Organization Report

2019 - 2023

Hemophilia
Ontario

heroixx

Our Path Beyond the Pandemic

Table of Contents

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 al 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.

LETTER FROM

The President

Emil Wijnker

What an incredible journey our organization has been on over the past five years! While we have been very busy in that time, Hemophilia Ontario has not published an Annual Report document since 2018. This document, the 2023 Annual Report, then also serves to bring our community and stakeholders up to date on our organization, and what we have accomplished most recently.

Since our last report, Hemophilia Ontario's operations model has changed significantly. Rather than having regional staff, our entire staff team now works in departments, addressing the needs of our entire membership provincewide. This model has streamlined many of our operations and provided for greater equity across our provincial membership. It has also allowed for many of our departments to flourish and expand their services. We have an amazing team working for Hemophilia Ontario, and their successes are rightly highlighted in this report.

The COVID-19 pandemic presented us with challenges, as it did with everyone else across the world. Hemophilia Ontario, however, found itself in a unique position to leverage some of our strengths to the benefit of our community and to continue to provide member-focussed programming when society was facing lockdowns and incredible social, physiological, psychological, and emotional strain. Since we had embraced a work-from-home model long before the pandemic, our staff continued to work close to normally throughout stay-at-home orders and lockdowns. Hemophilia Ontario was also very experienced with the Zoom online meeting platform (we were using it long before it was cool!), and we transitioned some of our in-person functions to webinars. This also allowed us to extend the invitation to these events beyond our provincial borders, and we not only welcomed participants from across Canada, but from around the world. We even hosted a virtual edition of Pinecrest Adventures Camp in the summer of 2020, which involved a partnership with Nurses from the IWK Health Centre Pediatric Bleeding Disorder Clinic in Halifax, Nova Scotia along with a contingent of Camp participants from the Maritimes as well. As social restrictions began to be lifted, Hemophilia Ontario embraced the ever-changing 'new normal', providing facemasks to members and providing safe, in-person events for our membership.

Among our marquee in-person programs are our summer camps. Hemophilia Ontario has over 30 years of experience providing meaningful, educational, and safe summer camp experiences for our members. Our infusion training program at YMCA Camp Wanakita is our most successful and popular program and continues to thrive thanks to the continued support of sponsors as well as our phenomenal Clinic nurses.

2022 marked the 30th anniversary not only of our partnership with YMCA Camp Wanakita, but also of Pinecrest Adventures Camp. Pinecrest was a residential summer camp program hosted in the South Western Ontario Region, in partnership with the London Bleeding Disorders Clinic. Unfortunately, due to a confluence of factors, including declining enrollment and facility issues, Pinecrest was shuttered after 2022. As a participant at the first iteration of Pinecrest in 1992, a former counsellor, camp director, and finally proud Pinecrest parent, I am sad to see the end of this program. I am, however, incredibly proud of the quality and variety of camping programs Hemophilia Ontario continues to offer, including Wanakita, Family Camp, our Youth Adventures and Mentorship Program (YAMP Camp), and Just the Dads, and I am confident that our membership is well-served in this regard.

Another crown jewel in Hemophilia Ontario's program portfolio is our Women's department. This department has seen tremendous growth over the past five years and continues to flourish as the global bleeding disorders community embraces a new focus on women's bleeding issues. The launch and continued success of our new online platform focused on these issues, Heroixx.ca, has been a monumental success for our organization. If you have not yet taken the opportunity to explore Heroixx yet, I encourage you to do so. As a father of three daughters, I have found many useful resources and connections within this fantastic resource.

At our heart, Hemophilia Ontario remains a grassroots organization. We could not be where we are today without the tireless support and continued engagement of our members. We continue to enjoy many local community-focussed events such as our community family days, golf tournaments, walks, fundraiser sales, and camps. Time and time again, our membership has told us that, more than anything, they want opportunities to connect in-person, and we have striven to provide that as much as possible for our members. We have also enjoyed a renewed presence and engagement with our Northern Ontario communities with increased presence at the Clinics in both Sudbury and Thunder Bay. We recently launched the John Plator scholarship program, in an effort to support and engage our young adults as they transition to post-secondary education. We continue to offer direct member support, a program area that has also seen tremendous growth since the pandemic. Working in collaboration with our clinic comprehensive team members, we strive to assist those in our community to meet their bleeding disorder-related needs, of which there have been many. We are grateful for the close, collaborative relationship with our clinics, as they are often the first point of contact for patients.

Our Board of Directors continues to strive for representation across our five provincial regions, as well as across our patient condition and experience spectrum. Each year, we employ an inward-facing skills assessment to identify gaps and highlight qualities to seek in prospective Board members. Additionally, we have engaged 'youth Board interns' as a way to groom future leaders for our organization. We also continue to enjoy a fruitful partnership with the University of Toronto Rotman School of Management through their OnBoard program. The result is a diverse, multi-faceted Board that works hard to provide our organization with shrewd yet heartfelt leadership. It has been my pleasure to serve on this Board yet again, and it has been my esteemed honour to serve as President and Board Chair. I cannot wait to see what lies in store for Hemophilia Ontario!

Yours truly,

Emil Wijnker
President, Hemophilia Ontario

Hemophilia Ontario

Byron James

Letter from the Executive Director

> “The point I am trying to make here is that this organization is all in for its members in everything we do. As you read this document you should be impressed by the do or die attitude and work ethic that this team puts forward for our bleeding disorder community, there is nothing we will not take on if it is an identified need for our community.”

This report will cover the period of 2019 through 2023 and focus on the way Hemophilia Ontario managed its services and programs in a period where every organization and individual had to adapt to a new way of life. No one was unaffected as the world tried to figure out the best way forward in the face of the COVID pandemic.

You will read in this report the way Hemophilia Ontario adapted its programs and services continually moving forward in its mission of supporting the bleeding disorder community of Ontario. From educational webinars, new materials on dealing with COVID with a bleeding disorder, increased financial assistance to those experiencing financial hardship due to the pandemic, Hemophilia Ontario was with our members every step of the way.

The bleeding disorder community in Ontario is at its best when it gets to come together through our camp and community day programs. They can meet new families; the kids and youth make new friends and get to enjoy a variety of activities in an outdoor environment. These programs had to be shut down during the onset of the pandemic. We had to cancel our youth infusion training camp for two summers in a row. Once vaccine protocols started being introduced, Hemophilia Ontario switched gears and started bringing our community together again while everybody else stayed virtual. Utilizing third party vendors and outdoor venues we were able to provide physical programing in a safe environment.

Examples include fall ziplining day and barbecue Kitchener area thirty-five members in attendance, White Water Rafting Day, and barbecue Ottawa, fifty-five members in attendance, Halloween haunted trail and lights experience with loot bags, done from your car forty members in attendance. Our biggest success in bringing our community together came when we found our youth infusion program at Wanakita was to be cancelled for the third year in a row. In meetings held with the camp director we found that if we purchased the entire camp with only our families, we could run a weeklong family camp and include our infusion training program for our youth. We had 157 members from our community attend for the week and it is still talked about.

All the events listed were run while everyone else was still doing virtual no face to face anything. Not one case of COVID was reported as a result of being at these events.

To reiterate, the point I am trying to make here is that this organization is all in for its members in everything we do. As you read this document you should be impressed by the do or die attitude and work ethic that this team puts forward for our bleeding disorder community, there is nothing we will not take on if it is an identified need for our community.

Best wishes,

Byron James
Executive Director
Hemophilia Ontario

Women's health in 2024

The start of the 2024 year has been a whirlwind! We have hit the ground running with our Physician Assessment Guide and are recruiting primary care providers to test out the guide and provide feedback. We have had heroixx.ca translated in French, Spanish and Chinese and are currently implementing the translation to the website. We have planned a variety of webinars that will be recorded for future use and displayed on our website including: a focus on mental health, iron deficiency, adolescents, and emergency room visits. Our Talk Series Episodes are also in the works so stay tuned!

Natalie Philbert

Manager

Women's Services & Programs

Women's Services & Programs

2019 – 2021: Years of change

In 2019, our women's health programs flourished with engaging events such as high tea gatherings and fundraising initiatives, bolstering community connections, and raising awareness about bleeding disorders. The onset of 2020 brought unforeseen challenges, compelling us to transition to virtual platforms. Despite initial hurdles, we successfully hosted educational sessions, reaching a wide audience across Ontario and Canada.

As the year unfolded, we creatively adapted, organizing safe in-person events amidst the pandemic, fostering cherished moments of community bonding. In 2021, our online programs thrived, offering valuable insights and educational resources nationwide. We initiated research for a dedicated women's bleeding disorders website, responding to members' expressed needs.

2022: Progress & Innovation

In 2022, our website heroixx.ca was launched, offering valuable resources on women's bleeding disorders, including videos, research articles, personal stories, and a talk series. Notable episodes focused on "Period Talk" with Amy Griffith and Dr. Pike, as well as discussions about the WeThrive app. We also conducted online educational sessions covering various topics like nutrition, exercise, rare bleeding disorders, and pregnancy. In addition, we resumed in-person meetings, including a session at our AGM and an inaugural adolescent session, promoting connection and learning. Moreover, we organized a community day at Centreville Island in Toronto, providing a fun-filled opportunity for everyone to catch up and engage in games. And of course, we continued our cherished annual Pots and Wreathes tradition in London.

2023: Advancing Advocacy and Outreach

Building on past achievements, we expanded our advocacy efforts, focusing on reducing diagnosis delays and enhancing care for women and menstruators with bleeding disorders. Initiatives like the Physician Assessment Guide aimed to equip primary care providers with essential knowledge. Our commitment to education and support remained steadfast, reflected in the expansion of online resources and engaging talk series episodes.

"My work with Heroixx and Hemophilia Ontario today is a personal mission. I made a promise to myself a long time ago that no woman or young girl should ever feel that they do not have a space in our bleeding disorder community. That their care, treatment, and overall sense of belonging should never be sacrificed because of their gender or diagnosis. I'm proud to be a cofounder of this website, and I'm so happy that you are here reading this story."

Amy Griffith
Board of Directors

Heroixx Inspires

I've shared my story countless times, often questioning why anyone would want to hear it again. Yet, each time I speak, I'm reminded of its resonance within my community of women. Despite being born into a family without a history of bleeding disorders, I was diagnosed with Von Willebrand's disease as a child. This diagnosis came about thanks to a fortunate family connection within the medical field, allowing for early intervention and management of my condition.

Growing up, my main focus was on blending in with my peers, sometimes to the detriment of my own health. I neglected to wear my essential MedicAlert bracelet and strived to keep up with the activities of my friends. It wasn't until my twenties that I recognized the power of education and advocacy. By sharing my experiences and educating others, I've been able to build a strong support network around me.

One of the biggest challenges I faced due to my condition was menstruation. Like many women with bleeding disorders, I suffered in silence, lacking the knowledge and understanding of what constituted a healthy period. This lack of awareness led to significant blood loss and a decline in my overall well-being. It took years for me to realize the importance of seeking proper treatment and support.

Fortunately, my journey led me to a women's specialty clinic in Toronto, where I finally found the comprehensive care and understanding I needed. This clinic has become a beacon of hope for many women like me, and I'm proud to champion its services and advocate for greater awareness and support for women with bleeding disorders across Ontario.

heroixx

Unity

Community

Advocacy

Expanding North

In Thunder Bay, Hemophilia Ontario has made significant strides in addressing the unique needs of our community, especially in remote regions. In 2022, we established connections at the Thunder Bay clinic, leading to tailored programming for remote areas. In 2023, a grant enabled us to introduce maintenance sites, enhancing healthcare accessibility. Collaborating closely with healthcare teams, we're devising plans for increased access in Indigenous reserves. By appointing a Northern Regional representative and organizing successful fundraisers, we're expanding our impact.

We also launched a Peer Support Program to partner members of our community with others in the hopes of supplying them with social and emotional support. Although small initially, we are hoping that this program will grow further in 2024 and we can include more individuals who are seeking support, community and friendship.

Sarah Levy

Manager

Member Services & Support

Financial Assistance & Member Services

2019 – 2021: Adapting to Changing Needs

From 2019 to 2020, Hemophilia Ontario made significant strides in Financial Assistance and Member Support, expanding our assistance program beyond medical equipment to ensure holistic community support. The challenges of 2020 prompted swift adaptation, transitioning events and support programs online and strengthening partnerships to extend support during the pandemic. In 2021, we broadened our focus beyond health management, developing webinars and resources on critical topics like gene therapy and Hemlibra, while enhancing our support network through partnerships with organizations like WHAI and OAN.

2022: Expanding Horizons

Building upon previous efforts, 2022 marked a year of growth and innovation. We launched a Family/New Member Support Program, fostering peer connections and community bonds. Despite restrictions, we revitalized clinic relations and welcomed a new Manager of Member Support and Services, Sarah Levy, to drive our initiatives forward. Generous community donations provided crucial aid to families in need, embodying the spirit of solidarity.

2023: Achieving Milestones, Cultivating Connections

In 2023, we celebrated significant milestones in Member Services, with a focus on addressing diverse community needs. Our outreach efforts to remote regions and Indigenous communities were fruitful, securing grants for maintenance sites and fostering meaningful relationships. We launched a Peer Support Program to offer social and emotional support, laying the groundwork for further expansion.

Looking Ahead to 2024

As we embark on a new year, our commitment to empowering communities remains steadfast. In 2024, we aim to diversify our funding sources, ensuring sustained support for our programs and services. Through continued collaboration and innovation, we strive to meet the evolving needs of our community, nurturing resilience and solidarity in the face of adversity.

Letter from Camps

I am writing to you today with gratitude and reflection on the journey that has brought us to this moment. As someone who has grown up within the folds of our organization's camp programs, transitioning from a youth participant to now finding myself at the helm as the manager of camp programs, I am deeply humbled by the transformative power of camp and the resilience of our community and this organization.

At the core of any camp program is the opportunity to spend time in the presence of each other and form bonds and relationships that last lifetimes. Reflecting on the past years amidst the challenges posed by the Covid-19 pandemic, I am reminded of the unwavering spirit and adaptability that defines this community. In the face of spending another summer without camps, Hemophilia Ontario organized a virtual Camp Pinecrest reaching participants across the country, and even put on a family camp program at Wanakita for a full week in the summer of 2021. Our camps department has faced unprecedented hurdles, yet through it all, Hemophilia Ontario has remained dedicated in its commitment to providing transformative experiences for our youth and their families regardless of the challenges.

From my own perspective, the importance of camp cannot be overstated. In my life it has been a beacon of light in times of uncertainty, a source of strength during moments of adversity, and a catalyst for personal growth and self-discovery. As a youth participant, camp provided me with a sense of belonging, a community of peers who understood and supported me, and countless memories that have shaped who I am today.

Transitioning into a staff role, I have had the privilege of witnessing firsthand the impact of camp on our participants. I saw timid smiles blossom into radiant confidence, heard laughter echo through the woods as friendships were forged, and witnessed moments of triumph as our youth embraced new challenges and conquered their fears. From virtual programming to socially distanced activities, we have adapted and innovated, ensuring that the spirit of camp continues to thrive, no matter the cost.

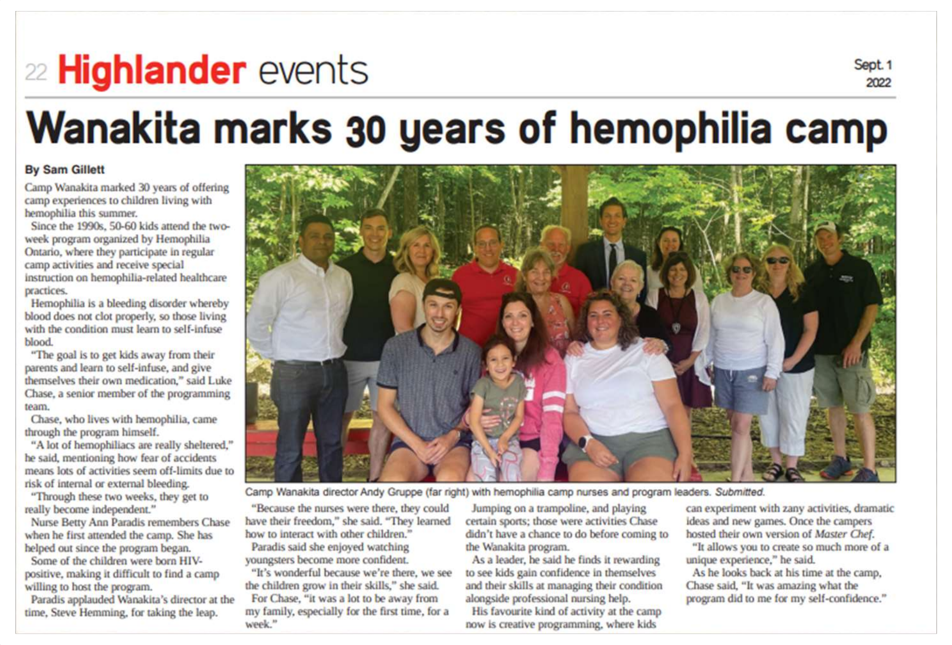
As we look to the future, I am filled with hope and excitement for the adventures that lie ahead. In 2022, we welcomed back the Youth Adventures and Mentorship Program (YAMP), a testament to our organization's adaptability and dedication to meeting the evolving needs of our community. YAMP has quickly become a cherished addition, offering high school youth a platform to connect, learn, and grow alongside their peers. With the return of beloved events like Just the Dads, Wanakita Summer Camp, and Community Camp, our camps will continue to play an integral role in shaping the lives of our youth and families, guiding them on a journey of self-discovery, growth, and empowerment.

Thank you, from the bottom of my heart, for being a part of this incredible journey. Together, we will continue to create moments of magic, resilience, and joy that will last a lifetime.

Luke Chasse

Manager of Camp Programs

RETURN TO CAMP



22 **Highlander** events

Sept. 1
2022

Wanakita marks 30 years of hemophilia camp

By Sam Gillett

Camp Wanakita marked 30 years of offering camp experiences to children living with hemophilia this summer.

Since the 1990s, 50-60 kids attend the two-week program organized by Hemophilia Ontario, where they participate in regular camp activities and receive special instruction on hemophilia-related healthcare practices.

Hemophilia is a bleeding disorder whereby blood does not clot properly, so those living with the condition must learn to self-infuse blood.

"The goal is to get kids away from their parents and learn to self-infuse, and give themselves their own medication," said Luke Chase, a senior member of the programming team.

Chase, who lives with hemophilia, came through the program himself.

"A lot of hemophiliacs are really sheltered," he said, mentioning how fear of accidents means lots of activities seem off-limits due to risk of internal or external bleeding.

"Through these two weeks, they get to really become independent."

Nurse Betty Ann Paradis remembers Chase when he first attended the camp. She has helped out since the program began.

Some of the children were born HIV-positive, making it difficult to find a camp willing to host the program.

Paradis applauded Wanakita's director at the time, Steve Hemming, for taking the leap.

Camp Wanakita director Andy Gruppe (far right) with hemophilia camp nurses and program leaders. *Submitted.*

"Because the nurses were there, they could have their freedom," she said. "They learned how to interact with other children."

Paradis said she enjoyed watching youngsters become more confident.

"It's wonderful because we're there, we see the children grow in their skills," she said.

For Chase, "it was a lot to be away from my family, especially for the first time, for a week."

Jumping on a trampoline, and playing certain sports; those were activities Chase didn't have a chance to do before coming to the Wanakita program.

As a leader, he said he finds it rewarding to see kids gain confidence in themselves and their skills at managing their condition alongside professional nursing help.

His favourite kind of activity at the camp now is creative programming, where kids can experiment with zany activities, dramatic ideas and new games. Once the campers hosted their own version of *Master Chef*.

"It allows you to create so much more of a unique experience," he said.

As he looks back at his time at the camp, Chase said, "It was amazing what the program did to me for my self-confidence."

Camper Testimonial

Dear Hemophilia Ontario

My name is Landon Bullock; I am a 12 – year old boy with severe Hemophilia B. I stated attending Wanakita camp when I was 7 years old.

Before attending camp, I felt like I was the only one with hemophilia, as I did not have others close to me. While at camp I was able to do things I would never have been able to where I live but with the safety of hemophilia nurses there to support me if I was injured. I had the chance to make friends with other kids that have hemophilia. Making these new friends at camp, I no longer felt like I was the only one fighting this battle. My first year at camp, I had a counselor named Luke, who was also a hemophiliac. Before I attended camp Wanakita I hated needles and I was scared of having infusions, but with the help of the nurses and look at my side motivating me, I came home knowing how to mix my own factor and helping hold the needle with a nurse or my mom when we infuse. Having Luke as a role model encouraged me to take interest in my own infusion. By the time I went back next summer, I was hitting my own veins at home. When I returned to camp, I was excited to see my friends from the previous summer and show the nurses my accomplishments.

My second year, I would go with my friends to the bear den even when I didn't need my needle I would go to support and encourage my friends to do their infusions. This camp has given me a place to feel normal, have friends with the same battle, and learn new activities in survival skills. If I had never had the opportunity to attend this camp, I think I would have struggled with confidence for my infusion and continue feeling isolated. I look forward to returning each year to see the friends I have made as well as the hemophilia nurses. This camp has provided me with lasting friendships, fond memories as well as confidence and independence in my treatments.

Thank you for providing support so kids like me can attend camp.

Sincerely,

Landon Bullock

Golf Tournaments

Despite the challenges posed by COVID-19 restrictions, our golf fundraising endeavors have thrived. In 2020, despite not being able to hold an in-person event, our golf committee organized online fundraising efforts, resulting in $11,200 raised for Hemophilia Ontario. Subsequent years saw successful modified and full-scale tournaments, including events at Nobleton Lakes Golf Club in 2021, Cardinal Golf Club in 2022, and The Club at Bond Head in 2023.

These events, with attendance ranging from 84 to 120 golfers, raised between $15,000 and $21,150 annually, highlighting the continued support of our golfing community.

Shawn Duford Golf Tournament

In 2023, Hemophilia Ontario proudly reintroduced the Shawn Duford Golf Tournament, honoring Shawn's commitment to supporting individuals affected by inherited bleeding disorders in the Ottawa and eastern Ontario region. Held at The Meadows Golf & Country Club, the tournament attracted 40 golfers and raised $10,000, reaffirming our dedication to grassroots leadership and local support initiatives.

Bingo

Hemophilia Ontario's dedicated volunteers have been instrumental in running our twice-monthly bingo sessions at Delta Downsview Gaming.

The revenue generated, currently at $4,500 per month, plays a vital role in supporting our programs and services.

Since 2019, we've utilized $115,000 from bingo funds to bolster our Camp Wanakita summer camp program and financial assistance initiatives.

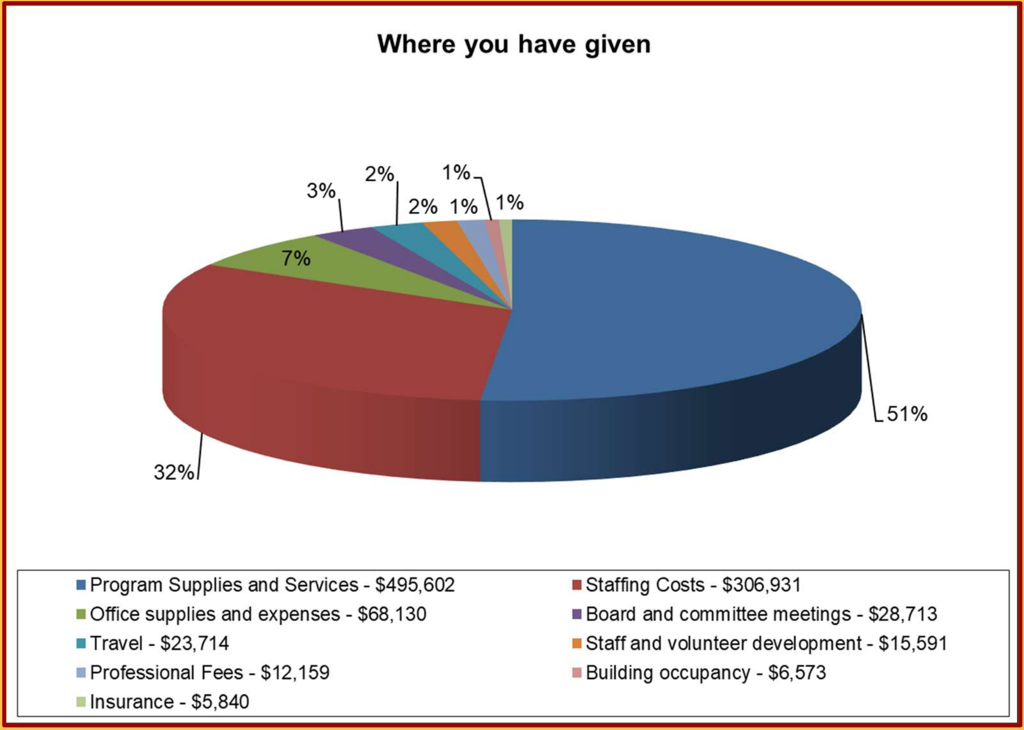
Nevada

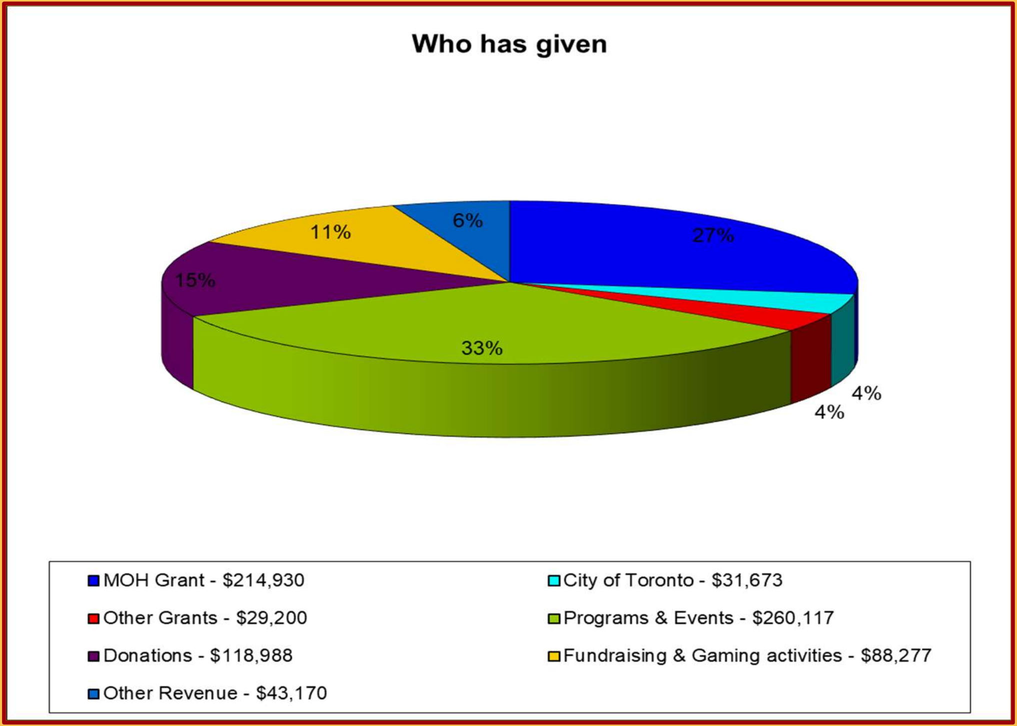
Our Nevada fundraising efforts have seen remarkable growth, with 29 locations across Ontario, up from 19 in 2021. Similar to bingo, funds from Nevada activities contribute significantly to our mission and cover program costs throughout the province.

From 2019 to 2023, $198,000 from Nevada funds has been allocated to various program expenses, including Camp Wanakita fees, camp nursing expenses, and financial assistance requests.

Hemophilia Ontario

Financial Report





REVENUE

MOH Grant	$ 214,930
Other Grants	$ 29,200
Donations	$ 118,988
City of Toronto	$ 31,673
Programs & Events	$ 260,117
Fundraising & Gaming Activities	$ 88,277
Other Revenue	$ 43,170
	$ 786,355

EXPENSES

Program Supplies & Services	$ 495,602
Office Supplies & Expenses	$ 68,130
Travel	$ 23,714
Professional Fees	$ 12,159
Insurance	$ 5,840
Staffing Costs	$ 306,931
Board & Committee Meetings	$ 28,713
Staff & Volunteer Development	$ 15,591
Building Occupancy	$ 6,573
	$ 963, 253

Board Members

President
Emil Wijnker

Vice-President
Amy Griffith

Past President
Cameron Peters

Secretary
Megan Reid

Treasurer
Prakash Singh

Member
Raja Ammoury

Member
Ashwani Kurichh

Member
Terri-lynn Langdon

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Youth-Intern
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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, 10 Milner Business Court, Suite 300, Scarborough, ON

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