	<b>-124,958.87</b>	<b>-11.17%</b>
<b>Net Ordinary Income</b>	<b>16,671.50</b>	<b>76,534.86</b>	<b>-59,863.36</b>	<b>-78.22%</b>
<b>Other Income/Expense</b>				
<b>Other Expense</b>				
STAT Accts	0.00	0.00	0.00	0.0%
<b>Total Other Expense</b>	<b>0.00</b>	<b>0.00</b>	<b>0.00</b>	<b>0.0%</b>
<b>Net Other Income</b>	<b>0.00</b>	<b>0.00</b>	<b>0.00</b>	<b>0.0%</b>
<b>Net Income</b>	<b>16,671.50</b>	<b>76,534.86</b>	<b>-59,863.36</b>	<b>-78.22%</b>

## WHO HAS GIVEN

MOH Grant  
**\$379,692 (43%)**

Pharmaceutical Corp Contributions  
**\$150,850 (17%)**

CHS National Revenue Sharing  
**\$55,780 (7%)**

Donations  
**\$54,518 (6%)**

Fundraising & Gaming Activities  
**\$41,559 (5%)**

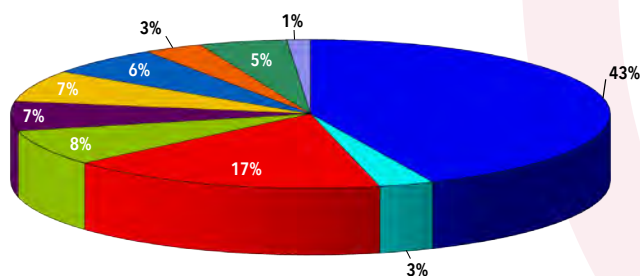
City of Toronto  
**\$25,925 (3%)**

Federated Health Charity  
**\$68,249 (8%)**

Events Revenue  
**\$60,395 (7%)**

Other Contributions  
**\$28,051 (3%)**

Other Revenue  
**\$11,113 (1%)**



## Revenue

A significant portion - 46% - of our revenue continues to come from MOHLTC funding. 5% of revenue was from gaming and fundraising activities. Pharmaceutical corporations continue to contribute – 17% of our recognized revenue - with their funding for our programs. Our donations this year compared to 2014 (excluding the significant bequest we received in 2014) have increased and account for 6% of our revenue. There was a slight reduction in bingo and Nevada revenue, as the number of participating Nevada retailers continue to decrease, and as a result their sales have decreased. Also, 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. 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 2015.

**Hemophilia Ontario  
Balance Sheet  
As of 31 December 2015**

	31 Dec 15	31 Dec 14	\$ Change	% Change
<b>ASSETS</b>				
<b>Current Assets</b>				
Chequing/Savings				
1000 · Cash and cash equivalents	881,414.00	841,781.19	39,632.81	4.71%
<b>Total Chequing/Savings</b>	<b>881,414.00</b>	<b>841,781.19</b>	<b>39,632.81</b>	<b>4.71%</b>
<b>Other Current Assets</b>				
1200 · Accounts receivable	60,274.71	68,369.33	-8,094.62	-11.84%
1300 · Prepaid exp. and other assets	18,878.42	22,277.92	-3,399.50	-15.26%
<b>Total Other Current Assets</b>	<b>79,153.13</b>	<b>90,647.25</b>	<b>-11,494.12</b>	<b>-12.68%</b>
<b>Total Current Assets</b>	<b>960,567.13</b>	<b>932,428.44</b>	<b>28,138.69</b>	<b>3.02%</b>
<b>TOTAL ASSETS</b>	<b>960,567.13</b>	<b>932,428.44</b>	<b>28,138.69</b>	<b>3.02%</b>
<b>LIABILITIES &amp; EQUITY</b>				
<b>Liabilities</b>				
<b>Current Liabilities</b>				
Accounts Payable				
2003 · Accounts Payable-QB	22,321.39	45,212.99	-22,891.60	-50.63%
<b>Total Accounts Payable</b>	<b>22,321.39</b>	<b>45,212.99</b>	<b>-22,891.60</b>	<b>-50.63%</b>
Credit Cards				
2001 · TD VISA CARDS	7,773.87	5,192.61	2,581.26	49.71%
<b>Total Credit Cards</b>	<b>7,773.87</b>	<b>5,192.61</b>	<b>2,581.26</b>	<b>49.71%</b>
<b>Other Current Liabilities</b>				
2005 · Accrued Payable	15,498.00	14,500.00	998.00	6.88%
2200 · Deferred contributions	166,388.77	135,609.24	30,779.53	22.7%
<b>Total Other Current Liabilities</b>	<b>181,886.77</b>	<b>150,109.24</b>	<b>31,777.53</b>	<b>21.17%</b>
<b>Total Current Liabilities</b>	<b>211,982.03</b>	<b>200,514.84</b>	<b>11,467.19</b>	<b>5.72%</b>
<b>Total Liabilities</b>	<b>211,982.03</b>	<b>200,514.84</b>	<b>11,467.19</b>	<b>5.72%</b>
<b>Equity</b>				
3200 · Retained Earnings	731,913.60	655,378.74	76,534.86	11.68%
Net Income	16,671.50	76,534.86	-59,863.36	-78.22%
<b>Total Equity</b>	<b>748,585.10</b>	<b>731,913.60</b>	<b>16,671.50</b>	<b>2.28%</b>
<b>TOTAL LIABILITIES &amp; EQUITY</b>	<b>960,567.13</b>	<b>932,428.44</b>	<b>28,138.69</b>	<b>3.02%</b>

## Expenses

As of December 31, 2015, Hemophilia Ontario employed 4 full time and 2 part time staff to provide 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. Staffing costs decreased from 2014 due to the reduction in the number of staff, an employee on sick leave, and other efficiencies. Programming costs remained fairly consistent with 2014. Occupancy costs also remained consistent with 2014, but will be significantly reduced with the moving of our Toronto office to smaller premises, and the closing of one of our regional offices.

## Net Effect

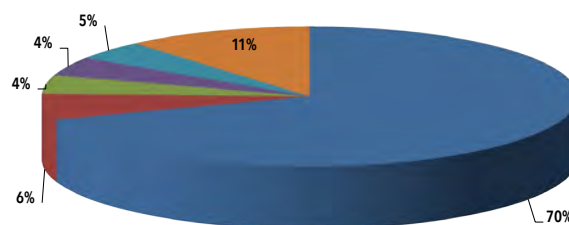
As can be seen on our Statement of Financial Position, our net assets increased in 2015 by \$28,138. This is largely due to contributions that were received in 2015 but deferred to future year(s) for program spending.

*It should be noted that percentages shown in the accompanying pie charts do not correspond to the above percentages, as salaries and other costs have been allocated to the relevant programs and activities in the pie charts.*

## 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 received charitable donations are used to support member programs and provide financial assistance. Our programs this year 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 (a great example is Camp Wanakita). We also provide financial assistance in various ways – such as travel/parking for clinics, therapy, medication, orthotics and dental work. What a great way to share our experiences and support our members in a way that is meaningful and will benefit them for years to come.

We thank everyone – staff, volunteers, donors, supporters and other stakeholders - for your generosity in making this possible in 2015, and we ask for your continued support in 2016 and beyond.



### WHERE YOU HAVE GIVEN

Education, Support and Care Programs	<b>\$598,341 (70%)</b>
Capacity Development	<b>\$51,314 (6%)</b>
Community Programs	<b>\$37,767 (4%)</b>
Admin	<b>\$97,234 (11%)</b>
Awareness Programs	<b>\$36,728 (4%)</b>
Governance	<b>\$38,077 (5%)</b>

# FOUNDATIONS AND SPONSORS

Thank you for investing in Hemophilia Ontario's mission to improve the health and quality of life of people living with inherited bleeding disorders. Your support allows us to meet the challenges of stretching limited resources to offer quality member education programs, financial assistance to those in need and ensure affected youth go to camp and learn how to care for themselves in new environments. We are deeply grateful for your support and know we would not be able to do what we do otherwise.

**"We donate to Pinecrest Adventures Camp because we believe that every child should live the life they choose. Not only are they having fun, they are being educated on how to live well with their inherited bleeding disorder."**  
 ~ Jim Higgins,  
**Cando Rail Services Employee, Southern Ontario Region**



## FINANCIAL ASSISTANCE

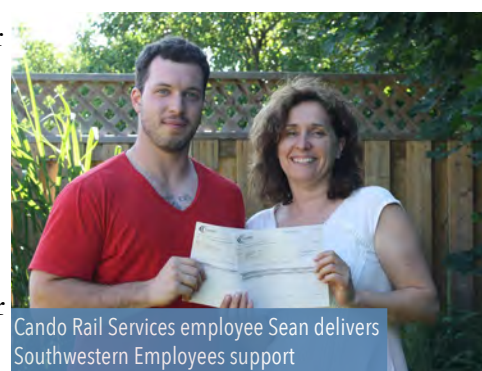


Brad Barbour delivers proceeds from Liam Barbour Golf Tournament

**"Hemophilia Ontario has been a great help for our family. My son has severe Hemophilia B and we wished to protect him the most we could as he learned to crawl and walk. They reimbursed the cost of a helmet and knee pads. Hemophilia Ontario has also been a great resource in helping us cover the costs of our weekly visits to CHEO for our son's weekly prophylaxis infusions. We would be at a loss without hemophilia Ontario's continuous support. Thank you!"**  
 ~ Parent of affected child

**"I had to have surgery done and ended up finding out that I had piriformis syndrome. In most cases, yoga poses are prescribed to help correct the issue, but unfortunately, I wasn't able to do the poses. With the help of my clinic team and physiotherapist, I was prescribed massage therapy. Hemophilia Ontario helped me get the therapy I needed to correct the issue before and after my surgery. Without their financial help, I wouldn't have been able to get the massage treatments I needed, and ultimately, improve my condition. Thank you."** ~Affected Member

**"I wanted to thank you and Hemophilia Ontario. I received my second Venofer IV infusion on Tuesday at St. Mike's and can already feel a marked improvement in my physical energy and cognitive capacity. I've been significantly anemic for so long that walking distances or concentration on anything was becoming increasingly arduous, especially after my most recent prolonged winter bleed. I forgot how much better one can feel with higher ferritin, hemoglobin and iron store levels. It's like night and day. I will be undergoing a third treatment on July 13th and then my hematologist will reassess to determine if I require further treatments."** ~Affected Member



Cando Rail Services employee Sean delivers Southwestern Employees support

## TO OUR DONORS

Every year women and men like you, as well corporations and foundations express their generosity by supporting and partnering with Hemophilia Ontario. Whether a large donation that funds a program or a monthly gift that supports the organization's ability to remain innovative to provide programs and supports, these gifts deliver a lasting change for our members. Thank you! Together, we truly can show that we care enough to make a real difference.

## PARTNERSHIPS

Through the development of strategic alliances, Hemophilia Ontario is involved in several supportive and collaborative partnerships, enabling the organization to not only increase programs, services and supports with mutual benefits to all involved. Every alliance has its own unique blend of strategic purpose and each have their own key milestones that are regularly evaluated to ensure the results meet the established criteria. Whether formal or informal partnerships, our engagement as staff, volunteers and members enhances our ability to maintain our commitment to a higher level of service to our members. A few of these key alliance include:

- **Federated Health**
- **Health Partners**
- **CATIE**
- **Ontario Organization Development Program**
- **Ontario's chapters of the Canadian Association of Nurses in Hemophilia Care, the Canadian Physiotherapists in Hemophilia Care, the Canadian Hemophilia Social Workers and the Association of Clinic Directors**



“It's been a very magnificent and productive year for Queen's Hemophilia Society (QHS) at Queen's University. The club has held several events throughout the two semesters and has raised great awareness about QHS as well as inherited bleeding disorders, in general. One of the first events, held early this year, was a large bake sale. The event was phenomenal with great response and feedback from the student community. The holiday jellybean raffle was another successful sponsored event through which QHS spread awareness and attention to those affected by inherited bleeding disorders. Members of QHS have always been eager to give back to the community and do so through various mediums and variations. Our presence on Facebook with weekly updates on research breakthroughs and stories surrounding inherited blood disorders have sparked interest in many. The club has also raised funds that will be used in the coming months/semesters to organize conferences and formals. Currently working on many projects that will not only aid the Kingston and Ottawa regions, QHS hopes to create local and large scale impacts in the near future. Make sure to check QHS out in the summer!” ~Saad and Charmy



# VOLUNTEERS

Volunteers remain the backbone of Hemophilia Ontario success and it is through their commitment and compassion that we continue as a well-respected provider of member education and support. Hemophilia Ontario excels at volunteer retention which provides continuity and quality of service and supports to members. The benefits of retention are immeasurable - 52 % of our volunteers have over five years of service and more than 40 of these individuals have more than 10 years. We have volunteers across the province that: fundraise, sit on the board or council, lead client groups, lend expertise and creativity, provide leadership, support/host events, support Hemophilia Ontario financially, ...the list goes on and on... as do the hours they contribute each year. Our volunteers are

## A SECOND FAMILY | Stephen Perry

Hi my name is Stephen Perry. Myself and two of my boys have VWD type 2B. I have been volunteering with hemophilia Ontario for approximately one year now. As a young child growing up with VWD I never thought much of it, and it wasn't until my boys were born that I felt the need to be an advocate for them in the best way that I possibly could. For me volunteering not only shows my children how important they are and that they need to take care of themselves as they grow older, it also helps to educate and bring awareness about bleeding disorders to the general public and others within our community. Being part of hemophilia Ontario is like having a second family we have grown to love over the years and I can only hope that my children follow in my footsteps and dedicate their time as they get older to an organization that greatly impacts each of our lives.



## MY BIGGEST PASSION? | John Lepera

My biggest passion? Just the Guys: The commitment and dedication of Hemophilia Ontario's volunteers enables us to continue as a dynamic, relevant and recognized provider of education, support and care to our members. As our community grows and changes so does the diversity among our volunteers, better reflecting our changing local community. I have been an active volunteer with the South West Region of Hemophilia Ontario since 1998. This has always been important to me, as it has helped me stay connected with the inherited bleeding disorders community. I have volunteered in many ways these past 18 years, with many fund raisers and program committees, but my biggest passion from its beginning in 2001, has been Just the Guys, a bonding weekend for boys with hemophilia and their fathers/ male role models.

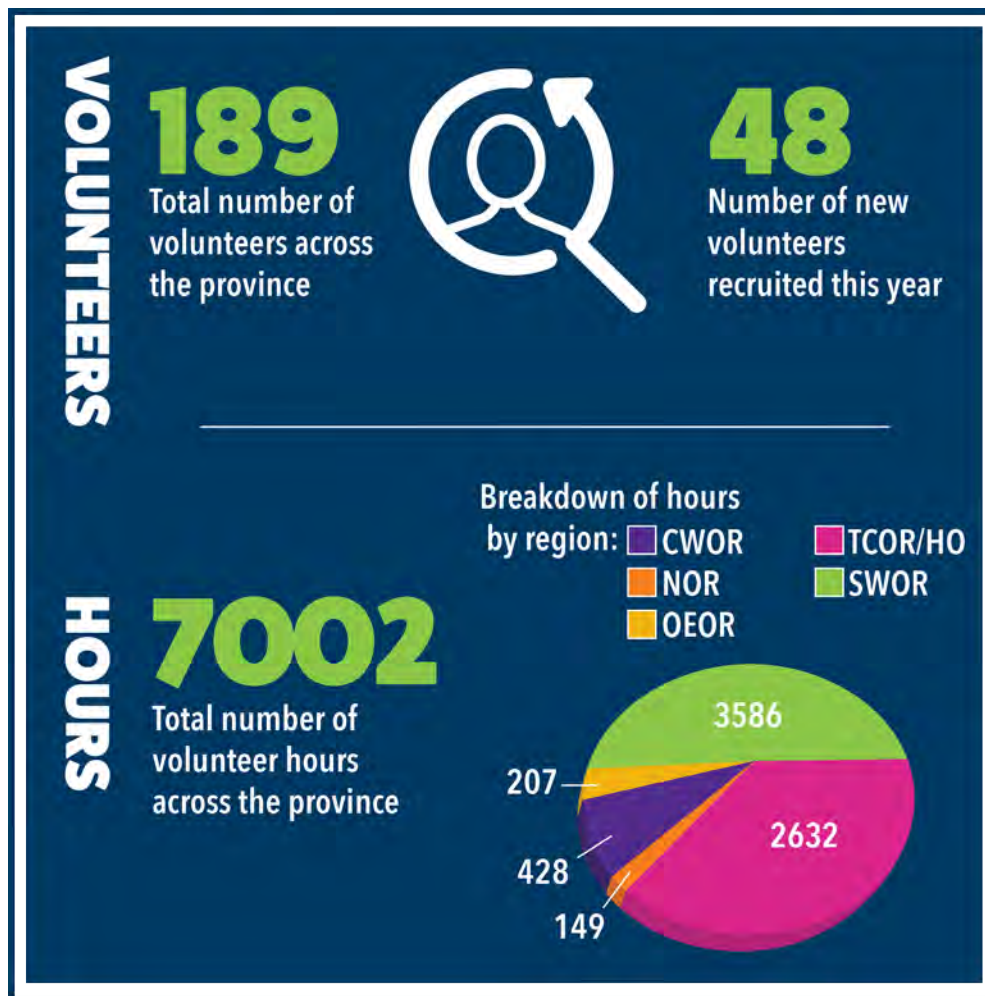




Being a part of this committee has always been near and dear to my heart. It has been rewarding and has allowed me to give back to the inherited bleeding disorders community. My son Johnny has severe hemophilia and this event strengthened our bond. The weekend consists of participation in activities such as ball hockey, kayaking, swimming, rock climbing, archery, camp fires, as well as attending valuable educational topics on inherited bleeding disorders. It is a confidence booster for all of us because we got a chance to create lifetime friendships and the boys were with boys just like themselves.

The JTIG weekend has blossomed into a “Spectacular Event” over the last 15 years. If you haven’t attended, “What are you waiting for”?

### VOLUNTEERS | By The Numbers



# APPENDICES

## OUR STAFF

Hemophilia Ontario's strives to create a work environment that nurtures creativity, collaboration, innovation and success. Whether they work at our headquarters in Toronto, work remotely from home or work daily in the communities we serve, our people understand and embrace Hemophilia Ontario's mission and organizational goals. They work hard to build programs that align with the Board's strategic priorities and demonstrate creativity through quality member programs as well as providing consistent support to our volunteers. We are honoured to recognize this dedicated group of individuals:

**Terri-Lee Higgins**, Executive Director

**Susan Turner**, Executive Assistant / Bookkeeper

**Marina Seliverstova**, Manager of Finance

**Alexsandra McGillivray**, Regional Service Coordinator CWOR (Central Western Ontario Region)

**Stephanie Morrison**, Regional Service Coordinator NEOR (North Eastern Ontario Region)

**Laura Tomkins**, Regional Service Coordinator TCOR (Toronto and Central Ontario Region) and NWOR (North Western Ontario Region)

**Matthew Maynard**, Regional Service Coordinator SWOR (South Western Ontario Region)

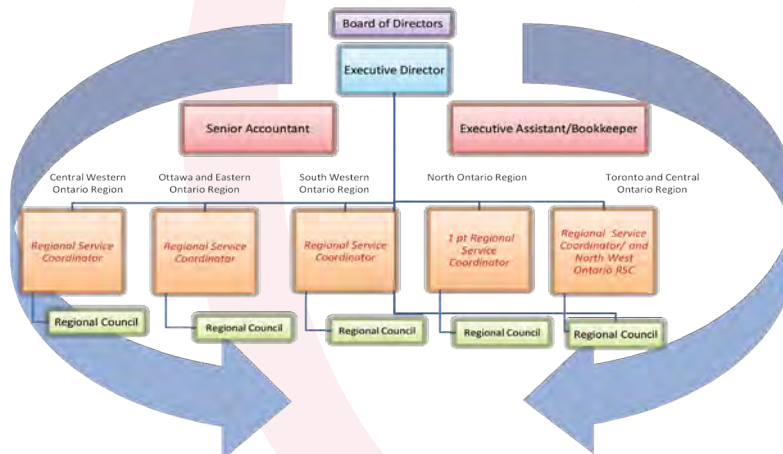
**Colin Patterson / Amanda Grant**, Regional Service Coordinator, OEOR (Ottawa and Eastern Ontario Region)

### TERRI-LEE HIGGINS | 2015 Leadership Recipient



I am deeply honoured to have been selected to receive this award. One of the fortunate ones, I can honestly say that I love my job. As I enter my 9th year with the organization, I am thankful every day that what began as an SWOR maternity leave has continued as an amazing journey. While every day presents new and unique challenges, every time I speak with a member who acknowledges how the Society has assisted them or how their involvement in programs or as a volunteer has positively impacted them, it reinforces I am in the right job. I have the utmost respect for my colleagues, every day we work toward the common goal of making the organization better, stronger. We are all capable of becoming more than we realize when given the opportunity to grow.

#### HEMOPHILIA ONTARIO ORGANIZATIONAL STRUCTURE



## BOARD OF DIRECTORS / GOVERNANCE

Hemophilia Ontario's Governance Board, is accountable to the membership which includes clients, volunteers and donors alike. The Board is responsible for: upholding the stated mission of Hemophilia Ontario; overseeing governance and managing risk; strategic planning; for the future sustainability of human resources; and ensuring financial accountability to our community, government and donors. Having an active and supportive Board of Directors has been essential to the organizational restructure that began in 2015. During this fiscal year the Board actively addressed member engagement, an organizational restructure and negotiating a 3-year funding reduction with the Ministry of Health Long Term Care AIDS Bureau.

Thank you to our volunteer Board of Directors. The Directors are selected to bring experience, effectiveness and perspective from a variety of backgrounds and live in the community we serve. Hemophilia Ontario strives to achieve community representation on its Board as well as an appropriate balance in diversity and experience of members. Hemophilia Ontario's Board is a small and active Governance Board. Given the smaller board size, issues are discussed and decisions are made at the Board level with committees taking on special projects. Directors are encouraged to attend volunteer and professional education sessions and community support events, ensuring that they remain independently informed as to the challenges and successes experienced by our volunteers and members.

**The following individuals were elected at the 2015 Annual General Meeting to the Ontario Board of Directors:**



**Paul Wilton**, President  
**Phyllis Gray**, Vice President Finance  
**Maia Meier**, Vice President

**Amy Griffith**, Vice-President  
**Julia Sek**, Past President  
**Zachary Adams**, Secretary

### Directors at Large:

**Monica Mamut**, Chair of Member Engagement Task Force  
**Rob Dinsdale**, Chair of Nominations Committee  
**Shelley Hewett**  
**Ashwani Kurichh**

## CHS Delegate:

Ontario has the opportunity to send one member as a delegate to the Canadian Hemophilia Society Board of Directors.

**Maia Meier** completed this role 2015-2016.

## The following Committees fall under the responsibility of the Ontario Board of Directors:

**Board Development Committee** responsible to develop and implement training that meets the Boards needs.

**Funding Review Task Force** completed their mandate that began in 2014 in response to the decreasing financial commitment by MOHLTC AIDs Bureau.

**Member Engagement Task Force** was initiated by the Ontario Board of Directors to examine the current state of engagement within the organization and identify potential strategies to increase member engagement.

**Nominations Committee** responsible to assist the Board to fulfill oversight responsibilities related to nomination of directors.

## Regional Committees:

In 2015 there were 2 **Golf Tournament Committees** and 8 **Program/Event Planning Committees**



2015 Panel Discussion

## Provincial Operational Committees include:

**Regional Councils** provide direction to the local Regional Service Coordinator on programming and supports.

**Care and Treatment Committee** exists to support and sustain Ontario's Hemophilia Treatment Programs, facilitate sharing of information among them, and help them to maintain the provincial and national standards of care for people with inherited bleeding disorders.

**Programs Committee** met twice to review submitted programs for the next budget year and provide recommendations to the board.

**Awards Committee** met twice to review nominations and determine recipients.

**Planning Groups** each group completed approximately 6 planning meetings (annually) per committee. Volunteers participated in the planning and implementation of the following programs in 2015: Wellness for Women and Just the Guys

**Financial Assistance Review Committee** meets as required to review and approve (if appropriate) submitted financial assistance claims great than \$1,000 for the province and \$500 for the Toronto specific Hunter Bishop Comfort Fund. In 2015 there were a total of 8 reviews.



Pam Wilton receiving the Honourary Lifetime Member award


# 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, 10<sup>th</sup> Floor, Suite 10100, Toronto, ON M2N 6K8


 [info@hemophilia.on.ca](mailto:info@hemophilia.on.ca)

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## HOW YOU CAN HELP...

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://events.hemophilia.on.ca/payments.php>

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 six 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.



**Hemophilia Ontario**  
**Hémophilie Ontario**

## HEAD OFFICE

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