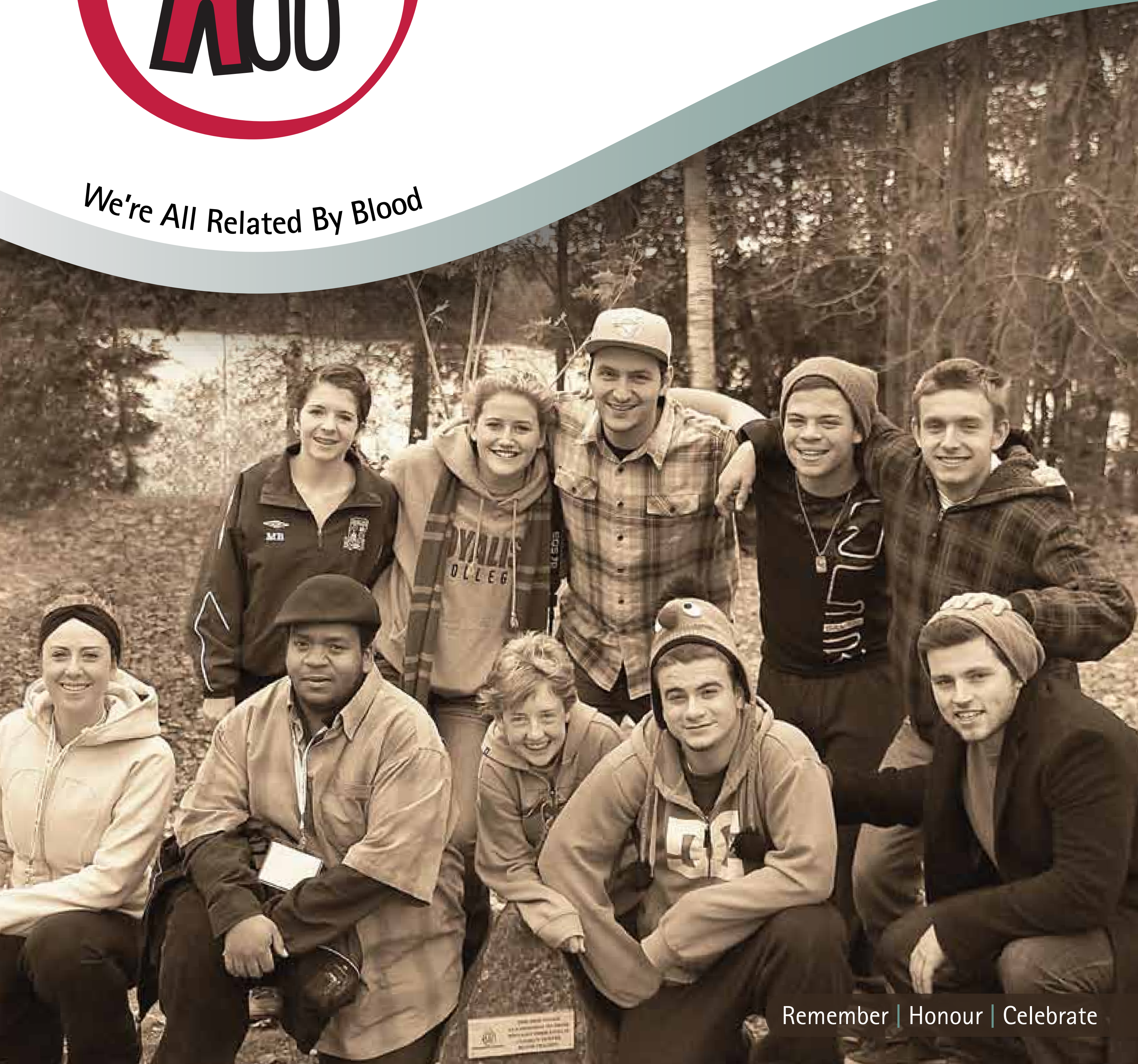
Hemophilia Ontario

2012 ANNUAL COMMUNITY REPORT

We're All Related By Blood



Remember | Honour | Celebrate

Hemophilia Ontario

We're All Related By Blood

Father and Son at Community Camp

Contents

■ REPORT COVER PHOTO

Hemophilia Ontario Youth (HOY) around commemorative tree, part of Camp Wanakita 20th Anniversary celebrations

photo courtesy of M.J. O'Grady

Executive Summary

Remember, Honour, Celebrate

We are committed to improving the health and quality of life of all people with inherited bleeding disorders and ultimately to finding a cure. Over the last 12 months we have furthered our progress towards accomplishing this mission.

Hemophilia Ontario has strived to meet our goal of care and treatment for all. $35,380 has been provided in financial assistance to 113 members. Assistance is offered to help with costs associated with bleeding disorder for members in financial need. Hemophilia Ontario has supported the Canadian Hemophilia Society's (CHS) CODErouge campaign; a program whose goal is to identify undiagnosed women with bleeding disorders and ensure that they have access to appropriate medical care from health care providers with expertise in bleeding disorders.

We are working to support care and treatment for all beyond our own borders. Honorary lifetime member, Candace Terpstra is developing a twinning proposal which will partner Hemophilia Ontario with a hemophilia organization in a less economically developed country. One of the goals of the partnership is to expand diagnosis and treatment for people with hemophilia and other inherited bleeding disorders.

Our awareness campaigns are extending their reach. Polar Bear Dip awareness events were held in South Western Ontario Region (SWOR) and for the first time in Toronto and Central Ontario Region (TCOR). We have expanded our outreach through social media, with our new and improved Facebook page achieving a fan increase of 162% in two months. A desired outcome is to increase the number of women and individuals with rare bleeding disorders diagnosed and receiving treatment in Ontario. Our ability to reach this goal will be strongly influenced by the success of our awareness efforts.

Our commitment to research was reaffirmed through our donation of $ 5,000 to the Hemophilia Research Million Dollar Club (HRMDC). We provide members regular updates on the latest research developments. An ongoing challenge to moving the research agenda forward is ensuring researchers have enough subjects to conduct studies. Hemophilia Ontario will continue to inform members of opportunities to participate in research. Members must remind leaders of this organization that finding a cure is a priority.

Core educational programs are offered by Hemophilia Ontario, including Camp Wanakita, Pinecrest Adventures, Just the Guys, and Wellness for Women. Our programs offer an opportunity for people with inherited bleeding disorders and their families to learn from each other and develop a sense of community. 50 youth attended Camp Wanakita and 40 youth attended Pinecrest Adventures. Our camps provide youth with bleeding disorders a unique environment to learn to self-infuse. Onsite Hemophilia Nurses help ensure a safe camp experience as well as help to develop strong bleeding disorder management skills in campers.

We cannot achieve our mission if we do not have a strong and cohesive organization.

One of our most important roles is our work as watchdog of the blood system. Hemophilia Ontario collaborates with CHS to advocate for access to a secure supply of the safest and most efficacious therapies for inherited bleeding disorders. A priority is to ensure we continue to have a strong voice in the blood system. This year Hemophilia Ontario secured increased representation on committees related to blood safety and supply. We now have representation on The World Federation of Hemophilia's (WFH) Blood Safety, Supply and Availability Committee, CHS' Blood Safety and Supply Committee, The Ontario Blood Advisory Committee, and the Ontario Factor Concentrate Working Group.

We remember the tainted blood tragedy and it motivates us to ensure a safe system for the future. At the 20th anniversary of Camp Wanakita and Hemophilia Ontario's partnership a commemorative tree planting took place to pay tribute to those affected by the tainted blood tragedy. Our community will always remember the friends we lost and the lessons learned because of this tragedy. A challenge for us is to ensure that decision-makers do not forget those lessons. We must demand that decision-making processes regarding the blood supply include recipients and are transparent.

We cannot achieve our mission if we do not have a strong and cohesive organization. The economic downturn has put stresses on our budget, industry is increasingly restricted in the support they can provide, governments pursue austerity budgets, and individual donors are feeling the pinch. We must work to find additional revenue streams to diversify our funding and help provide stability moving forward. Working cohesively with CHS allows us to reduce expenses, and capitalize on expertise from across the country. We all need to continue to do our part to help ensure we have the necessary financial resources to sustain our efforts.

Ensuring effective advocacy in the future requires us to focus on leadership development and succession planning today.

continued ... page 4

One of our desired outcomes is to have young people as leaders at the provincial level and in each of the five regions. The recently completed regional manual indicates each Regional Council should have two youth and each operational committee is required to have at least one youth member. It's not enough to have youth participate, we have a responsibility to ensure we are developing in them the experience and skills they need to be effective leaders in the future. We have provided funding opportunities for young leaders to attend the WFH's World Congress and CHS's Rendez-Vous scientific symposium.

In July, we lost a tireless advocate and friend in John Plater. Fellow advocate Mike McCarthy, astutely summed up what must happen for us to maintain and grow the progress John helped us achieve.

> *John was our voice and we gladly let him speak for us. We, now, need to come to the realization that we can only replace John's voice with the addition of many other voices yet unheard. Our community can pay John the highest honour by continuing in his footsteps, to advocate for others who don't have the voice to do so.*

We call upon each of our community members to get involved, and contribute in any way they can, large or small, to help us improve the health and quality of life for all people with inherited bleeding disorders, and ultimately find a cure.

Hemophilia Ontario

Our Values

By acting honestly, openly and with accountability; By remaining connected to our grassroots community; By setting high standards while remaining open to change; By fostering relations and strong partnerships with our diverse stake holders; By providing information, programs and services and; By treating people with whom we interact with dignity, fairness and compassion we will achieve our values:

Inclusiveness | *Connectedness* | *Advocacy* | *Excellence* | *Collaboration* | *Integrity* | *Respect*

Founded in 1957, Hemophilia Ontario is the Ontario Chapter of the Canadian Hemophilia Society. A volunteer driven organization, we are a provincially incorporated charitable organization with offices in Ottawa, Toronto, Sudbury, Hamilton and London.

Hemophilia Ontario provides information, programs and services to:

- people with hemophilia, von Willebrand disease, rare factor deficiencies and inherited platelet disorders
- their families and friends
- the health care providers in the Canadian network of inherited bleeding disorder comprehensive care clinics
- the patient's community (daycare workers, teachers, employers)
- the health care providers (primary care practitioners, dentists, specialists, etc..) who may come into contact with those who remain undiagnosed.

Our vision is a world free from the pain and suffering of inherited bleeding disorders.

Hemophilia Ontario's mission is to improve the health and quality of life for all people with inherited bleeding disorders and ultimately to find a cure.

Hemophilia Ontario works toward this mission by endeavouring to:

- achieve optimal comprehensive care for all people with inherited bleeding disorders.
- raise awareness among people with inherited bleeding disorders, their immediate communities and health care partners.
- promote and fund research to improve treatment and to ultimately find a cure.
- provide effective delivery of information and support to patients and their families.
- advocate for access to a secure supply of the safest and most efficacious therapies for the treatment of inherited bleeding disorders.

Executive Director's Report

For those that have not met me, please allow me to introduce myself:

- I began working for Hemophilia Ontario South Western Ontario Region (SWOR) in March 2007. The SWOR Council, members and the Hemophilia Treatment Centre team embraced me and I became a member of the community. The more I understood about living with an inherited bleeding disorder, the more I wanted to continue to be involved in this community.

- In January 2011, I became Acting Provincial Program Manager covering a medical leave, becoming permanent in November 2011. Throughout this timeframe I worked closely with Acting Executive Director David Page (CHS' National Executive Director) and the Ontario Board of Directors. We worked together to begin realigning the Society and how we operate with a goal of stronger financial reporting abilities and enhanced transparency.

- In February 2012, I applied to become Executive Director. April 20th 2012, at our Annual General Meeting in Ottawa was my first day in the new role.

Regional Service Coordinators (RSC's) are the cornerstone supports of our communities. They work with their local Councils, volunteers and Hemophilia Treatment Centres toward ensuring that Hemophilia Ontario meets our mission of improving the health and quality of life for people living with inherited bleeding disorders. Last year, we provided 19 programs for 750 people and participated in 13 community presentations to 530 people raising awareness. The RSC's not only facilitate and provide local programs and events but also help organize provincial programs such as Just the Guys and Community Camp. They willingly work evenings and weekends and sometimes miss personal and family functions to make sure our programs and events are delivered. They help each other with programs and events and as needed, have worked another region while working in their own during a peer's absence. Thank you!

The past year has provided many opportunities. As supervisor to my former peers, with open communication and trust we successfully navigated the transition. The Ontario Board of Directors welcomed me, my thoughts and ideas. They supported my learning curve, approved challenge and supported growth. Our stake holders have continued to support us knowing that we are presenting organizational information as transparently as possible and were recognized as a Volunteer Sector Reporting Award Finalist in December for transparency in financial reporting, a nice wrap up to an eventful year.

Our community suffered the loss of John Plater in July. John was a tireless advocate and champion of the bleeding disorders community and all Canadians as he fought for a safe and secure blood supply. He is greatly missed. Both Camp Wanakita and Pinecrest Adventures Camp celebrated 20 years of providing safe camp experiences for youth living with inherited bleeding disorders. CWOR introduced the pilot program "Aging with a Bleeding Disorder" and by 2014 we hope to have this program available across the province. We have achieved much in the last year and we thank everyone who contributed.

I was asked what I most enjoy about my job. It is meeting and working with so many people across the province committed to our mission and vision.

With the involvement of those in our community Hemophilia Ontario has clear direction around what is needed.

We also faced challenges. A 25% reduction in sponsorship from our industry partners and a decrease in Nevada revenues meant leaner program budgets resulting in the provision of more streamlined educational programs. Internal policies and procedures were implemented where there were identified gaps and this will be an ongoing process. A conscious effort was made to reduce costs where possible such as eliminating regional FAX lines and implementing one provincial number and moving from the expensive VOIP telephone system back to conventional office phones ending the year with a surplus.

2012 was a year to Remember, Honour and Celebrate. We remembered and honoured those lost through the tainted blood tragedy by planting a commemorative tree at Camp Wanakita (pictured on report cover) and speaking at World AIDS Day vigils.

With the involvement of those in our community, Hemophilia Ontario has clear direction around what is needed. It's up to us to figure out how to ensure we continue to identify and meet these needs.

In this report we share our successes and challenges from the past year and I am deeply grateful to each and every person who has contributed to them.

Together we are achieving our mission of 'improving the health and quality of life for all person with inherited bleeding disorders and to find a cure.'

Thank you,

Terri-Lee Higgins
April 19, 2013

President's Report

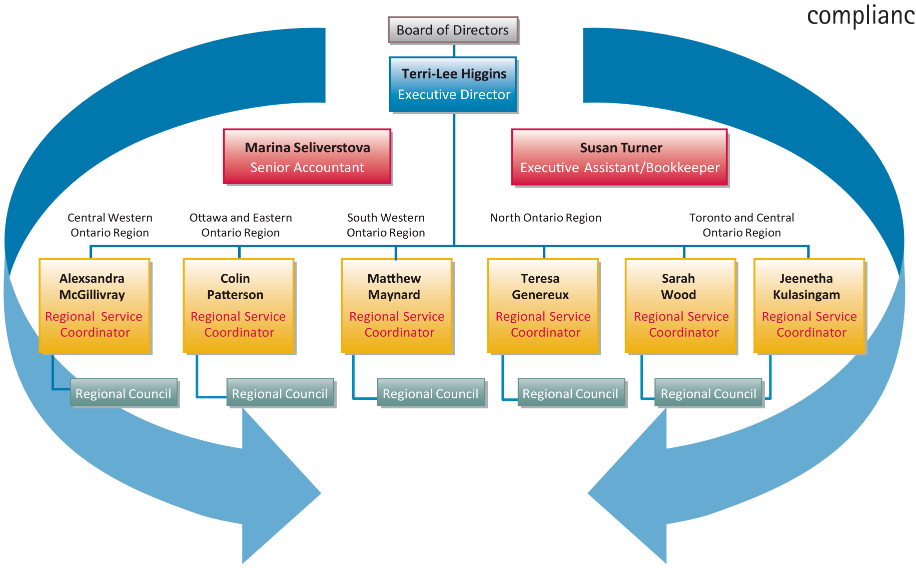
Paul Wilton 2012|2013

Over the past year significant progress has been made towards building a strong Hemophilia Ontario:

- Significant progress towards Amalgamation between Toronto and Central Ontario Regional Hemophilia Society and Hemophilia Ontario has been achieved. Amalgamation should be complete shortly.
- The Regional Volunteer Manual has been completed. The manual's purpose is to support the grassroots of our organization while clearly defining regional responsibilities across the province. All regions have endorsed the manual and the manual has been approved by the Board of Directors.
- Outcomes policies have been completed. These policies will help focus the work we do to meet our mission and allow us to measure our progress towards our goals.
- Partnerships with the Canadian Hemophilia Society, Hemophilia Ontario's Regions, Hemophilia Treatment Centres and Funders have continued to be strengthened.
- A smooth transition between Interim Executive Director David Page and Executive Director Terri Lee Higgins has occurred.
- Emphasis has been put on the importance of succession planning and leadership development to ensure continuity of strong and effect leadership for the inherited bleeding disorders community.

In the interest of building a strong and cohesive organization, in 2013-2014 the Board of Directors should focus on the following tasks:

- Ensuring Hemophilia Ontario and the Canadian Hemophilia Society have a strong voice in the blood system. This will require developing the knowledge and skills of young leaders, and ensuring our membership is well informed on issues regarding blood safety, supply and availability.
- Working to ensure that people with inherited bleeding disorders 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.
- Ensuring all people with an inherited bleeding disorder in Ontario have access to comprehensive care, delivered according to national standards of care.
- Continuing to develop our contributions to Research efforts. Hemophilia Ontario should support the national goal of growing the Hemophilia Research Million Dollar Club, inform members how they can participate in research studies, and keep member aware of the latest research developments.
- Ensuring young people are involved as leaders at the provincial level and in each of the five regions.
- Building Hemophilia Ontario's membership base, and ensuring more women with bleeding disorders, people with Von Willebrand disease and rare bleeding disorders are involved as members.
- Updating bylaws to adopt processes which are best practice for not for profit organizations and to ensure compliance with the Not-For-Profit Corporations Act.



Hemophilia Ontario Organizational Structure

Provincial Program Report

Reflecting Benefits of Program Involvement

Hemophilia Ontario strives to improve the health and quality of life for all people with inherited bleeding disorders and to find a cure. 2012 was a year of celebration and strengthened community involvement.

Through innovative programming we have opened the door to education and linked members with information and resources they have asked for. The Annual General Meeting and Regional Annual Meetings provide more than learning opportunities and business, they also provide time to connect with friends and build support networks with others who understand what it means to live with an inherited bleeding disorder.

Elderly hemophilia patients currently represent a small portion of the overall hemophilia population, so there is little clinical data to guide recommendations. For the first time in many years Hemophilia Ontario and its members find themselves in the unique position of needing to educate ourselves as a growing number of people with bleeding disorders, many of them also infected with HIV and hepatitis C, are living well into their 50's, 60's and beyond. While this is good news for them, medical systems may be under prepared to treat this influx of patients who have bleeding disorders and other disease brought on by age. Many face the same medical conditions associated with aging as the general population. We are engaging individuals over 40 years of age and their family / support persons, in their health care through new innovative workshops. Whether diagnosed with mild, moderate or severe bleeding disorders all will face potential changes to their health and care needs. By raising personal awareness individuals can make key decisions and develop comprehensive care plans that can help coordinate future medical services. Central Western Ontario Region (CWOR) successfully implemented a key pilot project in 2012 Aging with a Bleeding Disorder. It is our goal to implement this program in all other regions over the next two years.

We celebrated the 20th anniversary of 2 cornerstone programs designed to educate youth about self care, encourage smart life choices and build self confidence by providing the tools necessary to live a healthy life.

- In 1992, YMCA Camp Wanakita opened its doors to offer boys with hemophilia a residential camp experience. Unlike other camps that were approached, Camp Wanakita was willing to accept the fact that some of these children were infected with HIV through tainted blood or blood products. From the very beginning, this camp program was a resounding success leading to a long-term relationship between Hemophilia Ontario and YMCA Camp Wanakita benefiting over 275 provincial youth. We celebrated this partnership as part of our Community Camp weekend in October at Camp Wanakita.

- In 1992 South Western Ontario Region (SWOR)'s Liz Clegg' and John Meyers' dream was realized with the first Pinecrest Adventures Camp. This 5 day residential camping experience for children with a bleeding disorder aged 5—16 and their siblings, is designed to meet the special medical needs of these children and provides respite to parents while providing campers the opportunity to experience camp as all children do. Pinecrest provides hands-on learning opportunities to help grow self esteem, benefitting over 145 Southwestern Ontario youth.

Our organizational identity and experience is based on the loss suffered by the hemophilia community, those with inherited bleeding disorders and others who were infected with HIV / AIDS and / or hepatitis C through blood or blood products they depended on for life saving treatment and therapy. With our first-hand knowledge of the devastation these conditions bring, Hemophilia Ontario works every day toward ensuring Canadians are safe and have access to not only a safe and secure blood supply but also prevention materials. Recent statistics indicate that every $1 invested in HIV prevention saves the health care system $51,000 in HIV related care costs. Regional Service Coordinators actively engage in community programs and activities and assist with outreach, a key prevention activity. These include distribution of prevention materials, participating on conference committees or provincial and national committees and attending educational sessions. Provincial staff participate in World AIDS Day activities which may include a community booth or attending / speaking at a Vigil Service focusing on the tainted blood tragedy, its impact on our community and our dedication to ensuring a safe blood supply for all Canadians.

continued ... page 8

Hemophilia Ontario benefits from the support and partnership of 9 provincial Hemophilia Treatment Centres. The staffs including Hematologists, Ontario Nurses, Social Workers, Physiotherapists and Administrative Assistants provide ongoing support and involvement. They make time in their professional and personal life to participate in our programs. Whether participating on a committee, as a speaker, sharing personal experiences or simply helping staff resolve concerns, these individuals continue to make a difference in the level of programs we offer. There are few other organizations that enjoy and benefit from the involvement of comprehensive care teams to this level. We are grateful for the involvement of our Hemophilia Treatment Centre staff and their commitment to helping Hemophilia Ontario provide strong and informative programs.

> *No other organization in Ontario offers services for people with inherited bleeding disorder.*

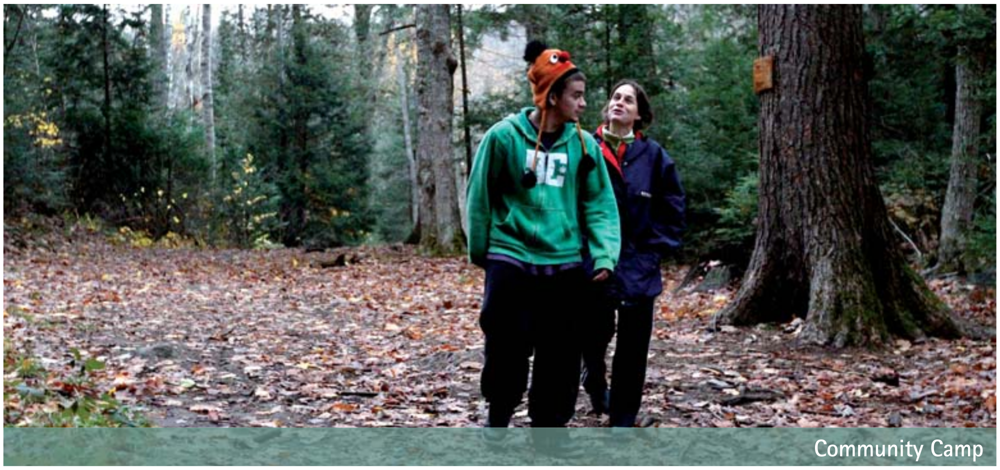
We provide lifespan support, education, financial support, member networking and moral support when assistance is needed. With this in mind, we will continue to work on identifying gaps in programs and services to help ensure all supports provided are timely and relevant.

Programs and Events

Pinecrest Adventure Camp

Hemophilia Ontario Youth Program

Community Camp



Community Camp

Just The Guys

SWOR In Action

CWOR Holiday Party

CWOR Bake Sale

OEOR Golf Tournament

NOR Walkathon Group

OEOR Holiday Party

Polar Bear Dips

TCOR

SWOR

Youth Report

Several activities took place this year; laughs were shared, memories made, and friendships formed. While, from the outside, these events can look like they are simply a good time and an excuse to have fun, these events are extremely important to the youth. Those affected by bleeding disorders form a support network that can help them through various issues they may encounter. HOY participants received instruction about their bleeding disorders, allowing them to learn in an interesting way. Educational discussions about how to care for oneself, issues in HIV/AIDS, travelling with factor or acquiring product outside of Canada, and even essential life skills are some of the few interesting talks that occurred.

The events that took place this year included the Montreal Trip, the Jays' Game, and Family Camp which was held at YMCA Camp Wanakita. Each event had scheduled formal education where a specific topic is discussed. However, much of the education is informal and learning always seems to find its way into casual discussions.

The trip to Montreal included a very long bus ride to the city. Historical and scenic sites were explored in a giant scavenger hunt. The group also went to a local university library to participate in a workshop and discussion on HIV/AIDS with reference to the Tainted Blood Tragedy. It was this trip where one individual took a city bus for the very first time, learning some essential life skills in the process.

The Jays' game outing began with pizza at the office. Role playing skits allowed individuals to explore the issue of bringing factor products to another country and acquiring products in that country. Individuals were able to learn a lot and have a bit of fun when one youth, who was playing a border official, announced that he would accept bribes in order to allow factor to cross borders.

At family camp, which took place at Camp Wanakita, the youth underwent leadership training in the form of education on public speaking. Participants were able to put their newly learned skills to the test through holding a discussion panel where parents who attended the weekend could ask questions about what it was like to grow up with an inherited bleeding disorder. At this event, youth also worked on 2013 programming.

These events are critical to the development of our young people. Those affected by bleeding disorders learn about themselves and how to deal with their bleeding disorders. They make friends who will play a critical role in their support network. Education is a huge part of these events, both formal and informal. Youth events help to develop these youth into future leaders.

For the future, youth are working toward having more events and developing fundraising initiatives. HOY promises to keep growing and becoming an even more important and central part of the life of those affected by bleeding disorders. Many thanks go out to the organizers, donors, and other supporters who are critical to making events like these happen.

Respectfully submitted by,

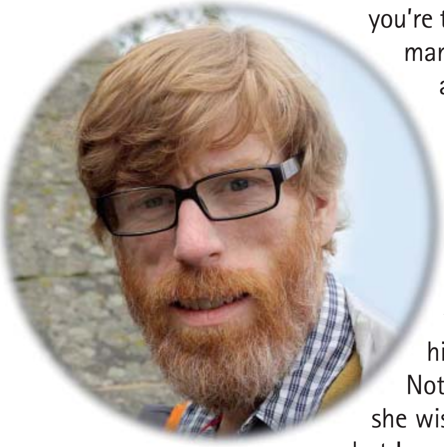
Ryan Kleefman
April 19, 2013

Making A Difference

Remembering John Plater

The society wasn't all about meetings. It was also about community. I have memories filled with laughter as I accompanied John to meetings and retreats. I think the only time we ever sang karaoke was at a hemophilia event. A highlight of our summer was hosting the lamb roast and the people who came from far and wide – because of their connection with the society and John. In the end, the friendships forged together as we worked for a safe blood supply, supported one another through life's milestones and attended far too many funerals cannot be broken. For John, being part of the Hemophilia Society was about getting involved, making a difference and giving your time and your heart. John saw how the Hemophilia Society could help not only people with hemophilia, but all people with bleeding disorders, and any person who might need to use blood or blood products; he helped make that dream become reality.

– Karen Plater, wife



When you enter law school, your deans and your professors will tell you that it's crucial to remember why you're there. That why will give you the necessary motivation to get through some difficult times. For many law students it's a rather difficult question, but for me it was actually quite simple. The answer has been the same for anything I've done in my life: I do it because of John Plater. Hemophilia has known some tremendous advocates over the years, but in my eyes none quite like John. John gave of himself fully and completely, day in and day out, to better the lives not just of his blood brothers and sisters but of the next generation such as myself. John went to law school not for himself, but because he understood it would help him make an even greater impact in his life's work. It saddens me daily knowing that our next generation will not get to know his warm smile, boisterous laugh, or that fiery red beard. But it's our weighty task to carry on his work. At his memorial service last summer, my mother approached his wife rather gingerly to offer her condolences, not sure if Mrs. Plater would even remember us. Not only did Mrs. Plater remember us well, but recalled my mother telling her upon my birth that she wished I'd grow up to be "just like John." John, I don't think any of us will ever be just like you, but I promise we will try our very best. *– Shaun Bernstein*

John Plater and James Kreppner dedicated their lives to the health and well being of those they knew and those they didn't. James passed away in May 2009, John in July 2012. Tireless advocates and human rights champions, these men fought for HIV and Hepatitis C (HCV) treatment and compensation for those infected through the tainted blood tragedy. Both were heavily involved in the Ontario and national AIDS movements. The Krever Inquiry, for which John and James were both interveners, ensured a safe blood supply for all Canadians. John and James were made Honorary Lifetime Members of Hemophilia Ontario and the Canadian Hemophilia Society. No words can give full justice to what these men accomplished. Their rich legacy of words and actions calls us to keep on challenging ourselves, and those around us, to build a better world.

– Terri-Lee Higgins, Executive Director

Making A Difference

Leslie Bauman

We are a family of 7, but our true family is so much bigger. Let me explain. My husband and I have five children. Of these, one daughter is a hemophilia carrier and our two sons Jesse and Eli are both severe hemophiliacs diagnosed since birth. We have many people involved in the shaping and moulding of our children. Along with loving grandparents, aunts and uncles, understanding and compassionate friends, the caring and knowledgeable clinic staff, we also have the support of the Hemophilia Society.

Through the society we have attended Christmas parties, summer BBQ's, family camp and I have attended the women's wellness weekend. A huge highlight for my boys is the Just for Guys weekend in September. They have never missed a year! Through the different events the society has offered education and a better understanding of the disease, strategies to cope and deal with the challenges we face, a chance to meet others facing similar experiences, opportunities for boys and girls with bleeding disorders to meet others like themselves and older role models to encourage our children along.

We are blessed to have a group of people who are doing their best to listen and respond to the needs of our community. I try not to ask myself "What can the society do for me?", but "What can I do to help, support and encourage others in our community with the support of the society?" After all, it's not about me. We are a team and I believe the saying goes, "There is no 'I' in team".

Thank you to all who work diligently for the good of everyone.

Kristen Luszka

I was less than a year old when I was diagnosed with Type 2 Von Willebrand's disease. Because both my mother and sister are affected, I was diagnosed at an early age. Throughout my childhood, my sister, my mom and I all rotated turns in the hospital for major bleeds. I was admitted for stomach bleeds, nosebleeds, throat bleeds, and major cuts and bruises. However, through all of those experiences, my mother never panicked; she never made us feel any different or 'special' because she was comfortable managing it herself. For us, it was our normal because we had a wonderful support group who understood and had gone through similar experiences. We had each other... we are a team.

Then came the day I realized I was different. I was living on my own in Australia attending grad school. I woke up to a racing heart and dizzy spells. Before I knew it, I was in ICU receiving blood for a spontaneous internal bleed. Receiving treatment was all too familiar to me, but being alone was not. I realized for the first time what it would be like to be a person with a bleeding disorder without a support group, without a team. I wasn't prepared for this. When I recovered, the hematologist explained that I should have been more prepared when travelling abroad.

And it's this experience that brings me here. Since coming back, I've decided to volunteer with Hemophilia Ontario to help strengthen the bleeding disorder 'team'. Everyone who is affected by a bleeding disorder should have a support group, education, and resources to help them manage a healthy lifestyle day-to-day. Although we will continue to search for a cure, building a sense of community and normalcy to those affected is irreplaceable.

We're all part of a great 'Team' !

Supporting Hemophilia Ontario

DDAVP, Cyclokapron, Vein Lights to teach vein access, ramps, clinic parking, orthopedic shoes; these are but a few of the items Hemophilia Ontario has provided through financial assistance in 2012.

By donating to Hemophilia Ontario you make it possible for us to be there for those in need whether an older member facing mobility issues, a parent whose infant child has been newly diagnosed or even sponsoring a youth learning to self-infuse and attend one of two provincial camps to better learn this skill. Your gifts are an investment in the work we do and what we accomplish.

In 2012 we provided $35,380

in financial assistance, meeting our mission of improving the health and quality of life for people with inherited bleeding disorders.

Monthly gifts are a stable, reliable source of income that allow us to budget and plan more effectively. Processing donations through credit card or direct banking reduces administrative costs. Hemophilia Ontario will provide a year-end tax receipt for your total donations.

Donations beyond financial include the following:

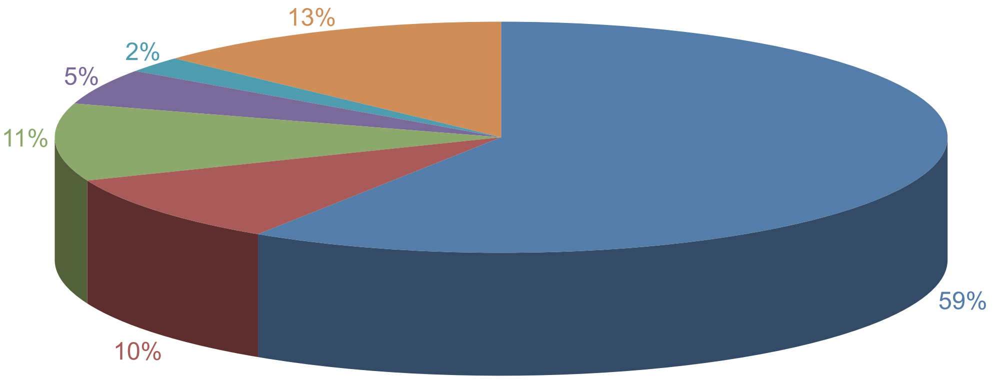
- Volunteer Hours
- Program and Event Sponsorship
- Donations in Kind

We would like to take this opportunity to express our heartfelt thanks to the donors, significant and modest, who each year assist this strong organization to deliver on its core values. Your generosity is a resounding vote of confidence in Hemophilia Ontario.

— Thank you

Where You Have Given

Education, Support and Care Programs	$459,216 [59%]
Capacity Development	$74,131 [10%]
Awareness Programs	$85,801 [11%]
Community Programs	$37,432 [5%]
Governance	$17,544 [2%]
Administration	$101,377 [13%]



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

Baxter
Bayer
CSL Behring Biotherapies for Life™
novo nordisk®
octapharma For the safe and optimal use of human proteins
Pfizer

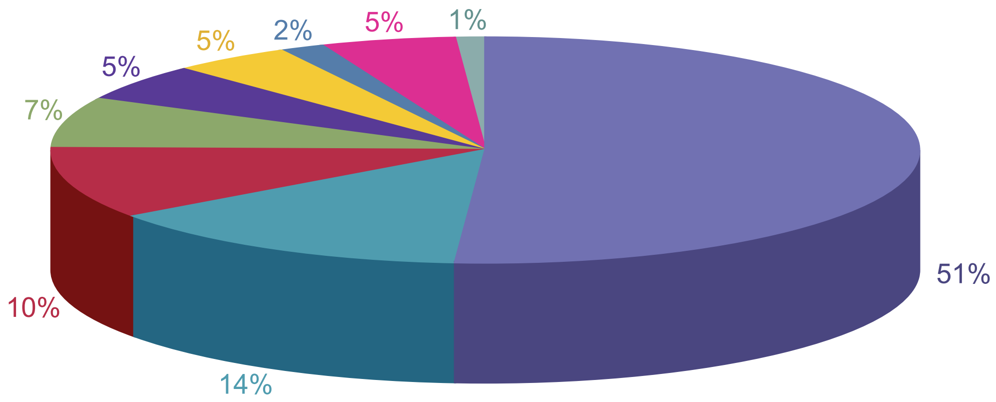
Abridged Financial Statements

Hemophilia Ontario finished the year with an operating surplus of $10,535. The results demonstrate that management and the Board of Directors are determined to maintain a sound financial footing while exercising responsible cost control. We would like to express our appreciation and thanks to the many volunteers, donors and dedicated staff without whom success would not be possible. Your dedication, hard work and financial contributions have been, and continue to be, the backbone of our success. We hope we may continue to count on your support in the years ahead.

– Paul Wilton, President

Who Has Given

MOH Grant	$400,793	[51%]
Pharmaceutical Corporation Contributions	$110,200	[14%]
Federated Health Charity	$79,897	[10%]
CHS National Revenue Sharing	$58,361	[7%]
Events Revenue	$40,493	[5%]
Donations	$35,380	[5%]
Other Contributions	$13,330	[2%]
Fundraising & Gaming Activities	$38,808	[5%]
Other Revenue	$8,775	[1%]



When you give generously, you help us assist those in need across Ontario. The change begins with you.

Notes

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**

Condensed Statement of Financial Position

HEMOPHILIA ONTARIO

Statements of Financial Position

As at December 31, 2012, December 31, 2011 and January 1, 2011

DRAFT

	December 31 2012	December 31 2011	January 1 2011
ASSETS			
Current:			
Cash and cash equivalents (Notes 2, 4 and 5)	**$ 662,188**	$ 565,219	$ 554,547
Accounts receivable	**63,233**	72,208	78,457
Prepaid expenses and other assets	**8,121**	8,297	18,049
	$ 733,542	$ 645,724	$ 651,053
LIABILITIES			
Current:			
Accounts payable and accrued liabilities	**$ 18,740**	$ 12,413	$ 10,509
Deferred contributions (Note 5)	**116,476**	45,520	59,934
	135,216	57,933	70,443
NET ASSETS			
Internally Restricted (Note 4)	**50,000**	50,000	50,000
Unrestricted	**548,326**	537,791	530,610
	598,326	587,791	580,610
	$ 733,542	$ 645,724	$ 651,053

Commitments (Note 7)

Approved on behalf of the Board of Directors:

______________________________ *Director*

______________________________ *Director*

Condensed Statement of Financial Position

HEMOPHILIA ONTARIO

Statements of Operations and Changes in Net Assets

Years ended December 31, 2012 and 2011

	General Program	AIDS Bureau Program	2012 Total	2011 Total
REVENUES				
Grants:				
Ontario	$ -	$ 400,793	**$ 400,793**	$ 436,262
Programs and events	150,693	-	**150,693**	207,629
Donations:				
Federated Health Charities	79,897	-	**79,897**	81,973
Individuals and bequests	35,380	-	**35,380**	50,383
Other contributions	13,330	-	**13,330**	31,581
Fundraising and gaming activities:				
CHS national revenue sharing	58,361	-	**58,361**	61,140
Bingo and Provincial Nevada	38,808	-	**38,808**	21,413
Interest	5,147	-	**5,147**	5,985
Municipal property tax rebate	3,250		**3,250**	5,799
Other	378	-	**378**	736
	385,244	400,793	**786,037**	902,901
EXPENSES				
Staffing costs	114,571	308,977	**423,548**	464,458
Programs	148,664	51,916	**200,580**	233,186
Office supplies and expenses	48,820	-	**48,820**	90,577
Building occupancy (Notes 6 and 7)	18,329	29,000	**47,329**	48,907
Staff and volunteer development	9,914	10,900	**20,814**	12,625
Travel	11,766	-	**11,766**	14,986
Insurance	10,779	-	**10,779**	10,547
Professional fees	8,200	-	**8,200**	10,925
Board and committee meetings	3,666	-	**3,666**	9,509
	374,709	400,793	**775,502**	895,720
EXCESS OF REVENUES OVER EXPENSES	10,535	-	**10,535**	7,181
NET ASSETS, beginning of year	587,791	-	**587,791**	580,610
NET ASSETS, end of year	$ 598,326	$ -	**$ 598,326**	$ 587,791

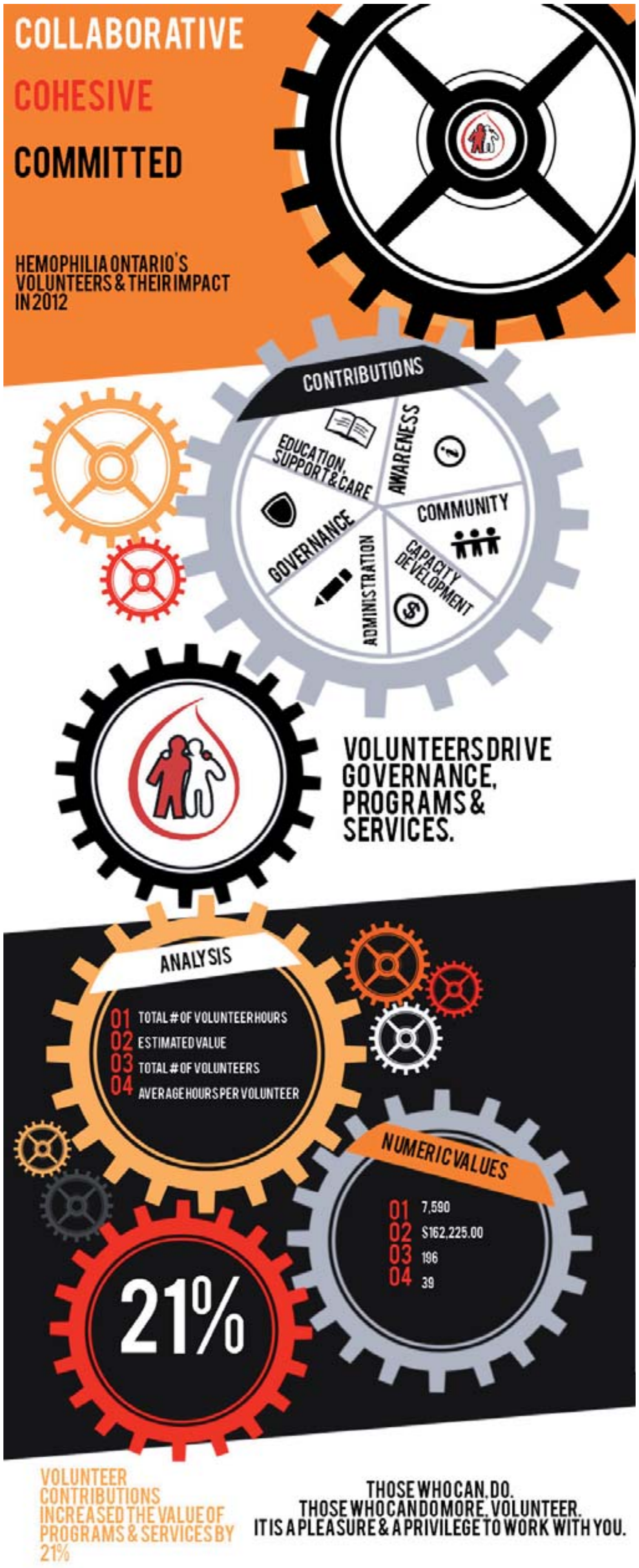
DRAFT

Appendices

Volunteers

We have a long history of successful community and volunteer engagement. Volunteers are an integral part of our success playing a crucial role in so many areas including governance, program support, fundraising and mentoring youth. We hold our volunteers in high regard.

We are proud to provide a range of opportunities and maintain a history of strong volunteer engagement. While we thank them throughout the year, annually through our Volunteer Awards and during National Volunteer Week, the impact of their contributions is remarkable.



Committees

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

- Nominations
- Executive

Operational committees include:

- Program – reviews submitted programs for next budget year, provide recommendations to the Board of Directors *(3 meetings annually).*
- Awards – review and selection of nominations to determine winners *(2 meetings annually).*
- Community Camp Planning / Wellness for Women Planning/ Just The Guys Planning (North, Ottawa and Southern Ontario) – planning and implementation of provincial programs with volunteer regional representation. *(approximately 10 meetings per program annually).*
- Financial Assistance Review – reviews submitted financial assistance claims above $1,000 to determine ability to provide assistance *(as required).*

Each region develops and utilizes committees as required. In 2012 these included:

- 3 golf tournament committees
- 8 program planning committees

Hemophilia Ontario Board of Directors | 2012-2013

Back to Front (l-r): *Ashwani Kurichh, Phyllis Gray, Steve VanDusen, Standing: Samuel Leon, Igor Ristevski, Raja Alami, Kiran Gopie, Mike Beck, David Neal, Victoria Kinniburgh* Kneeling: *Jace Pedersen, Paul Wilton, Mojtaba Kherzy*

Paul Wilton
President

Jeff Beck
Past President

Mike Beck
Vice President

David Neal
Vice President

Jace Pedersen
Secretary

Directors:

Raja Ammoury
Venanzio D'Addario
Maury Drutz
Phyllis Gray
Kiran Gopie
Travis Hazelwood
Mojtaba Khezry
Victoria Kinniburgh
Ashwani Kurichh
Samuel Leon
Kristen Luszka
Paul McNeil
Igor Ristevski

CHS Delegates:

Raja Ammoury
Mike Beck
Mojtaba Khezry
Ashwani Kurichh
Paul Wilton

How to get involved:

Hemophilia Ontario welcomes the interest of individuals in our organization. The Board of Directors is elected at our Annual General Meeting for a 1 year term. The Regions elect their representatives as part of the Regional General Meeting as local and provincial delegates or as non-council delegates. These individuals comprise the slate of officers presented to attending members at the Annual General Meeting for approval. For further information please contact:

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

Hemophilia Ontario Staff Team 2012-2013

Terri-Lee Higgins
Executive Director

Susan Turner
Executive Assistant

Regional Service Coordinators:

Alexsandra McGillivray
Central West Ontario Region

Matthew Maynard
South West Ontario Region

Sarah Wood
Toronto Central Ontario Region

Colin Patterson
Ottawa and Eastern Ontario Region

Jeenetha Kulasingam
Toronto Central Ontario Region

Teresa Genereux
Northern Ontario Region

Learning and Celebrating

Regional Representatives accepting the Ontario Accord

Dr. Klaassen Presentation at 2012 AGM

World Congress Participants – Paris, France

2012 Leadership Award Recipients

Hemophilia Ontario
We're All Related By Blood

www.hemophilia.on.ca

Head Office
Hemophilia Ontario
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