

A publication of



Hemophilia Ontario
Hémophilie Ontario

BLOOD

matters

"We're all related by blood."

Volume 3 • Number 3

Fall 2012



John Plater
Farewell to a Friend

Hemophilia Ontario

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A publication of



Hemophilia Ontario
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Hemophilia Ontario is a certified chapter
of the Canadian Hemophilia Society.

Cover photo credit: Karen Plater archives

What's in this issue?

Fall 2012 • Vol. 3, No. 3

Information from Hemophilia Ontario and its Regions

	Page
Leadership Messages	3
Tributes to John Plater	5
Hemophilia Ontario News	8
Canadian Hemophilia Society News	11
World Federation of Hemophilia News	13
Central West Ontario Region	15
Northern Ontario Region	17
Ottawa & Eastern Ontario Region	19
South Western Ontario Region	19
Toronto & Central Ontario Region	21
Bleeding Disorders News	23
HIV-HCV News	24
Pharmaceutical	25
Hemophilia Ontario Youth Section	25

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Hemophilia Ontario
501 – 65 Wellesley St. E., Toronto, ON M4Y 1G7
416-972-0641 or 1-888-838-8846.
Fax: 1-888-958-0307 • www.hemophilia.on.ca

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PRESIDENT'S Message

by Paul Wilton

THE FIRST PERSON I remember meeting at a Hemophilia event was John Plater. I must have been three or four years old tagging along to an Annual General Meeting with my parents. I could sense my parents' eagerness for me to meet the man with the big red beard. Even at that young age I could tell this was someone my parents hoped could be a role model for me, and that maybe I would grow up to be a little bit like John.

During this first encounter, I could tell this man was different. He was obviously younger than most of the others at the meeting, but despite his youth, seemed to be the leader, the brightest, funniest, most outgoing and warmest. Over the years I would get to know him better, but still each time we met he amazed me with these qualities.

His commitment to the community was inspiring. Whether he was hosting a group of young bleeders at his place in Toronto on marathon weekend, opening his farm to our community for a lamb roast or cracking us up with Star Trek references while emceeding an event, he always gave our community members a sense of belonging. He was compassionate and willing to give so much of himself to help achieve justice for others.

John clearly had the respect and admiration of his peers on the Boards and Committees he served on. Most people would probably attribute this to his brilliance. I think it was more than intelligence though his peers

admired his character and commitment. You could have a disagreement with John but you trusted he would always be honest with you. You knew he always had the best interest of our community and the pursuit of truth as his primary objectives.

Even when John stepped back from a formal leadership role with Hemophilia Ontario to allow a new generation of leaders to take over, his presence was still felt around the Board table. I became involved the year immediately after John retired from the Board. For the past four years at almost every meeting, when a challenging issue has come up someone has said, "As an action item, can we have someone ask John, and report back at the next meeting?" Even though John had refocused his advocacy efforts in areas away from our Board table, he always made himself available when we requested his advice.

When John was sick and when he passed, it was difficult to explain to my friends outside of our community just what John meant to us. I wanted so badly to tell them what a hero he was. Finally I told them, "If the bleeding disorders community were civil rights, then we just lost our Dr. King." That's the way I felt around John; I had so much admiration for him that it was sometimes difficult to be myself. The only committee we ever participated on together was CHS' Blood Safety and Supply Committee (BSSC). There was such a sense of comfort when that boom-

ing voice came on the line and said "John Plater." It's rare that I'm quiet, but I barely said anything in three years on BSSC. In part I felt like when you have someone as informed and skilled as John, you just need to listen and learn. But I also felt as though if I ever got too comfortable around John I would say something stupid and my cover would be blown; he would figure out what a neophyte I was.

I believe John was the person he was because of great parenting and because of the love and support he had from Karen. Our community is forever indebted to John's family for sharing him with us. On behalf of the younger members of our community I want to thank John and all those who stood shoulder to shoulder with him during our most challenging times to create a safer blood supply and stronger standards of care for the next generation.

What a great role model my parents introduced me to some 20 years ago! I did not have the opportunity to work with him as closely or know him as well as many members of our community, but the younger generation understood the difference he made. He made us think, laugh and feel a sense of belonging. He inspired us to work harder, learn more, expect more, and to always, always give nothing less than our best. I hope the next generation of leaders will use John's example and work to make a positive difference in the lives of our community members. 📌

EXECUTIVE DIRECTOR'S Message

by Terri-Lee Higgins

ALBERT EINSTEIN SAID “Only a life lived for others is worth living.” John Plater embodied this. Although I did not have the opportunity to know John as long or as well as others in the community, he was someone who inspired me and like countless others he interacted with, he made a big impact on my life. Well beyond the few years that I knew John, he dedicated his life to the health and well being of those he knew and those he didn't. He was a fierce crusader for individuals living with inherited bleeding disorders and for all Canadians as he fought for a safe and secure blood system. A tireless advocate and human rights champion, John fought for HIV treatment and opposed criminalization of HIV. John led the call for the Krever inquiry and to get compensation for those infected with

HIV/AIDS and hepatitis C through tainted blood remaining focused on improving the lives of all. John was awarded Hemophilia Ontario's Honorary Lifetime Membership in 1995 and was President of Hemophilia Ontario 1991, 2001 to 2003 and 2004 to 2006.

More than an advocate, John was an integral part of many communities. Besides the life he shared within our community (and the summer lamb roasts), he was a husband, son, uncle, friend, farmer, camper, cook and was involved with his church. John felt the simple sense of belonging and the joy associated with this. He was accepted in and comfortable with many groups. He recognized what he had in common with others and saw how their experiences mirrored his values and sense of



Terri-Lee Higgins

purpose. Whether one on one or in a large group, he connected with people and changed lives.

The impact of John's life will live on beyond my years. He will be missed. May the force be with you John. ♦

Message from the EDITOR – Time to Get a MOVE ON!

by Tom Beer

FOR OVER 50 YEARS I have been a teacher. First, as an elementary teacher in Lucan and London, and then, having finished my Arts degree at UWO, I moved to secondary teaching in English and Drama. During my part time courses at UWO, I was the President of the Summer School Students' Association, and got my first taste of producing a newsletter, as well as being a neophyte drama critic for the Summer Theatre at Talbot College.

After I moved to Oakville, in 1982, I continued to teach secondary school, and also, became a faculty member for Sheridan College and the Faculty of Education, University of Toronto. I retired from full time teaching in the mid '90s and made a lateral move to using my marking and editorial skills gained while teaching.

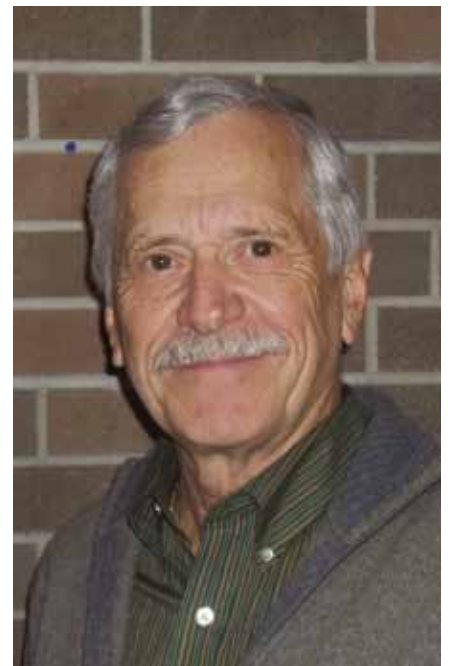
My editorial experience took off as I became the Yearbook editor for The Muskoka Ratepayers Association, and gradually assumed the role of newsletter editor for it and the Three Mile Lake Association.

This summer, I got an e-mail. “Hey, do you want a job?” Knowing who and what I would be working for I said, “Yes.”

The theme of “Community” drives this issue of *Blood Matters*. Take a close look at the levels of involvement—from a cookie sale, to a World Congress; from lives dedicated to treating blood disorders to volunteers who give of themselves every day; from the youth who live and share their stories, to those who work diligently and share with us through their reports- we are all part of a community that cares and shares our truths, our troubles, and our triumphs.

The adage says, “It takes a village to raise a child.” In this issue we glimpse the “global village” that shares our task.

Enjoy. ♦



Tom Beer

Life with JOHN

by: Karen Plater

OUR VERY FIRST DATE in November 1992 was to a benefit for TCOR. When John asked me out he didn't say what type of benefit—just that it was for the Hemophilia Society. I skipped a forestry class to go. After all it sounded important, and I didn't want to miss the opportunity to get to know John Plater better.

What John forgot was that he also had a national teleconference scheduled that night. So when I arrived—in tall black boots, a short black and white checked skirt and black velvet jacket—he was already on the phone. (Apparently it had rung just as he was getting ready to go.) “I'll just be a few minutes,” he said. An hour and a half I sat on his couch, legs crossed, flipping through magazines, watching him talk. Every once in a while he would sit up to make some point or other, and then lean back into the chair, which would squeak in protest. Later I would learn the cross-Canada call was strategizing on the best way to demand an inquiry into the tainted blood scandal.

It wasn't until we were at the door of the Horseshoe Tavern that I realized I was overdressed. But it was in that smoky bar, with a loud rock band whose name I can't remember, that I had my first introduction to the people, the community, the family, that John loved. Little did I know that the next 20 years would be spent waiting for him on hemophilia conference calls and at hemophilia meetings and hanging out with him at hemophilia events.

That's what the Hemophilia Society meant to John. At the time John was already the youngest president of Hemophilia Ontario. But his involvement with the Society had begun long before, as a young boy, accompanying his mother to Hemophilia Ontario Board meetings, often helping serve tea and coffee, and later graduating to counting and destroying the votes. Before becoming a board member of TCOR, and then Hemo Ontario and finally CHS, John had spent hours

listening to people plan programs and make policies. The Hemophilia Society was his introduction to the democratic process and the need for civil engagement.

As a young boy, John participated in many programs designed to improve life for children living with bleeding disorders. He learned to self-infuse at hemophilia-sponsored camps and later, as a counsellor, he would show other young hemophiliacs how they too could gain their independence. He is often recognized as the horse-riding hemophiliac in the video which was used to educate people throughout the '90s and even into the early 2000s; and a puppet bearing his likeness continues to educate children in school about bleeding disorders.

By the time John was taking an active part in the Society's governance, the impact of the tainted blood scandal was taking its toll. John knew it was time to take action and he embroiled himself in the fight for compensation—first for those infected with HIV and then Hep C—and the call for the inquiry. For over two decades John would dedicate his efforts to the safety of the blood system. But he didn't stop there; he took the skills he learned around the board room tables at the Society and applied it to work for all people infected with HIV and Hep C: first on the Ontario Advisory Council on HIV/AIDS (OACHA), then the Ontario Hepatitis C Task force and Federal Ministerial Council on HIV/AIDS. In the most recent years he was glad to watch as many of the young people he had mentored take on leadership positions in TCOR, Hemophilia Ontario and the Canadian Hemophilia Society, and he was always only a phone call away with advice on anything and happy to participate in their programs. I remember staying up late one night with John as he worked on a presentation for the Just the Guys retreat. He was making his presentation witty and funny – as he always did – but also poignant, seeing to the heart of issues that were important to all: how to be normal, what to do when you fell in love and how to achieve what you wanted in life.



John's decision to become a lawyer was in part influenced by his experience fighting for those infected with tainted blood. The hemophilia society introduced him to ARCH – a legal resource centre for persons with disabilities, where he would eventually article as a law student and then work for the first years as a lawyer, before opening his own practice.

But 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 married John on August 7, 1993.

They would often joke that she was also marrying the Hemophilia Society.

Remembering JOHN PLATER

John Plater, One of a Kind

by Ann Harrington, as told to Terri-Lee Higgins

I HAD THE PLEASURE of knowing John very well as both his nurse and his friend. He was an extraordinary man who had a way of looking at really hard situations, teasing them out and presenting them in such a way he could get people to listen. In his short life of 45 years, John contributed a large amount not only to the hemophilia community but also to the community at large.

I fully credit his parents. They are an amazing family who were determined from the start that he would have a strong mind. They allowed him to live his life without limits. Margaret once told me that his body may have its challenges but his mind would be strong, and it was.

He and James Kreppner were a great pair. They were able to present an incredibly difficult situation to the government—they didn't allow themselves to get rattled and they won a huge victory. James told me once that an official told him that they were being unrealistic in their expectations. James lifted his head and responded, "With respect sir, that's just your opinion." In the end they won their case.

At his funeral, I recognized the large number of hemophilia families of all ages which showed the impact John had on people of all ages. He left an incredible legacy as a tremendous role model and mentor for today's youth.

It was my very great privilege to have known John and to have provided care to him. He was one of a kind. 💧





How John Plater CHANGED MY LIFE

by Mike McCarthy

I MET JOHN PLATER in 1994. Like many hemophiliacs, I kept my personal health status to myself for fear of discrimination. One has to remember what it was like to be a hemophiliac in the 1980s when AIDS became a death sentence and those suspected of having it were shunned and avoided. I was very fortunate to dodge the AIDS bullet; however, I was told in the early 1990s that I had hepatitis C.

I wanted to find out more about it and volunteered with SWOR. That was when I first met John Plater. Here was a guy who openly disclosed that he had both HIV and hep C and he acted as though this was normal. He made no bones about it and to me was a pillar of strength because of his attitude. These obstacles were just challenges to overcome and that wasn't going to stand in the way of having a 'life.' For anyone who watched the video of John riding horseback and announcing as he approached the camera that he was a hemophiliac, the image is unforgettable. What courage! He made me feel normal! If he wasn't going to hide from these challenges I decided I

wouldn't either.

That was the beginning of 20 years of friendship that helped me realize that the greatest thing one could do is to stand up for others. John Plater was inseparable from fellow hemophiliac, James Kreppner. Between the two of them they were a force of strength.

John and James showed me the ropes of advocacy. John had a powerful presence and was incredibly effective in advocating for the rights of HIV/HCV infected. But he was no one-trick pony. He was instrumental in getting financial assistance for those infected through the blood system and, that alone, would be an effort of a lifetime. But John didn't stop there. He advocated for a safe blood system, safe blood products, enhanced hemophilia treatment centres and access to improved treat-



John enjoys lunch with his mother, Margaret and wife, Karen

ments and care.

John was successful in moving the yard sticks forward with gains for not only the hemophilia community but also for the general public as well.

John helped craft the MPTAP settlement for individuals infected with HIV through the blood system in Canada. No one would have complained if he had decided to stop with that effort. Instead, he threw himself into supporting efforts to advocate for HCV infected Canadians. He travelled with me many times to Ottawa, Toronto, and across the country to pressure elected officials to 'do the right thing'. Many times the media would interview me and I would give a bombastic interview (I was always the bad cop). John would, then, be interviewed as a voice of more reason (sort of a not so bad cop even

with that blazing red beard!). It was a perfect balance of outrage and reason that ultimately led governments to agree to compensate all tainted blood victims.

John spent thousands of hours of his own time fighting for the rights of others. Behind him was the support of his fantastic wife, Karen, who sacrificed many of those hours that should have been spent with her. Our hemophilia community owes her a great big "thank you" for sharing John with us.

Since John's untimely death, I have given much thought to the gift that he was to all of us and how we might repay the effort that John made for us. I know that John would insist that he did what any other hemophiliac would have done if put into the same position.

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. I call upon our community to pick up John's mantle and get involved. There remain many important issues such as advocating for better access to treatments and care for individuals with hemophilia and other bleeding disorders, protecting a safe blood system, and improving supports for those infected with HCV and HIV. ♦



Hemophilia Ontario News

CELEBRATING OUR VOLUNTEERS

FINANCIAL ASSISTANCE Policy

by David Page

THE GOAL of the Financial Assistance Policy is to provide exceptional financial support to people with bleeding disorders and their families to reduce the burden caused by their condition. To be eligible for financial assistance, these individuals must be members of Hemophilia Ontario or, if not, clients of one of the province's hemophilia treatment centres, and in financial need.

Financial support is generally provided to cover reimbursement of items including, but not limited to, tutoring, dental costs, medication, hospital parking, taxis to hospital, gas to attend clinic, assistive devices (e.g. MedicAlert bracelets, crutches, brace), equipment (e.g. protective helmets), in-hospital costs (e.g. TV, telephone) and other emergency funding. Hemophilia Ontario will pay for the first MedicAlert bracelet, first year of membership and a replacement bracelet if worn out. Lost bracelets are the responsibility of the family except under exceptional circumstances.

Hemophilia Ontario is the payer of last resort and will first of all attempt to have these costs covered by other social agencies including government. When an individual's costs are to be reimbursed by a social agency at a later date, Hemophilia Ontario can enter into an agreement whereby the funds are advanced and then later recovered.

Each year, Hemophilia Ontario allocates a set amount of money for this fund and once these funds are exhausted, no further claims will be processed in that year. For information about the new guidelines or to receive the Financial Assistance Forms to complete and submit with receipts, please contact your local Regional Service Coordinator. ♦

Gloria ALLAIN

by David Neal

GLORIA ALLAIN has been a rock for TCOR when it comes to Bingo. She has volunteered her time at our Bingo sessions at the Delta Downsview Hall in Toronto for almost 10 years and has worked well with the staff at the Hall and with current and new volunteers. She is one of the most dedicated, sweet and caring people that I have come to know, and she volunteers her time because she knows how important the revenue from Bingo is for TCOR. Without Gloria, TCOR would not have received the money it has over the years that has allowed the organization to run its programs, to assist our members and to send our young people to Camp Wanakita. Gloria's contribution to TCOR has been invaluable, and she is a role model for all volunteers within TCOR, Hemophilia Ontario and the Canadian Hemophilia Society. ♦

CWOR Council

by Alex McGillivray

WHEN THINKING about nominating a single volunteer for recognition, it was a very difficult task given that each volunteer contributes so much to this region; that's why the entire CWOR Council is being recognized. Pardon the cliché quote, but every member puts their "blood, sweat, and tears" towards the planning and implementation of the region's programs and services. To Mary Pedersen, Igor Ristevski, Rob Dinsdale, Meagan Bordi, Jace Pedersen and Debbie Bordi, your continued efforts are a great support to your RSC, and her work is made easier by all that you do. Thank you for the value and enthusiasm you bring to this region each and every day. ♦



▲ Lyanne CABRAL

by Alex McGillivray

AS MANY OF YOU may have read in our past edition, Lyanne Cabral was the first recipient of the Shawn Duford Grassroots Leadership Award. However, the reasons why Lyanne won this award were not given.

Lyanne is a mother of two; one is a son with hemophilia. While she prides herself on this job first, she puts her heart and soul into volunteering for the Ottawa and Eastern Ontario Region (OEOR). Each year, Lyanne chaperones the region's Wanakita campers to and from camp, and more recently, she has taken on a role with the regional council and golf committee. During the planning and implementation of the Shawn Duford Golf Tournament, Lyanne spent countless hours organizing sponsor signs, as well as purchasing and putting together all of the prizes for the tournament.

However, it is not just Lyanne's hard work and dedication that make her a great volunteer. In everything that Lyanne does in her volunteer roles, she does them without judgment and with a sense of humour that puts everyone at ease. It is because of these qualities that she has become a valued volunteer to the bleeding disorders community and the recipient of this distinguished award. ♦



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Check out our **NEW** **FACEBOOK** Page!

by Alex McGillivray

OVER THE PAST few months the Hemophilia Ontario staff worked diligently with TCOR volunteer Kristen Luszka on revamping our Facebook page. Some new things our fans can look forward to seeing are daily posts, a fan of the week, a fan of the month, contests, and much, much more!

If you are already a fan, we encourage you to engage with us every day, and if you're not a fan yet, we encourage you to join the community. The new Hemophilia Ontario page was officially launched on November 5, 2012.

We look forward to connecting with you. ♦

Factor Concentrate **WORKING GROUP**

by Matthew Maynard

MATTHEW MAYNARD is representing those who receive factor concentrates in Ontario with the Factor Concentrate Working Group. It is a multidisciplinary advisory group to the Blood Programs Coordinating Office within the Ministry of Health and Long-Term Care. Working with the members of this group from across Ontario ensures community input for the goal of reducing the waste and optimizing the use of factor concentrates in Ontario. Matthew's participation in the advisory group is to develop the utilization practices with benefit from the unique perspective of someone who receives factor concentrates. ♦

THE TIME OF MY LIFE!

by Jordan Cabral

I HAVE BEEN going to Camp Wanakita for about 11 years now, and this year, I returned not as a camper, but as a staff member. Working at Wanakita has been one of the best experiences of my life. This summer, I felt that I had lots to learn, as well as lots to teach. so I took on the role of Assistant Counsellor (AC).

I left home at the end of June for a week of pre-camp training, where I participated in drills and educational sessions, and also became friends with other staff members. After this week, we were all more than prepared for anything.

As an AC, you experience two types of camp. One type is cabins. When I received a cabin, I had one goal in mind, to give them the same amazing experience I had when I was a camper. This is the goal of all of the staff members and you can truly see it by the way they interact with their kids. The other type is programming. Programming is all the stuff that goes on behind the scenes; basically, everything that is needed to ensure campers have the greatest experience of their lives. During my programming, I worked east kitchen. This role saw me helping out the kitchen staff with food prep as well as dishes. Now, I know this doesn't sound like the greatest way to spend the summer, but you truly have to experience it in order to understand that it was the *best* of times. I had a blast! I was partnered with one of my best friends at camp, Stephen Watt, and what a time we had! I learned that camp isn't just about taking care of children in cabins. There is so much more to it, and in order for camp to be amazing, everyone has to work together; and work together we did.

Wanakita is filled with the friendliest and most helpful people. Among the staff, there was no such thing as negativity. We all helped each other when needed. I never felt nervous to ask for help. During my time at camp I became instant friends with all of the staff members and have continued to talk to them throughout the year.

I can truly say it was the best summer of my life. Meeting new people and developing incredible friendships was a daily activity at Wanakita. Although it was a different experience, it was the best experience. I learned that all the staff at Wanakita work very hard throughout the summer to make camp what it truly is: *the place to have the time of your life.* ♦

CAMP WANAKITA 2012

by Alex McGillivray

THIS SUMMER Hemophilia Ontario had 46 campers attend Wanakita with representation from all across the province. In addition, camp was attended by six hemophilia nurses from the provincial Hemophilia Treatment Centres with the goal of educating campers on self-infusion and self-care. Feedback has indicated that it was another successful year at camp. Please stay tuned for information from your local region on registration for 2013. ♦



LEADING at Just the Guys

by Ryan Kleefman

FOR MANY YEARS, I have been involved in the Just The Guys weekend. I started off as a participant, came back as a youth volunteer, and was able to act as Youth Volunteer Coordinator this past September.

First, it is important to understand what “Just the Guys” actually is. This unique event is designed to strengthen the bond between affected boys aged 4–17 and their male role models. It also provides great opportunities for members from different regions to form meaningful connections.

Through educational events, organized activities, and free time (which is often spent playing road hockey), males of all ages form support networks composed of peers their own age as well as those older and younger. These new friends and companions, along with those organizing and running the event, provide valuable insights into what a bleeding disorder is, living with a bleeding disorder, how factor works, how to embrace a bleeding disorder (not just cope), and almost everything else.

This past year, youth volunteers took an active role in education. In the sessions, they spoke about their own experiences and then opened the floor to questions. Often these questions ended up being too plentiful to fit into the question period and spilled over into the following activities. The youth volunteers willingly made themselves available for questions, even giving out e-mail addresses in case there was a need for future contact.

The “Just the Guys” weekend is an excellent example of how and why community is important for those with an inherited bleeding disorder. Diffusion of knowledge, sharing of experiences, asking for and giving advice, formation of a support network, and so many other aspects all illustrate the immense need for community events. ♦

JUST THE GUYS South – CWOR, OEOR, SWOR and TCOR

by Matthew Maynard

AHOY! It was a pirate’s weekend for sure! The theme developed by the Just the Guys planning committee was “infused” into the entire weekend attended by 40 boys ages 4-17 with bleeding disorders and their fathers or other adult male role model. The pirate theme was part of the education sessions, the activities and the fun events of the weekend. Every boy left with his very own customized pirate name.

Ryan Kleefman, youth volunteer, took on a larger role this year in supervising and training the other youth volunteers in their own program over the weekend. The four youth volunteers (including Ryan) did a tremendous job in leading many of the activities and ensured that everyone had fun throughout the weekend. ♦



The JTG group from CWOR, OEOR, SWOR and TCOR



The JTG group from NOR

NOR's Just the Guys Weekend

by Teresa Genereux

NOR HELD ITS FIRST Just the Guys Weekend in September and it was a great success. Although the weather was cold, damp and rainy, it did not stop the boys from having a great time. The weekend started off a little hectic when our group did not receive our original T-shirts for the weekend, but the camp chef came through and donated T-shirts for all of the boys to wear proudly. It was a great surprise that led to many smiles on the faces of all the boys.

The group painted bandanas and enjoyed activities like kayaking, hiking, archery, lots of card playing, and puzzles. They also had a campfire sauna and swim in the rain. Go boys!

Nicole Graham, our physiotherapist, came out and provided the fathers and sons with a very interactive presentation that encouraged them to share their stories. Betty-Ann Paradis, our HTC nurse, also did a presentation on Hemophilia 101 with the group.

I would like to extend a special thank you to Betty-Ann Paradis, Nicole Graham, Stephanie Morrison, and Rob and Michelle from YMCA Camp Falcona for all your help and support in this weekend. ♡

“Hey Teresa, thanks for a great weekend! Michelle and I both really enjoyed working with your group this weekend and we both came away feeling like we took something away from it and would love to continue working with your organization.”

– Rob ♡

Just the Guys – Winnipeg Style

by Matthew Waboose

MY FAVOURITE part of the weekend at “Just the Guys” in Winnipeg was zip-lining at Hy Wire Zip-Lining Adventures. It was really fun because it was a “real rush” going down the side of a mountain. I was the first one to go down on all of the zip-line runs.

There were eight different lines and it took us about an hour and a half to ride them all. There were other fun activities too. I also learned a lot from the education sessions. It was worth the 24 hour van ride. I would love to go zip-lining again one day. ♡

Canadian Hemophilia Society News

Why is CHS Membership Important to You?

by Helene Bourgaize

THE CHS has been working to improve the health and quality of life of people with inherited bleeding disorders since its founding in 1953. The organization will celebrate 60 years in 2013. The national organization and its chapters in each province have worked closely with healthcare professionals to make available the best care possible in all clinics across the country. The CHS has been instrumental over the past two decades in making sure that people with bleeding disorders have access to the most advanced clotting factor concentrates.

In addition, the CHS invests close to half a million dollars each year in Canadian research to improve care and find a cure.

The Ontario Chapter offers many local programs and services. These include summer camps for children with bleeding disorders, youth activities, educational events to learn the latest in care and treatment, resources on aging with hemophilia, orthopedic options and peer support, to name only a few.

Only by being a member will you be sure to know about the programs and services offered by the CHS and its chapters and be able to take advantage of them.

What is the cost of membership? Membership is entirely free.

What are the privileges of membership? As a member, you have a **vote and role** to play in both your chapter and national organizations. We believe a strong Ontario Chapter with a large membership is important to the future of care and treatment in Ontario. We also believe the CHS can be a valuable source of information and support for you and your family.

Please contact your Regional Service Coordinator or the CHS National office at chs@hemophilia.ca to obtain a membership registration form. ♡

CHS Survey on Novel Factor VIII and IX Products Extended

HEALTHPULSE is an independent market research organization located in Toronto. They have been involved in working with hemophilia patients for a number of years having most recently partnered with the Canadian Hemophilia Society (CHS) to conduct patient research. The survey is aimed at improving the lives of patients through a better understanding of their needs regarding new Factor development. The principals at HealthPulse support the activities of the CHS to better patient lives.

CHS is conducting this survey with the help of HealthPulse. At the end of the survey, you are required to provide your name and contact information

to HealthPulse. This is so that 1) HealthPulse can follow up with you for clarification, if necessary; and 2) HealthPulse can contact you to invite you to participate in future market research of its own or in collaboration with the CHS. Your personal information remains confidential at all times and will not be shared with others.

At this time, this survey requires more responses from people with hemophilia B. Factor IX products may be first on the market. Please consider completing the questionnaire and be assured your answers will remain confidential.

To participate in the survey, please visit the following website: www.fluidsurveys.com/s/CHS276EN/ ♦



Photo credit: BigStockPhoto.com/28707464

CHS & AGING Working Group

by Matthew Maynard

THE CHS & AGING Working Group is a multidisciplinary team working across the country to improve the quality of life of people with bleeding disorders as they age. I have participated in this working group since it started and have shared my ideas and perspectives on the issues of aging with a bleeding disorder. A survey of the Hemophilia Treatment Centres was done and followed up with a focus group during the 2011 CHS Rendezvous in Calgary. The purpose was to lead to the development of programs and resources which address the issues around aging. There is a personal benefit of being involved in your community: when it stretches across the country, everyone has diverse ideas and solutions; when it is across many disciplines we gain much broader knowledge and understanding than would be otherwise possible; and our network grows as we build great relationships with those we assist and those who offer their help. ♦



Youth representatives from across the country

CHS NATIONAL YOUTH WORKSHOP

by Jeenetha Kulasingam

Mojtaba Khezry's Perspective...

THE DELTA MEADOWVALE in Mississauga, Ontario was brimming with young adults with inherited bleeding disorders and professionals that work with these individuals on the weekend of Sept 7, 2012. Mojtaba Khezry, was one of the many keen members that attended.

He states that the two day workshop primarily focused on advocacy; advocating in the ER, advocating for factor supply, and advocating for insurance coverage. One of the things he appreciated was learning about the priority zones for an individual

with a bleeding disorder in the triage, and if he ever found himself placed in a situation where he had to see a triage nurse, he will now make sure to be in the yellow zone at the least.

He valued learning how to advocate for himself while in the emergency room or in any emergency situation, in general, to receive optimal care. When it comes to advocating for factor supply, it couldn't be stressed enough how important this was. Due to the provincial cutbacks in health-care and the expense of factor these days, it's important to advocate for continuous supply and to make sure that the government does not stop the supply of factor in prophylactic regimens.

Lastly, the workshop taught young

individuals to be aware of, to encourage and to promote insurance coverage when travelling outside of Canada and to be aware of the laws that exist when travelling outside of Ontario. Mojtaba also enjoyed the "Knowing our Rights Presentation." "It's helpful to understand your rights regarding accessing your medical file and records and rights regarding getting involved in clinical trials," says Mojtaba.

The conference also allowed him to spend quality time with his fellow "bleeders." He learned so much in two days and enjoyed reconnecting with familiar faces; he recommends this workshop for any youth wanting to attend in the future. ♦

World Congress Report

by Terri-Lee Higgins

With contributions from Michelle Lepera, Julia Lepera, Holly Valenta, Ryan Kleefman and Raja Alami

HEMOPHILIA ONTARIO and the province of Ontario were well represented at the World Federation of Hemophilia's World Congress in Paris, France from July 8 – 12, 2012. The largest meeting of the global bleeding disorders community, there were over 5,000 delegates from 130 countries. The provincial medical community was well represented through the attendance of both adult and pediatric hematologists, clinic nurses, laboratory technicians and the Hemophilia Provincial Coordinator. Our members were well represented through the attendance of Raja Alami (OEOR), Paul Wilton (Hemophilia Ontario), Terri-Lee Higgins (Executive Director), Ryan Kleefman (CHS Khartik Shaw Award), Michelle Lepera/Julia Lepera and Holly Valenta, all sponsored by SWOR. Also in attendance were Marion and Eric Stolte and Pam Wilton, active in the World Federation.

WFH strives to teach people skills and knowledge that will motivate individuals with bleeding disorders and their caregivers to take steps to improve their own lives through education and the resulting better choices. The reality is that approximately 75 percent of people with inherited bleeding disorders around the world still receive inadequate treatment or no treatment at all. The World Congress provides access to numerous topics, and one is challenged to select one topic over another as sessions run concurrently. The seminars at WFH challenged our basic assumptions about life, helping, achieving and succeeding. Leading experts shared the latest in scientific research, prevention and treatment strategies. Organizations and members shared the successes



L to R: Holly Valenta, Ryan Kleefman, Maureen Schaus, Terri-Lee Higgins, Alicia Brard, Julia Lepera, Michelle Lepera at World Congress in Paris, France

and challenges they have or have yet to overcome. New networks are established and existing strengthened.

Below is an overview of the key learning from the Ontario reps:

- We need to continue to empower members to share ideas, convey messages and support all through advocacy.
- Every person with hemophilia grows up in a unique environment within his community, and culture and ethnicity makes it more complex. A strong message was received, "A bleeding disorder is just one aspect of your life, don't let it take over who you are." Cultural issues can lead to delay in diagnosis; the assumptions we make of other cultures are where barriers to care arise.
- Many countries remain without optimal care and a priority should be to improve the level of care that those affected by bleeding disorders receive in less wealthy or developing countries; for example, hemophilia in countries such as India is harder to manage as caregivers often lack information on how to handle the child and manage the disorder.
- There were many positive and courageous women, all role models. A woman from Latvia was actually told by the doctors in her country that she does *not* have a bleeding disorder, and yet she did. So she has set out to make a difference in the bleeding disorder community and is the beginning of a new generation. These women and women all over the world are the reason I want to make a difference, starting in Canada.
- As a caregiver and parent watching bleed after bleed, I didn't recognize the seriousness of a bleed in the joint. The accumulating effect of the bleed residue on the cartilage shocked me and reinforced the importance of the patient's awareness, empowerment, and the allowing of help when things go wrong. Preparation doesn't include only having a stock of factor at home and applying prophylaxis treatment.
- The chance of joint damage increases with age. If a person is overweight before 40 years of age, they have a lifetime risk of arthritis.
- Management of hepatitis C in hemophilia patients (though not infected with HIV) must be addressed more openly.
- Identified common symptoms such as auto-immune disorder, chronic fatigue and depression

and noted that antiviral treatment has evolved rapidly. The new Triple therapy (interferon, ribavirin and protease inhibitors) has been approved recently and the results of clinical trials show a clear added benefit in terms of sustained virologic response in patients without previous clinical trials. This is considered a step forward for patients with hepatitis C.

- Oral health – 53 percent of populations with medical conditions report problems with their mouth. Younger persons with hemophilia are demonstrating poorer dental oral health resulting in quality of life changes (pain, chewing issues). Dentists can be afraid to treat persons with bleeding disorders. Environmental factors in the mouth change with age.
- E Communications: Benefits and Pitfalls focused on ways to get the word out about bleeding disorders, using the internet. An e-patient has an active role in their treatment; they can deal with information, partner in their health care and participate in their medicine. *But of course*, there are

some risks with patients using the internet because they could look for advice without checking the source and date on the information they find and it could be wrong.

- Good patient records help identify target joints—every bleed needs to be treated adequately. Personalized treatment plans based on pharmacokinetic analysis may improve protection from bleeding beyond that provided by standardized prophylaxis.
- Inhibitors are becoming more and more predictable and may one day be completely prevented.
- Gene therapy at this time is primarily being tried for hemophilia B with the gene transfer converting a severe hemophiliac to a mild one. Similar trials for hemophilia A are to be commenced within three to five years.
- Long lasting product clinical studies have begun and are based on recombinant technology with no virus concerns. The idea of infusing once a week is almost a cure.
- Drugs don't work in people who don't take them. 30-60 percent

of prescribed regimens are not followed. Poor adherence leads to disease progression, complications, reduced function and quality of life and sometimes death. Medical staff must identify patients' reasons behind non-adherence (fear, complexity of regimen, poor understanding of risks and benefits of adherence, time constraints), elicit their feelings, and design supports accordingly, providing clear and simple instructions.

Empowerment is a process that challenges our assumptions about the way things are and what can be. It is the goal we strive toward in our educational programs whether for volunteers, caregivers or members. Hemophilia Ontario is committed to ensuring our members have access to the care and supports they need to live the life they choose.

We would like to express our sincere thanks to Hemophilia Ontario, SWOR and the CHS for the privilege of representing our community. ♦

INVINCIBLE

by Terri-Lee Higgins

I HAVE BEEN GIFTED with the experience of learning from people of all walks of life, ages, cultures, levels of ability and varied communities. By definition community is a group or society helping each other. Hemophilia Ontario is such a community and I consider myself fortunate to have been welcomed and included. Those that know me, recognize that I learn by asking questions and listening to the answers, gathering information, and through experience. I cannot grasp what I have not experienced or learned, thus, I rely on this learning to help me better understand new areas. This article is my perspective of a branch from the learning tree I continue to climb and I welcome your feedback.

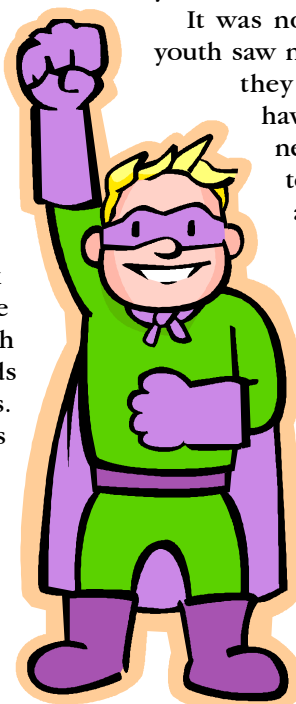
No matter where I travel, I hear a consistent concern—many young

people don't see the need to complete and track infusion and bleed diaries. One of the youth told me that because I don't self-infuse I can't understand what a pain in the butt it is to maintain those diaries. They don't always want to infuse and to be honest sometimes they don't, but most do when they think they need to. When done they just want to get on with life, get with their friends and back to doing things. Tracking the details isn't as important.

I asked these same youth, "What if recording everything helped you and your HTC team to identify a new bleed issue? What if always treating every bleed and tracking

these details made a difference in your future health? What if it saved your life?"

It was not surprising that most youth saw no reason for concern—they are healthy now, they have their factor when they need it and the future is too far off to really worry about. At a recent conference, a patient said "Not treating a bleed can significantly impact your quality of life for the rest of your life." This man is in his early 40s and facing multiple joint replacement, walks with two canes and uses a wheelchair for longer mobility needs. He chose which bleeds he treated, which he didn't. He didn't al-



ways tell his medical support team accurate information and admitted that, at times, he made things up so he didn't get in trouble. His quality of life is not what he wants or what he ever thought he would face—he never thought he was anything less than invincible.

With advances in care, enhanced factor life and access to world class care, younger persons with inherited bleeding disorders may not yet have experienced a bleed. Many say they probably wouldn't know if they had a bleed and thus wouldn't take the time to infuse—what if it's nothing? Having heard the man speak, my response would be “What if it's something? What if making time to infuse and letting your clinic know made a difference in how you recovered *and* what you could do physically even one year from now?”

Every time a person experiences a bleed, a small amount of blood dries in the area, beginning the deterioration of the joint. With each bleed, the damage to the area continues. After a few bleeds in the same area, the joint becomes more unstable and is easily re-injured usually resulting in a target joint. Even with factor and physiotherapy, this can become a life changing situation.

There is no pat answer and the youth are right—I don't self infuse so maybe I don't “get it” from that perspective. What I do understand are the wishes of those individuals who didn't have the chance to live with available factor products. They suffered the devastating pain and the debilitating body and mobility changes that brought them to their life today, living with the complications many wish they had the choice to avoid.

When I think about everything in my life, the many challenges and amazing opportunities, I know that I have not always made the best or the right choices and decisions and that my life is a direct result of them based on the information I had at the time. At this point I can honestly say I don't think I would change a thing. What about you—it's your life, how do you choose to live it? ♦

Our Global Community: WORKING TOGETHER to Close the Gap



by Sarah Ford, Communications Manager, World Federation of Hemophilia

SINCE ITS FOUNDING in 1963, the World Federation of Hemophilia (WFH) has made remarkable progress in improving care for people with bleeding disorders. However, 75 percent of people with a bleeding disorder still do not receive adequate care or any care at all. In many of the poorest regions of the world, people remain undiagnosed and untreated.

To mark its 50th anniversary, the WFH has launched a three-year campaign to close the gap in care. “As a person with hemophilia born at a time when there was little known about the disease, I have lived through pain and the fear of the unknown,” says WFH patron Jan Willem André de la Porte. “But now I know that pain is not inevitable. There is hope. With the right foundation of basic care, sustainable development is achievable.”

André de la Porte announced a challenge grant to the entire bleeding disorders community during the Opening Ceremony of the WFH 2012 World Congress—every dollar donated to the campaign will be matched 2:1. “I am pledging half a million dollars—but alone it is not enough. We must all help. I hope that my personal pledge will inspire our community to give generously so that together we can close the gap in care and achieve our vision of Treatment for All.”

Contributions to the WFH “Close the Gap” campaign can be made online at www.wfh.org/closethegap. ♦

CWOR

Central Western Ontario Region

THE BIG SALE on the Little Street

by Mary Pedersen

WHILE OUR ORIGINAL day of Saturday, September 8 was rained out, the Big Sale on the Little Street eventually took place on September 22, with much success. With the help of Bob, William, Oliver and Robin we began the day with setting up tents and tables.

I would like to thank Rob and Jane Dinsdale and Igor Ristevski for volunteering their time to help with the sale. Thanks to Dane Pedersen for lending extra tents and tables from the SuperCrawl event. Thanks to all who donated goods, especially Lesia and Jack for their contributions, and for coming out in the pouring rain on the 8th.

While we did not sell everything, I am happy to report that some of the leftover goods were given to Value Village to be used towards the Canadian Diabetes Donation Campaign. I'm even happier to report that we raised \$800.

This fundraiser would not have been possible without all of the volunteers mentioned above, as well as Debbie and Paul Bordi and Alex and Tyler McGillivray. Thank you all for your support ♦





Our First SUPERCRAWL Booth

CWOR WAS ABLE to represent the bleeding disorders community through the opportunity of setting up a booth at Hamilton's SuperCrawl Festival—Ontario's largest art festival with upwards of 50,000 people in attendance.

This year, CWOR volunteers Mary Pedersen, Rob Dinsdale, Igor Ristevski, and Meagan and Debbie Bordi shared their personal stories and educated the public about bleeding disorders.

Our goal was to raise funds for programs and services in the region, and while we raised some money, something more important occurred. While educating the public, we experienced a mission moment. One of the visitors to our booth was actually looking for information about how to get tested for a bleeding disorder and where they could learn more about it. They have since been connected with the local Hemophilia Treatment Centre.

It is at community opportunities like SuperCrawl where the volunteers work towards our mission that the heart of this organization is actually seen and felt. ♦

Regional Board/Council and Staff

Rob Dinsdale, Mary Pedersen
Jace Pedersen, Igor Ristevski
Debbie Bordi, Meagan Bordi

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LIAM BARBOUR Scholarship Award

THE CENTRAL WESTERN REGION of Hemophilia Ontario (CWOR) is proud to present the Liam Barbour Scholarship Award, made possible through the generosity of the Barbour Family. The Liam Barbour Scholarship Award will offer a \$500 award to any affected member for their first year of post-secondary education. This amount is to be evaluated on an annual basis, and based on the amount of funds raised by the Liam Barbour Charity Golf Classic.

Scholarship Requirements

To qualify for this award, the applicant must reside in the Central Western Ontario Region, be an active member of CWOR, and have a bleeding disorder.

The applicant must provide proof of their enrolment at a post secondary institution to CWOR.

CWOR has been empowered with the selection of the award on an annual basis. The award will be paid in/around the first week of October of the first year the student is enrolled in post secondary education.

The deadline for receipt of scholarship applications is August 1, 2013. Faxed or late applications will not be accepted. For more information or to obtain a Liam Barbour Scholarship Award application, please contact Alex McGillivray, Regional Service Coordinator. Applications can be mailed to Hemophilia Ontario CWOR, 10 George Street, 4th floor, Office 19, Hamilton, ON L8P 1C8 ♦

Save the Date – Annual Holiday and Wanakita Registration Party

SAVE THE DATE of Saturday, December 8, 2012 for CWOR's Annual Holiday and Camp Wanakita Registration Party. The program will take place at Stoney Creek United Church, 1 King Street West, Stoney Creek. We will have a pot luck lunch with lots of fun activities, and, of course, all participants will have the chance to register for Camp Wanakita in person.

Keep your eyes peeled for our flyer in the mail. We hope to see you there. ♦

Get Involved: Join us at our Community Meetings

CWOR IS ALWAYS LOOKING for new volunteers and fresh ideas. We encourage you and your family to come out and join us at our monthly meetings to share your ideas on how we can serve you better. For more information on our current list of programs, please contact Alex McGillivray, Regional Service Coordinator at 905-522-2545 or amcgillivray@hemophilia.on.ca. ♦



All articles in this section, unless otherwise indicated, are by Alex McGillivray.

DATE	WHAT AND WHERE?	Events Calendar
December 8	Annual Holiday and Camp Wanakita Registration Party Stoney Creek United Church	
January 19	Winter Walk Christie's Conservation Area	
March 1	Regional General Meeting Location TBD	

Northern Ontario Region

All articles in this section, unless otherwise indicated, are by Teresa Genereux.

WAYLON'S WORLD of Tai Chi

by Bobbi Rushton

WAYLON IS A BRIGHT, friendly, ginger-haired 8-year-old. He has severe hemophilia A with no family history of hemophilia. Like most boys his age, he enjoys movies, shows and games that involve martial arts and some sort of battle. Waylon has taken this a step or two further. He is intensely interested in martial arts movies, Chinese culture, and even Buddhism. It all started a year ago when Waylon, then 7, and his brother Eamonn, then nearly 5, watched the movie *Avatar: The Last Airbender*. In the movie, the hero meditates and battles his enemies without contact, using controlled movements to summon the elements of air, fire, water and earth. What a revelation for a boy who is becoming aware of the dangers of roughhousing! The movements in the movie are similar to tai chi, so he and I enrolled in tai chi classes with the local chapter of the Taoist Tai Chi Society. They were surprised that someone so young would be interested in such an activity, but did not turn us away. We were told that Waylon was the youngest who has ever joined their chapter. There were no other children, but we attended every week and learned all the 108 foundation moves, and practiced at home too. The two-hour classes didn't start until 7:00pm (bedtime is normally 7:30pm) so quite often we only stayed until tea time halfway through. Even though we have been practicing for almost a year, Waylon's youthful presence is still quite a novelty.

This year, Waylon attended Camp Wanakita for two weeks. The drive from the Sault is far enough to warrant an overnight stay, so Waylon and I opted to stay overnight in

Orangeville where the International Tai Chi Centre is located. I thought it would be nice for us to see some advanced tai chi, and learn more about the practice. When we got there, we learned that the Centre in Orangeville is the centre of the universe for tai chi enthusiasts!

We arrived at the entrance which is "guarded" by two enormous white lion statues. When Waylon saw this, his jaw dropped and his face just lit up as if to say "I'm home!" The long driveway took us past several more statues, each of which got Waylon increasingly more excited. After registering, we took a walk through the extensive grounds. There are practice buildings for classes and workshops, a Buddhist temple, paths, groves, a large pond with fish jumping, and more statues. As we walked around, Waylon spotted a tree-shaded area and announced, "Mom, that is the perfect place to meditate. Will you wait while I go get centred? You can take a picture if you want but don't disturb me, OK?" Seriously, this boy is truly one of a kind.

Everywhere we went, there were people from different parts of the world. We had dinner and breakfast there, prepared and served by volunteers from around the world. In that short time we met people from Scotland, Spain, New Zealand, Netherlands, Germany, Australia, plus Vancouver and Montreal. Tai chi brings people together in much the same way music does, but here the common language is the tai chi movements. After supper, we were invited to watch a "sword set," a "sabre set," and a Lok Hup set. These are advanced moves which Waylon found very exciting. The resident chief took



Waylon Rushon

a particular interest in Waylon as he tried to copy the sword moves. The chief later pulled out a futon-type mat and showed Waylon some tumbling type tai chi moves. It was pretty difficult to top that!

At breakfast the following morning, we learned that 40 "youth" from around the globe were expected to arrive for a week-long workshop. Youth week at the tai chi centre means anyone of any age and some were expected to be as young as 16 years old. We still think Waylon is the youngest member to date though. Further, another 650 people from around the globe would be attending instructor training during the same week. Each of these people pay their way to get to Orangeville, volunteer while at the centre when they are not in workshops (doing dishes, laundry, cleaning, weeding, painting and anything else that needs doing) and when they return to their homes they volunteer their time and expertise to teach tai chi in their local chapters. The element of service to others is pervasive through all of the philosophy of the Taoist Tai Chi

Regional Board/Council and Staff

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Society. For the past year, when asked what he wants to be when he grows up, Waylon has responded "I want to be a Tai Chi Master and a chief in China." Well, Waylon has finally met a large number of people who neither laughed or looked at him like he had three heads. In fact, he met people other than his family who said, "I'm sure you'll make a fine Tai Chi Master and chief in China one day."

I have a feeling that the journey to Camp Wanakita each year will involve a stopover at the International Tai Chi Centre. If you ever run into Waylon, ask him to show you a few of his favourite moves. ♦

Thunder Bay Auxiliary Donation

by Susan Turner

HEMOPHILIA ONTARIO was the recipient of a generous donation from the Thunder Bay Hemophilia Auxiliary. This group was formed in the mid-60s by the late John Petrick. The fund was built primarily through donations from the relatives and friends of the Petrick family.

The group is no longer active as the tainted blood tragedy took a large toll on this family and left few behind to continue the work of the group. The \$28,387.00 was donated to Hemophilia Ontario with the wish that it be used to directly assist individuals and families affected by bleeding disorders living in Northern Ontario, especially in the Thunder Bay Region, for educational and transportation assistance. The second wish is that a portion of the funds be applied to the future Twinning Project by the Canadian Hemophilia Society at the Ontario level.

Thank you from Hemophilia Ontario to the Petrick family of Thunder Bay for your generous donation to help those living in Northern Ontario. ♦

Third-Party Fundraising Made to Look Easy

OVER THE PAST FEW YEARS, Alana Brassard from Sault Ste. Marie Ontario and her family have done many third-party fundraising events for NOR. Alana has always made it look so easy. Here is a short write up of what she did this summer. Thanks so much Alana. You are so appreciated!

"We had a family garage sale today. While I was planning this I was trying to think up ways to keep the kids busy. Finally we decided to have them sell cookies with the proceeds going to Hemophilia NOR. Our goal was to sell 100 cookies. I over shot and made about 125, however this was not enough. Not only did we sell 100 cookies, we ran out an hour before the garage sale was over. I am happy to say that we raised \$165! We did not set a price on our cookies and simply asked for a donation of any amount. I've attached a photo of Sebastien selling the goods." ♦



Clinics:

- Thunder Bay held its clinic October 1 and 2, 2013

Reminder to NOR Clients

I have relocated to Red Lake, ON. I am always available for your questions or concerns. My new contact information is:

302 Howey St. Box 418 Red Lake, ON, P0V 2M0
 Toll free #: 1 866 545-1647
 Fax #: 1 888 958-0307
 E-mail: tgenreux@hemophilia.on.ca ♦

DATE	WHAT AND WHERE?	Events Calendar
December	Thunder Bay Christmas and Bowling Party Date and time TBA	
December	School Presentation on VWD Date and time TBA	

Ottawa and Eastern Ontario Region

18th Annual Shawn Duford GOLF TOURNAMENT

by Alex McGillivray

2012 MARKED the 18th year of the Annual Shawn Duford Golf Tournament for OEOR. The tournament was held on August 11 at the beautiful Meadows Golf and Country Club. While the day was grey, and the participants experienced a few torrential downpours, the tournament was an amazing event raising \$8,000 for programs and services in the Ottawa and Eastern Ontario region.

Highlights of the day included our police patrol, comprised of youth volunteer Cameron MacNeil, and volunteer Tyler McGillivray. Their charges to golfers were very creative and unique. The golfers that return next year will probably think twice before taking a swing.

Thanks are extended to the OEOR Golf Committee for their support and efforts to put this wonderful event together; in particular, Steve Van Dusen, Ash Kurrich, Jennifer Van Noort, Bruce Myers, Lyanne Cabral, Bruce Duford, Dawn MacNeil, Nancy Sauvé and Darlene Villeneuve.

Without the support and efforts of the golf committee and volunteers, this event would not be possible. Neither would it be possible without the support of our generous donors. Thanks to all of the hole sponsors, as well as Rexall, Pfizer and CSL Behring for their contributions.

We look forward to seeing everyone again next year. ♦

Regional Board/Council and Staff

Raja Ammoury-Alami
Jordan Cabral
Lyanne Cabral
Ashwani Kurrichh
Nancy Sauvé
Brian Van Dusen
Steve Van Dusen
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OEOR

South Western Ontario Region

Summer CELEBRATION

HILARY AND STEVE Kusterman of Kustermans' Blueberry Farm, hosted our summer celebration and BBQ this year. What a great event as children, parents and grandparents participated from all corners of the region—from Windsor, Goderich, Woodstock and St. Thomas. Of all the activities and food, the favourite was definitely the sand pile!

We hope you have a chance to visit the Kustermans' Berry Farm (<http://berryblue.org>) during their annual fall festival. Thanks to Kathleen for her help organizing and during the event, to Marco our burger and hot dog grill master, everyone that joined us, and especially the Kustermans for their hospitality. ♦



Sandpile fun

All articles in this section, unless otherwise indicated, are by Matthew Maynard.

Regional Board/Council and Staff

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Kathleen Hazelwood
Travis Hazelwood
Ryan Kleefman
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SWOR

Pinecrest ADVENTURES Camp

by Nick Higgins, Director

THE 20TH ANNIVERSARY of Pinecrest camp was celebrated with the theme of “Blast from the Past.” The theme had campers travelling back through time and having to work to get back to the future so that we could all go home on Sunday. It’s hard to imagine, but somehow Pinecrest manages to get better every year in large part due to our volunteer staff’s preparation and dedication. The staff not only gave up their time that week, but also put countless hours in before camp. A big thank you is owed to all the staff. Also, I want to thank the medical staff for continuing to dedicate a week to come to camp and helping to ensure that the camp will happen. Lastly, I want to thank the campers who are great fun and the main reason why I return year after year to Pinecrest. It is great watching them grow up and I hope they all continue to come to camp and consider becoming staff when they are of age. ♦



Barry Haarde – WHEELS FOR THE WORLD

ON JULY 27 in London, ON, Matthew Maynard met up with Barry Haarde who was biking across America for Save One Life! Barry is the first person with hemophilia, HIV and hepatitis C to ride across North America on a bicycle. His ride began in Oregon and finished in New Hampshire, USA. From London, Barry continued his ride to Brantford, then to Niagara Falls, NY.

Barry has severe hemophilia A and is a 30+ year survivor of HIV and hepatitis C, contracted through tainted blood products. Barry, with his training, prophylactic treatment and a lot of support, raised awareness and funds for hemophilia through his ride across America.

Visit Barry’s Facebook page to see the results of this remarkable achievement, or read about his stop in London on the following websites: www.londoncommunitynews.com/2012/07/a-survivors-celebration/ and www.thelondoner.ca/2012/08/15/a-tale-of-two-advocates ♦



Barry and Matthew

2012 Commemorative TREE PLANTING

SWOR CONTINUES to build the forest of trees planted in the region to commemorate the tainted blood tragedy. This year our ceremony was held during the Just the Guys Weekend at the YMCA Outdoor Centre, host of Just the Guys for the last 10 years. The ceremony was planned by Ryan Kleefman, Youth Volunteer and SWOR Council Member.

The tainted blood tragedy has impacted the families and communities of the province in many ways. The ceremony focused on its impact from the perspectives of the grandfathers, fathers, sons and future generations. Participants during the weekend were invited to play each of these roles and present their unique perspectives of the tainted blood tragedy. It was a moving ceremony with the full participation of everyone attending.

“I also want to thank you for the opportunity to be part of such a special event and play a role in the tree ceremony. I never realized how much this would mean to me, knowing that my father-in-law has hep C, until I was put in that position. It really bit home and I am grateful...”

– Ceremony Presenter ♦



Commemorative Tree Planting and JTG Noah



Fifth Annual GOLF TOURNAMENT

by Travis Hazelwood

THE BIG DAY! September 28, 2012, Matthew, Terri-Lee and I all met at Bear Creek at 10:00am with Matthew's Honda Element and my Dodge Caravan nearly bursting at the seams with everything required to make the day a success. Our day started several hours earlier in preparation for the tournament. Lynda, Chris, Judy, Rosemary, Kathleen and Ryan arrived later that morning to help set up. This was a much needed boost as golfers started arriving as early as 11:00am to register.

I watched as our dedicated volunteers went from set up to full blown registration in the blink of an eye. Truly astounding! To be quite honest, the entire morning for me was a complete blur, and while I can't remember the exact details that transpired, I know I was running around getting questions answered, communicating my appreciation to the golfers for attending, and dealing with a variety of other administrative duties. By 12:30pm I was attempting to switch into participant mode, which was difficult, let me tell you!

We had a shotgun start for the first time in five years and it went extremely well. I was so pleased to see a sponsor at all 18 holes which has never been done in our tournament's five year existence. This speaks volumes to the diligent work of Fred, Lynda, Chris, Charlie and Matthew—our Golf Committee. It was a perfect fall day for a round of golf.

The evening went smoothly as Terri-Lee prepared to be our emcee after charging the golfers like Robocop on steroids as our police patrol. I could tell the entire room was getting a bit hungry as we waited for a few stragglers, but Terri-Lee kept the evening going so that everyone could head home at a reasonable time. The day was busy, and at times stressful, but in the end it was a fantastic day. SWOR raised \$8,000.

Thanks to our volunteers, planning committee, sponsors, donors, supporters and golfers for making this a great event and for making a difference in South Western Ontario. ♦

Answers to Crossword Puzzle on back cover

Across

3. Canadian Hemophilia Society
4. Royal
5. Human Immunodeficiency Virus
7. Carriers
8. Nine

Down

1. Christmas
2. Hemophilia Treatment Centre
3. Hemophilia A
4. von Willebrand Disease

Toronto and Central Ontario Region

Two Outs with ONE PITCH

Families in Touch/Wanakita Registration Party is Coming

by Jeenetha Kulasingam

ON DECEMBER 8, get ready for a double dose of TCOR fun as we combine our Families in Touch program with our second annual Holiday/Wanakita Registration Party at the **Black Creek Pioneer Village**. As both events were particularly successful last year, and both events drew in our amazing TCOR kids, we thought it was only fitting to combine the two.

Parents will have the opportunity to participate in yet another inspiring Passport to Wellbeing educational session. New families can come out and learn about the provincial bleeding disorders program at Camp Wanakita. All families will have the opportunity to register in person for Wanakita early in the game and receive all necessary documents to complete the registration. Lastly, kids and adults will have the opportunity to explore like a pioneer by churning butter, baking in a woodstove oven, weaving on a gigantic weave ball and much more.

Watch for our flyer with all the information to register. ♦

Regional Board/Council and Staff

David Neal, Maury Drutz
Mike Beck, Mojtaba Khezry
Samuel Leon, Kristen Luszka
Victoria Kinniburgh, Kiran Gopie

Staff

Susan Turner, Executive Assistant/Bookkeeper
Jeenetha Kulasingam, Regional Service Coordinator
Sarah Wood, Regional Service Coordinator

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TCOR

How to WALK A MILE IN MY SHOES in Three Minutes

by Kristen Luszka

SEEMS IMPOSSIBLE, doesn't it? We've all heard the saying, "You'll never truly understand someone until you've walked a mile in their shoes." When asked to join the Speaker's Bureau for Healthpartners, I was tasked with doing just that, helping my audience walk a mile in my shoes...and in just three short minutes.

I was diagnosed with Von Willebrand's Disease, Type 2. Because my sister and mother are also affected, I was diagnosed at an early age. For us, it was our normal; we were and still are a team. As you can imagine, over the years, we've experienced many challenges along the way. It's those experiences that led me to volunteer both for Hemophilia Ontario and Healthpartners – I wanted to make sure that every person affected by a bleeding disorder also had a "team." With the support of our volunteers, programs and donations, we are able to achieve this.

Which brings me back to the challenge of "walking a mile in my shoes in three minutes." As a member of the Speaker's Bureau, I was tasked with writing and delivering a speech to encourage donations to Hemophilia Ontario. In just three short minutes, I had to somehow share my entire life story and hope that my audience truly understood the value they would bring to our community. Seems daunting doesn't it? Surprisingly, it wasn't as hard as I thought.

I was fortunate to have had the opportunity to attend a speaker's training session, held by a member of Healthpartners. He said it brilliantly, "You're not listing facts, you're telling a story about a real person." Suddenly the burden was lifted; all I had to do was tell my story—the same story I told you. It's simply, "I have vWD, I have a team and I want everyone else to have a team too." Based on those three points, I created my personal and compelling story—in three minutes. Who would have thought?

For those who want to help to continue to build our support "team," consider joining the Speaker's Bureau for Healthpartners. It's been a rewarding experience for me and I hope it will be for you as well. For more info contact Hemophilia Ontario. ♦



Photo credit: BigStockPhoto.com/27170942

TCOR

Annual TCOR GOLF CLASSIC

by Susan Turner

THE 13TH EDITION of TCOR's Hemophilia Golf Classic took place on September 14, 2012 at Nobleton Lakes Golf Club. Despite Mother Nature's best efforts, an enthusiastic group of 44 golfers came out to support the programs and services of TCOR.

After a shortened day of golf because of the heavy rain, the group gathered for a dinner, auction and presentation of golfing awards. The lowest score of the day was 32 with two teams in a tie. The foursome of Randy Neal, Ivan Leong, Stephen May and Bob Gibson, along with the foursome of Stephen Polley, Steve Hartman, Jeff Collins and Jack Woods were recognized as the best golfers of the day. A special prize was awarded to our most honest group of the day—Darryl Gray, Jeff Kinniburgh and Kathy Stranks.

Special thanks to Amy Griffith, a youth member from the TCOR community, who spoke to the group about how TCOR has provided her and her family with the opportunity to attend many educational programs. Amy also spoke of her years as a camper at Camp Wanakita and how she eventually became a counselor, and the impact this had on her life.

Thank you to our Golf Committee: David Neal (co-chair), Maury Drutz (co-chair), Mike Beck, Gerry Mudge, Don Tucker and Darryl Gray. Many thanks to our dedicated team of tournament volunteers who ensured the day ran smoothly: James Beckwith, Samuel Leon and Nancy Melcher.

Special thanks to David Goodman who donated his time and effort to run the "Beat the Pro" contest and also to Darryl Gray who filled in at the last minute as our emcee.

TCOR staff, board and golf committee members would like to thank all who came out and helped to make the day a true success. The 2012 Hemophilia Golf Classic raised more than \$12,000 to support programs and services for the TCOR community

Thank you to our sponsors. ♦

DATE	WHAT AND WHERE?	Events Calendar
December 9	Families in Touch/Camp Wanakita Registration/Holiday Party	
February	TCOR Aging with a Bleeding Disorder Program Date TBA	

Bleeding Disorders News

PRE-CLINICAL TRIALS on Subcutaneous Injections

by Sarah Wood

YOU HAVE PROBABLY heard the words “Sub Q injections” used recently, as these are very important and promising words in the bleeding disorders world, but you might not really know what they mean. Well, there are some very exciting advancements being made to hemophilia treatments right now that you should know about so let’s go through the who, what, and why.

A partnership between two companies occurred at the beginning of this year; Pro Bono Bio Group (PBB), an international healthcare group, and Poly Therics Limited (PolyTherics), whose focus is on the development of better biopharmaceuticals. They partnered with the goal of producing longer lasting versions of blood factor proteins. Using a technology called TheraPEG, they previously were successful in their efforts to create a longer acting factor treatment for hemophilia B and for people who had immune responses. Now, they have successfully turned their focus to treatments for people with hemophilia A.

They have now completed a series of pre-clinical trials and have created long acting subcutaneous blood factors, meaning they have a longer half life and can be injected under the skin rather than into the veins. They accomplished this by attaching a PEG (polyethylene glycol) molecule to each blood factor molecule in a specific location that is remote from the active site on each blood factor and by covering the part of the antigen that often activates immune responses. This may not sound that exciting, but potentially it could really change the world of hemophilia treatment. The benefit of having subcutaneous, longer lasting treatment is that it makes treatment a whole lot easier to administer, and therefore a lot easier to do at home. Because it is easier to treat, this could lead to improvement in treatment compliance and less chance of joint bleeds and damage; because treatment is taken less often, it simplifies dosing regimens as well as saving a huge amount of money for the healthcare system by lessening the need for regular IV infusions. The benefits to vein care will be huge as well, since injections into the veins is done either much less often, or not at all if treatment is taken subcutaneously.

Numbers from the pre-clinical trials support the companies’ claims of success. The subcutaneous form of Factor VIII treatment for hemophilia A maintained hemostasis (the process which stops bleeding) for 72 hours, which means it would only need to be taken twice a week, as opposed to the average of three times a week, and may be given at higher doses if wanted to allow for only *once a week* treatments. The subcutaneous form of Factor FIX treatment for hemophilia B maintained hemostasis for 10 days, meaning treatment may be done *less than* once a week.

PBB has already made great advances with these trial results, but they expect even greater advances and are confident that they can optimize these treatments so that both can effectively last at least one week and possibly two weeks between infusions. If this can be achieved it would greatly change the lives of many people living with hemophilia. ♦



GOOD NEWS—the Disease is Getting Even Better

by Mojtaba Khezry

BIOGEN IDEC and **SOBI**, in a collaborative effort successfully completed Phase 3 of their long-lasting coagulating factor IX for treatment and prevention of bleeds in hemophilia B patients. (Phase 3 is a clinical test phase before licensing and marketing of any pharmaceutical product.)

Their product named B-LONG is a factor IX recombinant protein product fused with FC protein, to keep the factor from becoming a target of the immune system and hence have the factor circulate for a longer period of time. FC stands for fragment crystallizable region and it’s a ticket or a tag attached to the factor protein that allows the protein to be recycled. This approach has been successfully implemented on other therapeutic “protein based” products.

This clinical trial involved 123 candidates over 12 years old. The modes of treatment studied included weekly prophylaxis, individualized interval prophylaxis, and on-demand therapy for preoperative and bleeding breakthrough. One hundred and fifteen of the candidates completed the study with no side effects or inhibitors, except one case of urinary complication which was resolved through medical management. Good to excellent outcomes were observed for all on-demand treatment (preoperative and bleeding breakthrough). Twelve patients were studied in the preoperative treatment group and they have undergone a total of 14 major operations. Very low rates of bleeding breakthrough were observed for candidates on prophylactic treatment (individualized and weekly). Now the collaborators are seeking licensing and Phase 4 testing in larger populations. ♦

HIV/HCV News

TWO GREAT MEN and Transplantation in HIV

by Antonia "Smudge" Swan

UNTIL A YEAR AGO, as a person living with HIV, a liver transplant for the late John Plater would have been out of the question. But this was a right, which he, alongside my late husband James Kreppner, and many others, fought for. Sadly, James died before access in Ontario was opened up and, unfortunately, despite having access, John wasn't able to recover to receive his liver transplant.

Prior to access opening up, people living with HIV with advanced liver disease had a choice if they needed a transplant: they could hope that future drug treatments would improve quickly enough to help them; or provided they had the money, they could travel outside Canada to get a transplant. Unlike Ontario, jurisdictions such as the US and Europe provided access to transplants for HIV-positive individuals.

Needless to say, forcing already sick people to wait for science to advance or forcing them to travel to gain access to solid organ transplants was not ethical. Part of the decision to restrict access to transplants in HIV-positive people was based on the notion that the organ would be wasted because it was assumed that the person with AIDS would not live long post-transplant. But with the advent of highly active antiretroviral therapy (HAART), which allowed HIV-positive people to live longer post-transplant, the argument of wasted livers no longer held.

For several years, key individuals including Louise Binder, Dr. Greg Robinson, Ruth Pritchard, Ron Rosenses, John and James, fought for access to solid organ transplants in Ontario for HIV-positive people. In 2003 the OACHA (Ontario Advisory Committee on HIV/AIDS) Working Group on HIV and Transplantation released the report *A Review of the Literature with Recommendations for Action*, to address this injustice. Then in 2009, sparked by the passing of James Kreppner whose HIV was stable and who had just died unnecessarily from hepatitis C induced liver failure, there was a final push for access for solid organ transplants in HIV individuals by the Canadian Treatment Action Council (CTAC). CTAC's multidisciplinary working group focused on changing policy to secure a dedicated HIV/AIDS transplant program. This included submitting a comprehensive business case to the Ontario government and to the Toronto General Hospital.

At the World AIDS Day Breakfast in 2010, I spoke about James and the tragic consequences of outdated policies leading to his premature death. At that breakfast, The Ontario Minister of Health, The Honorable Deb Matthews, made her "stay tuned" speech on the issue of transplantation in HIV. Then, exactly a year later in December, 2011, I watched the same Health Minister as she delivered on her promise to ensure that HIV-positive people would finally no longer be denied access to solid organ transplantation in Ontario. It was a bittersweet moment which I will never forget. Bitter because it was too late for James, but finally all his efforts and the efforts of those who had also fought for years on this issue had paid off.

To date, the Toronto General Hospital has performed two successful transplants in HIV-positive patients, and according to staff at the TGH, both are doing well. Despite facing the obstacles of hemophilia, HIV and hepatitis C, and despite the fact that neither of them received a transplant, James Kreppner and John Plater demonstrated that determination, combined with a sense of justice, can inspire others and result in saving lives.

For a short video by James Kreppner on this issue, visit: www.youtube.com/watch?v=D6AzuXcqCts ♦

New Ruling on HIV DISCLOSURE

by Sarah Wood

A RULING has been made by the Supreme Court that will affect members of our community living with HIV. In the past, the law stated that any person living with HIV was obligated, by law, to disclose their status to any sexual partners or else face the risk of prosecution. That law still stands, but a ruling made last week stated some specific factors that could exempt a person from it. The Supreme Court stated that if a person living with HIV has a low viral load *and* wears a condom, they are not required to disclose their status before engaging in sexual behaviour because they do not pose a significant risk of transmitting the virus. It also stated that this decision was open for reconsideration in the future, meaning this may not be the last change that is made to this law. This ruling was met with mixed feelings by the public and the HIV community. ♦

HCV Vaccine

by Sarah Wood

THE WAIT for a hepatitis C vaccine has been a long one, and although it's not over yet, the Burnet Institute is currently undertaking studies that they believe could bring us one step closer to this goal. The primary reason that the creation of a vaccine for the hepatitis C virus has been so difficult is that, unlike many other viruses, hepatitis C is forever changing its form, making it challenging to replicate it for a vaccine. Associate Professor Drummer and her team from the Burnett Institutes Centre for Virology believe they have figured out how to work around this challenge by creating a potential vaccine that can protect against a variety of different hepatitis C strains.

"Our vaccine is unique as it contains only the most essential, con-

Hemophilia Ontario Youth Section



Together WE ACHIEVE MORE

by Amy Griffith

COMMUNITY IS A WORD that I believe loses its very powerful meaning within cliché valedictorian speeches and *Webster's Dictionary* definitions. What makes the idea of a community so limitless is that it is ever-changing in order to meet the needs of its members, or in turn, for its members to meet its needs.

There is a common saying, “Together we achieve more,” that I believe is the best way to describe how a community functions. To me, a community is formed and thrives from a feeling of togetherness that is instrumental in accomplishing bigger and more meaningful goals.

I am a member of a few different communities. I am an alumni member of my two previous university communities, a volunteer in my local Best Buddies community, and more commonly recognized here, I am a member of the bleeding disorder community. I was diagnosed with vWD when I was four years old. Back then, TCOR was represented by a handful of friendly faces who reminded my parents that medicine aside, I was going to be okay. We were all introduced to services, programs and other families who helped us make this life-changing transition in our lives. Now, as a healthy and happy 23-year-old, volunteering and being an active TCOR member is something that I hold in very high regard. I have the opportunity to be involved in an organization that dedi-

served parts of the major viral surface protein, eliciting antibodies that prevent both closely- and distantly-related hepatitis C viruses from entering cells, thereby preventing infection” (Associate Professor Drummer).

In other words, this means that although the virus is forever evolving and changing, this vaccine could potentially be broad enough to protect against the virus in its many possible forms. They are currently putting the vaccine through formal preclinical studies to test its abilities to do this. If successful, this could be a tremendous breakthrough and have a huge health impact as hepatitis C affects millions worldwide.

Source: www.marketwatch.com/story/major-breakthrough-in-hepatitis-c-vaccine-development-2012-08-13 ♦

Pharmaceutical News

**Brand names of treatment products are provided for information only. Their inclusion is not an endorsement of a particular product or company.*

Xyntha Solofuse® reconstitution system from Pfizer NOW AVAILABLE IN CANADA



THERE IS NOW another infusion tool available for people to choose from when deciding which treatment device is right for them. Pfizer Canada has released a tool called Xyntha Solofuse® and what sets this one apart is that you no longer have to go through the process of mixing the factor and the liquid, as they come with a pre-loaded syringe. This product is available in 1000, 2000, and 3000 IUs. The elimination of this step makes the procedure just a little bit easier. ♦

Is LIFE WITHOUT BLEEDS a Possibility?

from Baxter Pharmaceuticals

IF YOU HAVE a bleeding disorder, you know—more than anyone—just how disruptive joint bleeds can be in your daily life. But how do you prevent bleeds from occurring while still doing all the things you love to do? Lots of ways.

First, know your treatment and play an active role in planning and executing it. Are you aware that prophylaxis treatment can be used throughout your life—from childhood through adulthood? If you are currently using on-demand treatment, ask your doctor if prophylaxis may be right for you.

You and your hemophilia health team have partnered together with the joint goal of reducing bleeds in your life. But what happens if you aren't completely satisfied with your therapy?

- Track your bleeds
 - Did something happen to start one?
 - When did it happen?
 - What did you do to treat it?
- Tell your hemophilia health team if you feel you aren't controlled
- The questions above will help point out where control is lacking
- Your doctor may be able to recommend a dosage or product change to help better control your bleeds

Bleeds may never disappear completely in all patients, but they can be reduced to a point where life without bleeds seems like a possibility. Talk to your hemophilia health team to ensure that you are doing all you can to manage and prevent joint bleeds. ♦

cates itself to one of my most defining characteristics. I am able to give back and mentor others who are at a time in their own lives that I can remember personally. Most of all, I am exposed to countless opportunities that are fostered by TCOR, such as the World Hemophilia Congress, CodeROUGE, and the Hemophilia Ontario Youth. I don't like to play favourites, but TCOR is my choice community.

You are not wrong in assuming that anyone can accomplish his or her goals while flying solo. There are times that we are at our most powerful, influential and groundbreaking when we work on our own, as a lone wolf. However, there are other times where we run as a pack, where we all just get by better with a little help from our friends. ♦

Community = HOME

by Jordan Cabral

AS A YOUTH with hemophilia, the opportunities to help out are endless, but why would I want to help my community? The answer to me is simple. The community is my home. It's filled with people who experience the same situations I had as well as situations that are yet to come.

If someone becomes active in their community, they discover a place where their questions can be answered, where the things they learn will always benefit them, and where they meet new people who are experiencing the same situations.

When I was a boy, I would go to events and leave with knowledge that would help me; knowledge that I still think about today. These events helped me throughout my life. This is what I hope to do for others—to share my experiences and teach people what worked for me and what I would do differently to better the lives of others. We are a community, we help each other, and together, we will stop the bleeding. ♦



My COMMUNITY

by Ryan Kleefman

SINCE I WAS DIAGNOSED with hemophilia at the age of six months, the bleeding disorder community has played a vital role in shaping my life.

At first, the community was there mainly for my parents. I was too young to comprehend what was going on, but the community was immensely helpful for my parents. Whether it was going to clinic to talk with the nurses and doctors or attending events such as the summer and winter celebrations, my parents learned what it meant to live with a bleeding disorder and gained valuable knowledge from those who had already been through the process of raising a child who had hemophilia.

As I grew into my teenage years, community became very important. The support network of peers who understood exactly what I was going through because they were going through the same things was extremely important. The critical need for a child to be able to relate with someone who is the same as they are cannot be over-emphasized. At school, a child may feel isolated and different because no one else in their school has a bleeding disorder. However, the bleeding disorder community provides valuable contacts, showing a child (and his/her family) that, though living with a bleeding disorder is not easy, they are definitely not alone.

Today I play an active role in the bleeding disorder community. I take part in Hemophilia Ontario youth events such as going to baseball games, traveling to Montreal, and so on. I participated in Just the Guys as a child and have now volunteered to help run the event for several years. Pinecrest Adventures Camp has become a very important part of my life. I volunteer for the week as a cabin counsellor as well as on the planning committee throughout the year. For just over a year, I have held a seat on the SWOR Council. In July, I attended the World Federation of Hemophilia Annual Congress. I have also participated in fundraiser golf tournaments as a volunteer, summer and winter celebrations, and various other community events. Being a part of the bleeding disorder community as I grow older has become increasingly important as I recognize the need for those who are affected, as well as their families, to have a support network.

For those looking to be involved, there are many opportunities. The bleeding disorder community provides a place to share experiences, learn important information, and also have an enjoyable time with those who understand issues that are relevant. Whether affected by hemophilia, von Willebrand Disease, or a rare factor deficiency, community can provide a feeling of belonging which cannot be found elsewhere. If you aren't already involved, I encourage you to look for an opportunity to become involved. If you are already involved, I thank you for the difference you have made in the lives of so many others and encourage you to continue seeking new opportunities to take part. ♦





Camp Wanakita and THE BAYER DEN



L to R: Terri-Lee Higgins – Executive Director, Keith Golding – Bayer Representative, Sherry Purcell – Hemophilia Nurse, Georgina Floros – Hemophilia Nurse, Lisa Thibeault – Hemophilia Nurse, Andy Gruppe – General Manager Camp Wanakita, Alex McGillivray – Regional Service Coordinator

SUMMER CAMP is a time-honoured tradition for Canadian kids. In Ontario alone, thousands of kids descend on the province’s over 600 camps for fun, adventure and learning each summer. A big part of camp is spending time in the great outdoors, but equally important for campers with hemophilia, is learning how to take care of themselves. Learning how to self-inject medication is an important step in the road to independence for those with the condition.

The YMCA’s Camp Wanakita, located near Haliburton, ON has been welcoming kids with hemophilia for over 20 years. It offers them a place to spend time with peers also living with the condition while experiencing camp activities just like anyone else. To give campers a safe and clean environment that meets their unique needs, Hemophilia Ontario, the YMCA and Bayer teamed up in 2004 to restore an old cabin, and the Bayer Den was born. Children with hemophilia can learn to take charge of their disorder by learning to self-infuse with the help of a hemophilia nurse. Camp Wanakita is also a place where children can safely bring sports into their lives under the supervision of a nurse to guide them and provide care. The Bayer Den sits at the edge of Koshlong Lake and features a fully-resourced treatment education centre. Other amenities include a kitchen, lounge and bedrooms.

This past spring, Bayer and the YMCA teamed up again to renovate the Bayer Den. The results include hardwood flooring throughout the building, new furniture and lights, and a new deck overlooking the lake.

“We’re proud to support Camp Wanakita and the opportunity it gives these campers” says Rena Battistella, Head of Hematology at Bayer Inc. “The Bayer Den is a great resource where kids with hemophilia can learn about taking care of themselves and find care from a nurse if they need it.”

Kids usually don’t want to leave camp when the time comes, but they often go with a newfound sense of independence and achievement. Thanks to the people and facilities at Camp Wanakita and the Bayer Den, campers with hemophilia are no different. ♦



Blood Matters Crossword

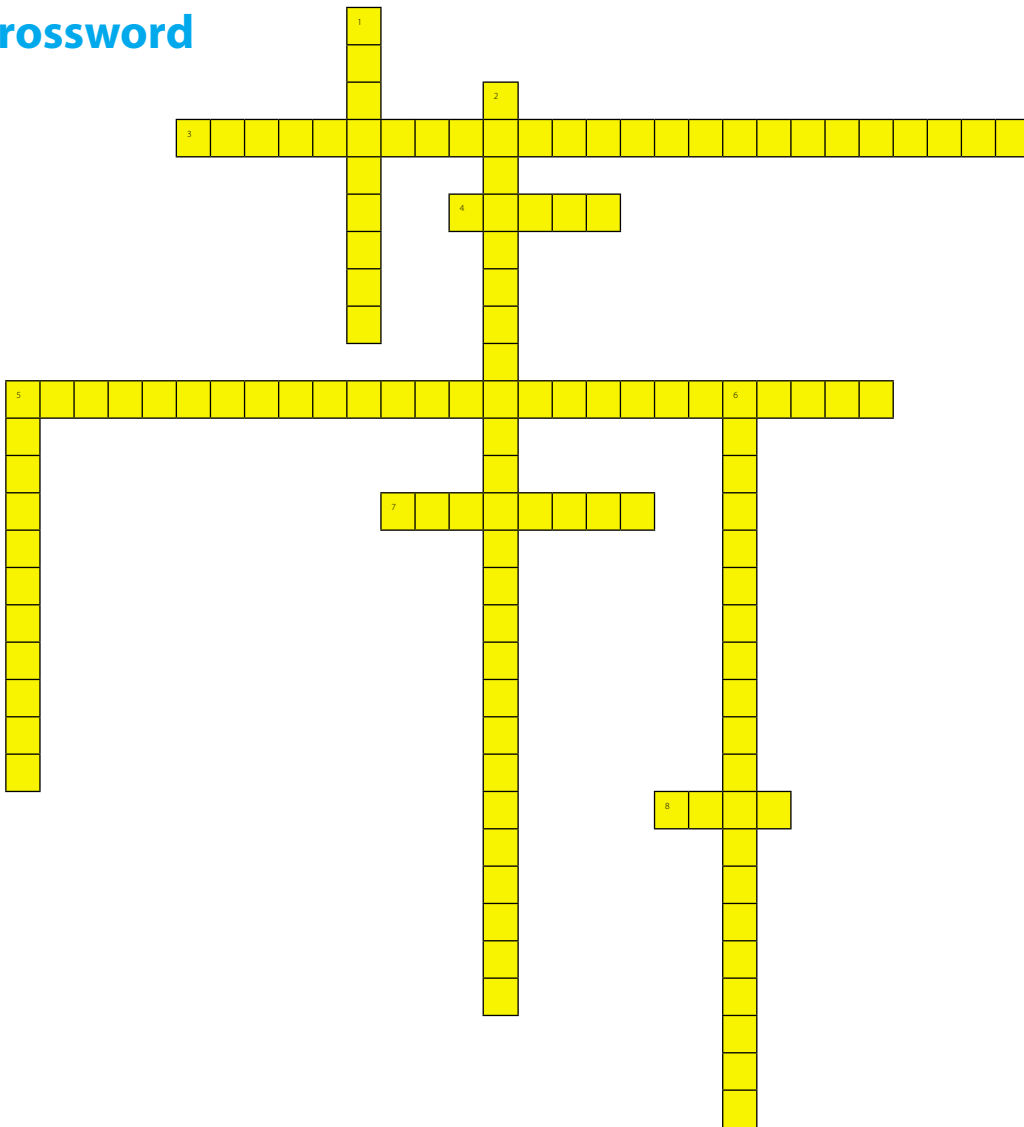
Across

3. What does the acronym CHS stand for?
4. Hemophilia is also known as the “___” disease.
5. What does the acronym HIV stand for?
7. Hemophilia is passed from mother to son. What is the term given to these women?
8. How many treatment centres are there in Ontario?

Down

1. Factor 9 deficiency also has the same name as what holiday?
2. What does the acronym HTC stand for?
5. Factor 8 deficiency is also known as?
6. What is the most common bleeding disorder?

Answers on page 21.



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