2017

ANNUAL COMMUNITY REPORT

Hemophilia Ontario

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LETTER FROM
The Executive Director

> “I am who I am today because of the choices I made yesterday.”
> ELEANOR ROOSEVELT

It can be hard to measure a year that sometimes feels endless but also passes in the blink of an eye. Thinking back on 2017, it seems to have gone so quickly and yet we also were able to do so much. The organization in some ways is very different and in other ways is just the same.

From the first day I was hired, I told everyone I spoke with that, “2017 will be a transition year; we will maintain the traditional programming while I learn the ropes and we evaluate our priorities and future direction.” And we put that commitment to the test! The staff balanced all the traditional programming our members would be used to seeing with an engagement strategy that saw us criss-cross the province talking to stakeholders, building relationships, and getting feedback on how we can be of better service to the community.

We had hard conversations and took a critical look at the impact our traditional programs were having, as well as assessed the efficiency of our staffing model. The Board spent a lot of time weighing the needs of our members with our continually shrinking revenues. Changes have slowly been made in a number of areas that will hopefully benefit the organization for many years to come.

My overall reaction to 2017 is to be proud. I am proud of the work that was done, the people who have participated, and the outcomes we achieved. I hope that in the near and distant future, Hemophilia Ontario will celebrate the choices that were made this past year. Thank you for the role that you have played!

Jenna Foley, Executive Director
Hemophilia Ontario

LETTER FROM

The President

The Hemophilia community is a special one. We are a group who have rare disorders that are lifelong. Because of this we build close relationships with our healthcare team, our families and others we meet who are living with the same conditions. Hemophilia Ontario is an important organization to help make connections and link us to each other. In a world full of so many connections through the internet and online media, we sometimes lose those personal and face to face connections. How do we maintain those? How do we stay connected to each other? And gain that invaluable support and information that we get from interacting with others in our community. These are questions and discussions that we've been having this year in determining the best ways to move forward in an ever changing landscape.

This past year we needed to focus on engagement and finding out what our community members are needing and the best way we can serve them to maintain these connections. Through our various outreach in the community we've received valuable feedback that has led us to some exciting changes going forward into 2018.

This past year has also been one of learning and trying to push things forward to better our goals of Care and Treatment. Hemophilia Ontario participated in an Advocacy workshop which led to the creation of our Advocacy Committee. This committee has been working hard to help our clinics advocate for the resources that they may be lacking in meeting the current Standards of Care. This work is a process and takes time but is showing progress and improvement.

We are continuing to work towards an accreditation from Imagine Canada. This will ensure we are meeting best practice standards for Boards. The CHS has just completed this process and we are planning to follow in their footsteps.

This has been a challenging yet exciting first year as chair and I look forward to the continued progress as we work together in 2018!

Maia Meier, President
Hemophilia Ontario

> “This has been a challenging yet exciting first year as chair and I look forward to the continued progress as we work together in 2018!”
>
> MAIA MEIER

Our Mission

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

TARGET POPULATIONS: Who We Serve

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

Our Vision

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

Our Values

INCLUSIVENESS

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

CONNECTEDNESS

By being well connected to our grassroots community.

ADVOCACY

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

EXCELLENCE

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

INTEGRITY

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

RESPECT

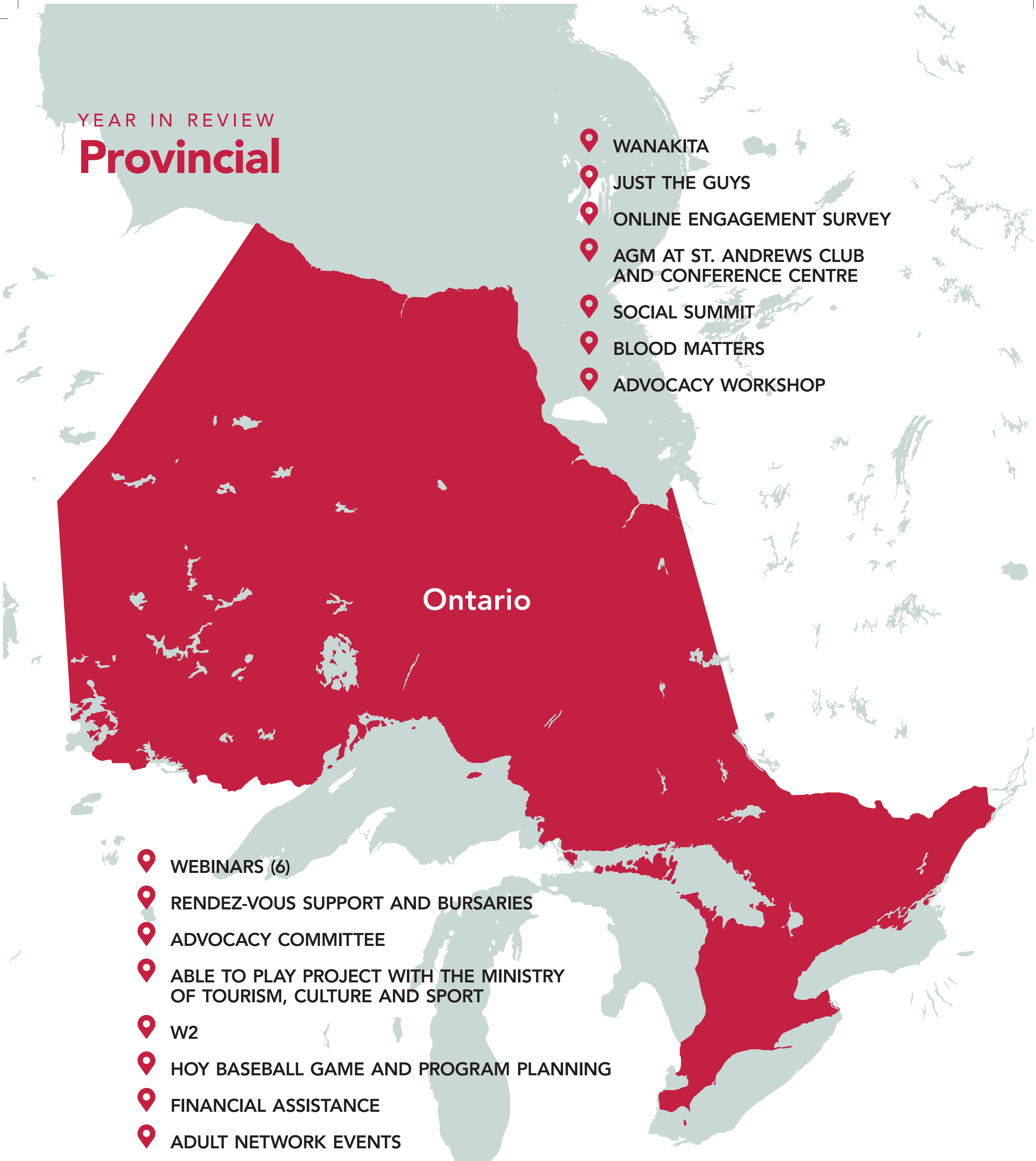
By treating the people with whom we interact with dignity, fairness, and compassion.

COLLABORATION

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

YEAR IN REVIEW

Provincial



- WANAKITA
- JUST THE GUYS
- ONLINE ENGAGEMENT SURVEY
- AGM AT ST. ANDREWS CLUB AND CONFERENCE CENTRE
- SOCIAL SUMMIT
- BLOOD MATTERS
- ADVOCACY WORKSHOP

- WEBINARS (6)
- RENDEZ-VOUS SUPPORT AND BURSARIES
- ADVOCACY COMMITTEE
- ABLE TO PLAY PROJECT WITH THE MINISTRY OF TOURISM, CULTURE AND SPORT
- W2
- HOY BASEBALL GAME AND PROGRAM PLANNING
- FINANCIAL ASSISTANCE
- ADULT NETWORK EVENTS
- OAN PHA SUMMIT
- OAN LEADERSHIP SYMPOSIUM AND OTHER MEMBER EVENTS

YEAR IN REVIEW

Regions

TCOR

- RGM at the Toronto Public Library Fairview branch
- Two Adult Network events (Barrie and Toronto)
- Focus Groups in Toronto and Mississauga
- Opening Doors Toronto
- Golf Tournament
- Families in Touch event
- Zoo Walk
- Wellness Day in Oshawa
- Toronto AIDS Vigil

CWOR

- RGM at Brux House
- Adult Network event in Ancaster
- Opening Doors Hamilton
- Focus Group in Kitchener
- Zoo Walk
- Barbour Scholarship

OEOR

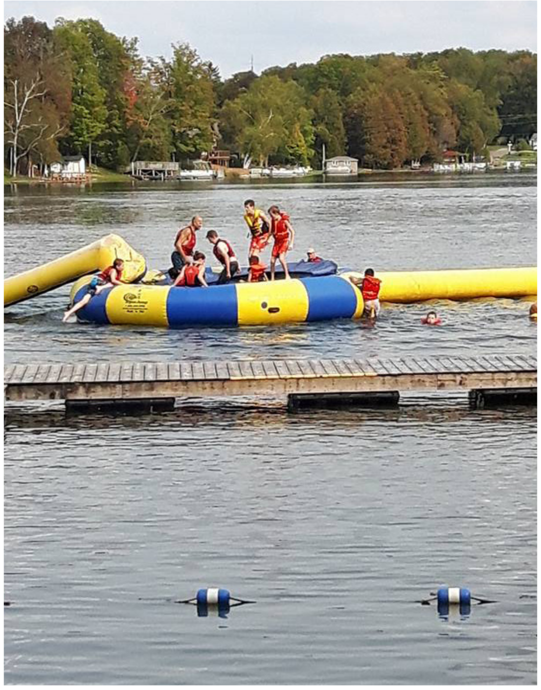
- RGM at the RA Centre
- Adult Network event in Ottawa
- Focus Group in Ottawa
- Summer Celebration at Logos Land Resort
- OEOR Holiday Party

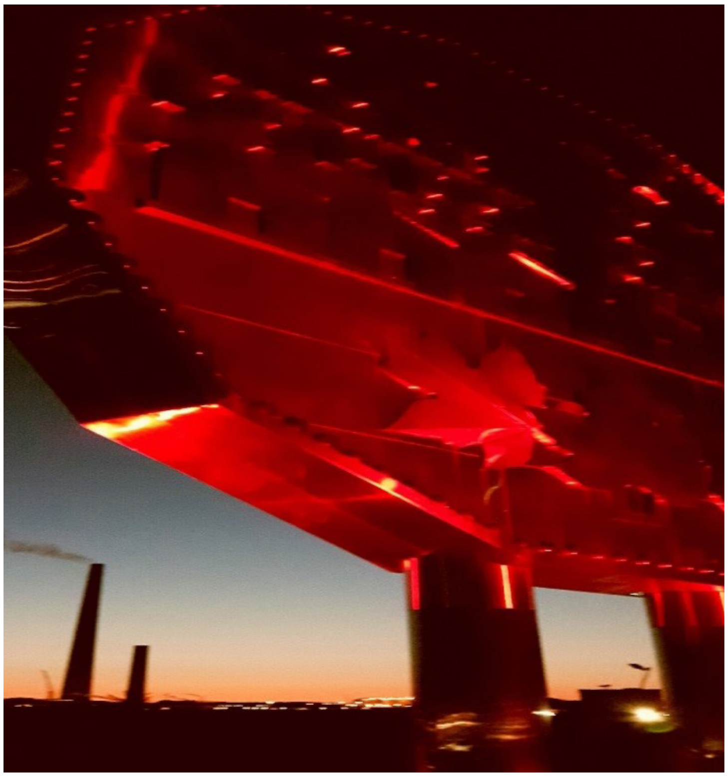
NOR

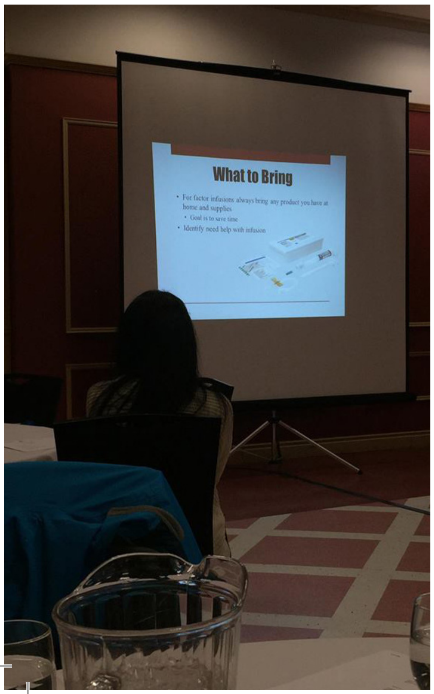
- RGM at Health Sciences North
- Outreach at 2 clinics in Sudbury
- Outreach at 1 adult clinic and 1 pediatric clinic in Thunder Bay
- Lighting the Big Nickel for World Hemophilia Day
- Just the Guys North and Family Camp

SWOR

- RGM at Kings College
- Opening Doors Windsor
- Small but Mighty Polar Bear Dip
- Focus Group Windsor and Woodstock
- World Hepatitis Day London
- Adult Network by the Lake
- Fresh Pine (OTF)
- Outreach at LHSC Pediatric Satellite Clinic at WRH
- Pinecrest Adventure Camp
- Pinecrest 25th Anniversary Reunion
- Pots Wreaths and Swags
- World AIDS Day Vigil Stratford
- World AIDS Day Vigil London







What to Bring

- For factor infusions always bring any product you have at home and supplies
  - Goal is to save time
- Identify need help with infusion

Pinecrest Anniversary Event

On November 26th, 2017, a celebration was held at the Best Western Lamplighter Inn in London, ON to recognize the 25th anniversary of Pinecrest Adventure Camp.

Starting with a handful of campers in the backyard of Nurse Liz Clegg's cottage in 1992, Pinecrest has grown and moved over the years, supporting hundreds of children and families across generations to develop leadership skills, learn to self-infuse, and develop lifelong friendships. 77 people registered to attend the reunion event, including Dr. Barry deVeber, a trailblazing pediatric hematologist who cared for many Pinecrest campers, some of the founding camp committee members, former and current campers, and former and current staff members. We were also happy to recognize the support of some of our long-time pharmaceutical partners who make the program possible. Thanks to everyone who came out!


Hemophilia Ontario
Help Stop the Bleeding
WOW


RAD
AWESOME


LEEBURN
PRESBYTERIAN
CHURCH


AWESOME


Pinecrest

Engagement Strategy

A big part of 2017 was the year-long engagement strategy that spanned the entire province and included multiple opportunities for feedback.

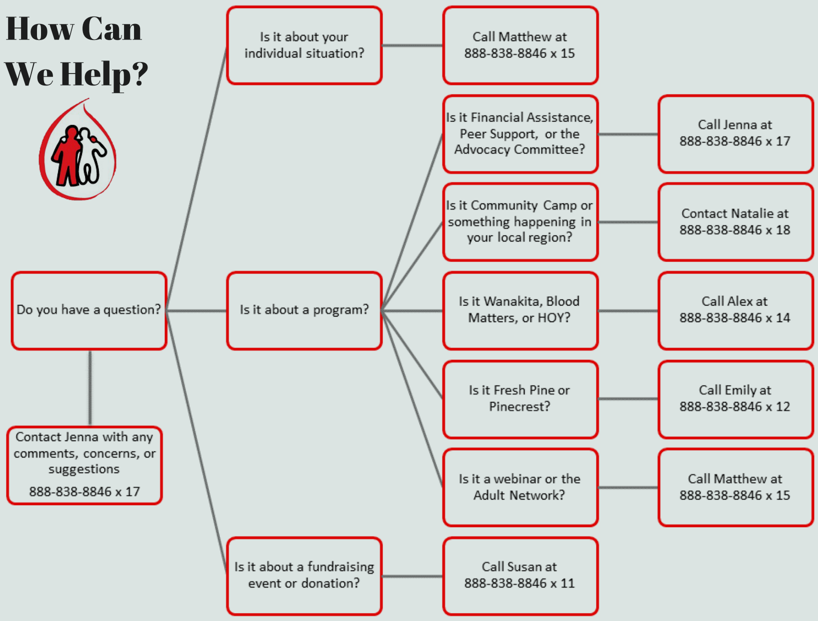
In addition to meetings with all of our HTC clinic partners, and one-on-one conversations with members and stakeholders, the strategy included:

- A social summit event to share Big Picture ideas and suggestions in a relaxed, conversational environment;
- An online engagement survey to get a broad cross-section of input on Hemophilia Ontario programs and priorities;
- A focus group series that sought in-depth answers and opportunities to dive deeper into areas of concern.

There were a number of recurring themes throughout the year and across formats. Some of the identified priorities were:

- The need to grow our membership base;
- The importance of collaborating with the clinics;
- Reaching out to newly diagnosed families;
- Increasing programs and opportunities for involvement at the local level;
- Re-establishing mentoring or family matching programs;
- Ensuring a big voice for Hemophilia Ontario at the CHS table;
- Becoming more results focused and able to articulate what we have achieved; and
- The importance of sharing stories from the membership.

That feedback was considered very seriously by the Board and formed a major part in our 2018 program plan and continuing outreach strategies. As a result, there has been major investment in two key areas: clinic attendance and local education programs. We look forward to serving the membership with a revised staffing structure to help meet these goals and other identified priorities. For more information, see the following chart.



TESTIMONIAL

Financial Assistance

The following email was received in December 2017 after the family was supported with a major expense related to their youngest son's bleeding disorder care.

Hi Jenna,

I just wanted to thank you for everything. I don't know if you realize how much this helps us out. We have had hit after hit. Especially in the last week.

Thursday we were up to Ottawa for bloodwork for his inhibitor. (Nothing new there). Friday the fever started. By Saturday his fever was 105.3. We brought him to emerge, and they said he had an ear infection. He cut both his top front teeth on Saturday and then Sunday. Sunday he developed a very painful diaper rash, that turned out to be a yeast infection. (From the tummy troubles from the antibiotics.) Monday he had broken out in a whole body rash. By yesterday, I had to take him back to the clinic where they said he was allergic to the antibiotics he was on. So, back out to the pharmacy for new antibiotics and benadryl. I got the call that his inhibitor is elevated again while at the pharmacy. So more bad news. Then he hit his mouth this morning and had a mouth bleed. So back to the pharmacy for that medication.

The poor guy can't catch a break. It just seems life keeps kicking us when we're down. And it's been very difficult to stay positive.

So what may just be another day or another task for you, means so very much to us! I hope you know how much this means to us. That we actually have something good happening. Thank you for everything. And to the whole foundation for helping families like ours. My sister in law wrote on Facebook last night, when I was having a pity party (lol) that she's hoping for a Christmas miracle. Well this is the closest thing to a Christmas miracle we could ask for!

I hope you have a great holiday with your family and friends. I've attached our family Christmas card, so you can put a face to the family you have helped.

Thanks so much again!
Amanda

All support provided through the Financial Assistance fund is made available through the generous donations of our community members and fundraising events.

TESTIMONIAL

New Member

As a wheelchair user, I have some very visible disabilities, but what many people don't see is that I have a platelet function disorder. When I was first diagnosed it became very clear to me that many medical professionals lack a sufficient understanding of bleeding disorders. During emergency room visits, this lack of understanding, has made some of these experiences scary for me. Educational tools for physicians is a body of work that Hemophilia Ontario is working to advance.

When any diagnosis is invisible it can be challenging to meet other people who share a similar embodiment of difference. It can be difficult to find people who are willing to discuss what it is like for them to take specific medications or be the owner of a shapes container. Hemophilia Ontario helps put me in touch with those folks. Perhaps because of its invisibility, perhaps because platelet disorders are less common, or perhaps because it involves discussing the ways in which our bodies can leak and fail us—this can be a condition that is tricky to discuss.

And with all of its tricky terrain, it is much more easily travelled with the support of peers and Hemophilia Ontario focuses on the significance of that.

Terri-Lynn Langdon
PhD Student, Social Justice Education,
OISE, University of Toronto, MSW,RSW

Twinning Final Report

BY CANDACE TERPSTRA

In a country the size of Tanzania (population 54 million) one would expect to have identified many more people with hemophilia/bleeding disorders. So the challenge is to find those individuals who are currently living with a bleeding disorder. Outreach presentations are thought to be the major way to find people with bleeding disorders through radio, TV, local talks or internet using MOH health websites. Ten youth received training through the Novo Nordisk Foundation in public awareness and outreach including writing and telling their stories, this latter method being used locally for outreach. The training provided great preparation for leadership.

Communication is always on ongoing challenge. However, communication among members in the Haemophilia Society of Tanzania (HST) has dramatically improved through the use of WhatsApp and SMS which are used to communicate plans and events as well as to provide emotional and educational support where needed. Educational resources in Swahili and English are sparingly used primarily for new families. We had hoped to print the booklet on Living with Hemophilia in Swahili because not everyone speaks English. Currently there are two resources available in Swahili and English, the HST brochure as well as a one page flyer emphasizing the importance of treatment.

Another ongoing challenge is transportation. Members will require assistance until care has been expanded to a broader network of hospitals in the country. Two medical outreach visits have already taken place in the northern part of the country.

The HST Executive Board is now comprised of patients and family members in keeping with the concept of a patient driven society. It has been recognized that additional skills on the Executive would be helpful as the work of the organization gets more complex involving new areas such as volunteer recruitment, finance and fund raising, public awareness, outreach and continued advocacy.

Another challenge will be to raise the funds needed to operate as an organization focused on education, support and advocacy. A fund-raising presentation was provided as part of the Education Day Sessions. In addition, several recommendations were made by the Hemophilia Ontario team to the Executive including those relating to finances and financial accountability. The HST will require the ongoing support of the WFH in order to continue to grow and develop more fully its capacity as a stable and strong advocate for people with bleeding disorders.

Tremendous progress has been made in Tanzania through the Twinning including:

- The identification of over 100 members with hemophilia (up from 24),
- Limited treatment with factor is now available through the WFH Humanitarian Aid Program (rather than only FFP);
- Regular care is now available at the Muhimbili National Referral Hospital using a basic hemophilia care team – this year adding a physiotherapist;
- In-country diagnosis is now available along with the implementation of a national registry;
- The first ever symposium on Hemophilia was held in 2016 with the support of the HST;
- The Ministry has pledged their support to the Society's efforts and government/hospital plans include the purchase of factor product in Tanzania for the first time, something not previously considered;
- In 2017, a second symposium for doctors treating hemophilia patients was sponsored through the Twinning.

Report on Rendez-vous

BY ASHWANI KURICHH

I would like to thank Hemophilia Ontario for the opportunity to attend Rendez-vous 2017. It was a great platform to learn about new and upcoming treatments for Hemophilia, advocacy, board governance and the opportunity to meet with other medical professionals and pharmaceutical representatives.

The first day of the conference was a Medical and Scientific Symposium that focused on the following topics:

- New and upcoming treatments for Hemophilia
- The Canadian Bleeding Disorder registry
- Women and Bleeding Disorders
- Sports and Activities for individuals with Bleeding disorders
- Aging with Hemophilia and a panel discussion on the journey from joint disease to joint replacement

The second day of the conference was dedicated to the Canadian Hemophilia Societies 2017 Annual General Meeting as well Community Engagement Workshops on Advocacy, Chapter Development and Ageing with a bleeding disorder.

The knowledge gained throughout the conference, on the various topics presented, was both educational as well as inspiring to enhance the mission of Hemophilia Ontario.

Vast knowledge was gained on the following topics:

NEW AND UPCOMING TREATMENTS

- Availability of Extended half-life FVIII and IX coagulation factors in Canada (i.e. Eloctate for factor VIII).
- Inhibitor Tolerance Induction – How to manage inhibitors in patients with Hemophilia and the best treatments available to patients.
- Outcomes of trials in Gene therapy and what the future holds in terms of its effectiveness and cost associated with it. Who will cover the cost of this therapy once it becomes available?

THE CANADIAN BLEEDING DISORDER REGISTRY

- New online tool to help patients with a Bleeding disorder and health care professionals in HTC's log factor usage and bleeds.
- Even though there are 15 out of the 23 HTC's in Canada live with CBDR, there is still a lot of work that needs to be done for more compliance and accurate data collection.

WOMEN AND BLEEDING DISORDERS

- Although there have been tremendous advances to treat women with bleeding disorders, there is still a lot more that needs to be done. Education is key. Even though there are more cases of women with bleeding disorders than patients with Hemophilia, there still is a disconnect and lack of education between GP's and there patients. Many women go untreated as many GP's are unaware of the symptoms, what VBD is, and the treatments available.

SPORTS AND ACTIVITIES FOR INDIVIDUALS WITH HEMOPHILIA

- Individuals with Hemophilia are not limited to the type of sports or activities that they can engage in as long as they are following a proper physiotherapy regime, factor treatment and under the care of a team of professional medical personal at the HTC's.

ADVOCACY

This was a key item presented at the conference. To effectively advocate for a cause, we must ensure that there is one voice/message that is being relayed to the stakeholders and partners about the organization.

As a patient organization, we have to effectively advocate for the comprehensive treatment and care for all individuals with bleed disorders will all levels of governments, HTC's and within our membership.

Advocacy can be comprised of any and all of the following:

- Lobbying different levels of government for the approval of new treatments and medications, covering the cost for the new treatments/medications.
- Lobbying HTC's for more comprehensive treatment and care by providing more medical professionals to help with the treatment of bleeds for Hemophilia patients (i.e. Physiotherapists, etc)

The best way that Hemophilia Ontario can enhance its mission by the above knowledge learned is by the followings means:

- Educate the members on new and upcoming treatments for Hemophilia and other bleeding disorders.
- Advocate pharmaceutical companies and other stakeholders to ensure that there is ongoing research and clinical trials for new treatments and possibly a cure. Ensure the membership is made aware of the research and any clinical trials so that they have the opportunity to participate.
- Work with the HTC's to ensure that each center has the appropriate medical staff and standards of care to treat patients with bleeding disorders.
- Advocate the different levels of government to ensure that new treatments/drugs are approved in a timely manner.
- Advocate the different levels of government to cover the cost of the new treatments (i.e. when gene therapy is approved, who will cover the cost of this treatment?).

Board Members

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Maia Meier

VICE-PRESIDENT
Amy Griffith

VICE-PRESIDENT
Bojan Pirnat

SECRETARY
Shelley Hewett

TREASURER
Jamie Hill

PAST-PRESIDENT
Julia Sek

Kwadwo (Michael) Bosompra

Ryan Kleefman

Meagan Bordi

Darlene Villeneuve

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Roche

WFH 50 YEARS OF ADVANCING TREATMENT FOR ALL
WORLD FEDERATION OF HEMOPHILIA
Fédération mondiale de l'hémophilie
Federación Mundial de Hemofilia

Ontario
MINISTRY OF TOURISM, CULTURE AND SPORT

HEMOPHILIA ONTARIO

Financial Report

BY JAMIE HILL, CPA, CMA | TREASURER

Hemophilia Ontario saw significant change in 2017 and continues to navigate uncharted waters as it begins 2018. Job descriptions have been re-aligned and a new position is being hired which means updating the Ministry of Health (MOHLTC) budget information.

Canadian Blood Services has re-tendered factor supply contracts which means many familiar products will no longer be available. Clinics are discussing the changes with their patients and we are seeing increased member concerns.

Pharma sponsorship requests have all been sent but no decisions from anyone at this time. In an effort to be fiscally responsible and to acknowledge constraints imposed by our funders, it is best to plan for less support.

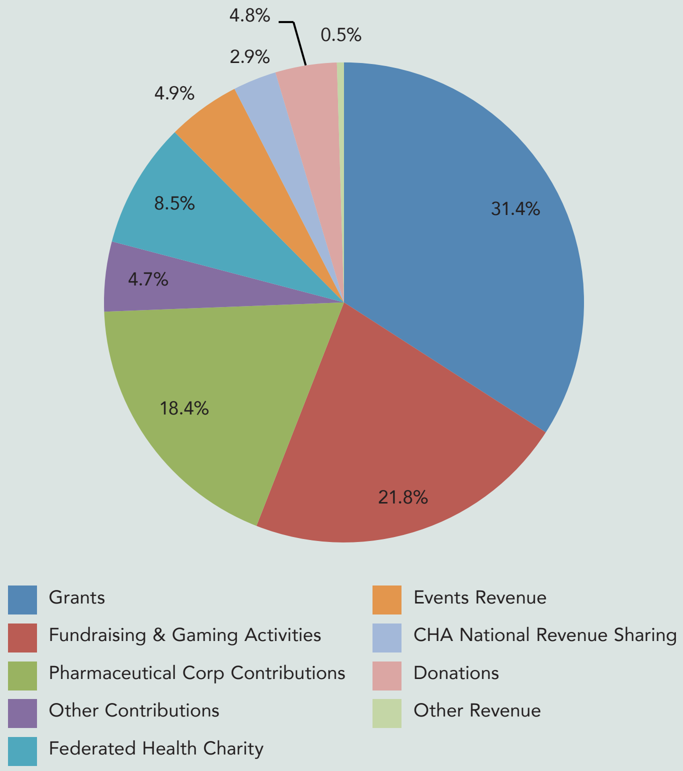
Hemophilia Ontario continues to advocate for needed resources in order to ensure Hemophilia Treatment Centres operate at full strength. Hemophilia Ontario also continues to offer education and support through clinic visits, social events, webinars and financial assistance.

A complete review and re-working of programs has been initiated. This process will continue into 2018 but significant changes have already been made. Most notably, for 2018, Just the Guys will be combined with Community Camp.

To accompany the change in programming orientation and any future changes to our mission and how we deliver them, policy and procedures will be changing too. Once our new objectives are in place, a comprehensive risk assessment can be completed which will look at various risks facing our organization in the achievement of our objectives. New policies will be implemented to address these risks. Such is the work ahead for 2018!

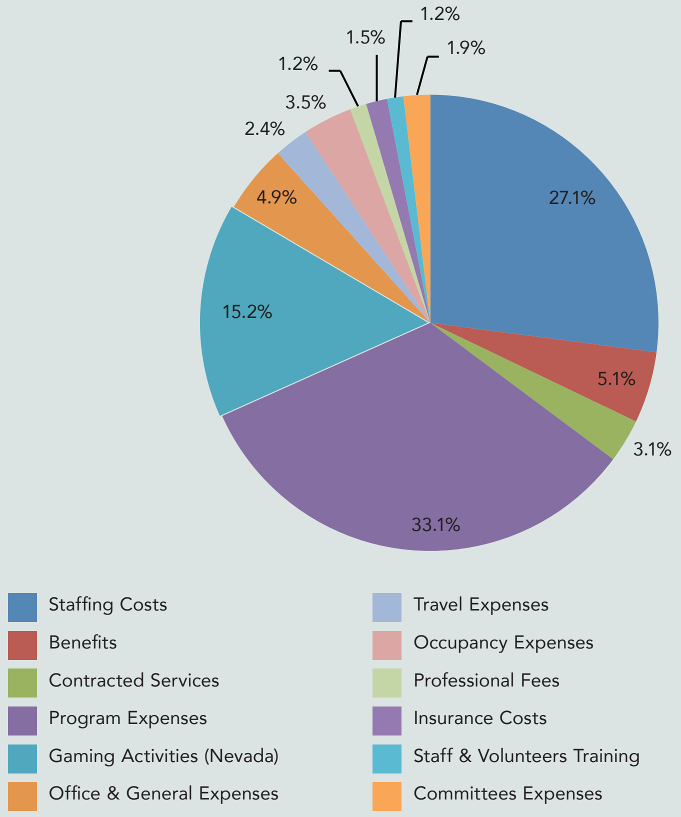
2017 REVENUE

Revenue received in 2017 by category as a % of the whole amount received.



2017 EXPENSES

Expenses in 2017 by category as a % of the whole amount spent.



REVENUE

Revenues for 2017 were **$840,510**, down **$93,656** or **10%** from last year. Grants were down **$44,749** or **13.5%** while donations were down **$25,581** (**42.4%**). Fundraising was down **$17,631** (**8.8%**).

This is the final tier of reductions in Ministry of Health funding. This was anticipated and we are now receiving the amount we expect to continue receiving for the foreseeable future. New grant funding was sought from the Ontario Trillium Foundation and Ontario Sport and Recreation Community Fund (Ministry of Tourism, Culture and Sport) to augment our existing programming and provide enhanced service to members, as well as assist in covering some administrative expenses. The reduction in Events and Donation is due to the elimination of the long-standing CWOR golf tournament event, reduced revenues from the Polar Bear Dip, and a large donation received in 2016.

This fiscal reality has led the Board of Directors to initiate a review of the way programs are delivered in order to be fiscally responsible.

EXPENSES

Expenses for 2017 were **$848 270**. In an effort to maintain a balanced budget, spending was cut by **$88,205** or **9.4%**. Most notably, staffing costs were reduced by **$77,059** or **25.1%** while the drop in gaming revenues was accompanied by a drop in gaming expenses of **$24,538** or **16%**. This left Hemophilia Ontario with a deficit of only **$7,760**. Further reductions have been implemented starting in 2018 (elimination of satellite offices).

Expenses increased for travel due to onboarding a new Executive Director (travelling across the province to meet with clinic teams and stakeholders) and the Focus Group series. Committee expenses include Board meetings and the creation of the Advocacy Committee. Programming in 2017 included the engagement strategy, Just the Guys, W2, Pinecrest, Wanakita, webinars, Blood Matters, Financial Assistance and local events like the OEOR holiday party. We are looking at how to implement a new program plan that reflects our lower revenues and still meets member priorities in 2018 and beyond.

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

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 St., 10th Floor, Suite 10100, Toronto, ON M2N 6K8

✉ info@hemophilia.on.ca
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/Hemophilia-Ontario
/HemophiliaON
HemophiliaOntario
hemophiliaontario

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

To 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

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