



Hemophilia Ontario
Hémophilie Ontario

BLOOD matters

We're All Related By Blood

Living life on our terms

Lifespan

New Baby



Treatment Centre
Lab Testing
Diagnosis
Support for New Families

Hemophilia Ontario
Education
Family Support



School

Healthy Lifestyles
Transition to Adult Care
Career Choices

Ontario Youth
Volunteering



Activity Choices
How & When to Treat
How to Self-Infuse

PEP
School Education
Summer Camp

Teen



Young Adult



Changes in Care
Travel
Increasing Responsibility

Emerging
Leaders
Lifestyle



Adult



Support from other
Health Care Services
Monitor

Aging Support
Wellness Choices
Caregiver
Support



Mature Adult

Changes in Condition
New Treatment Plans

Family Support
Community
Advocacy

You are not alone

2014 - 2015
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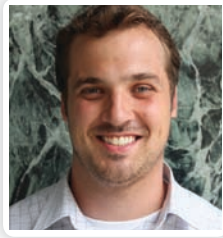
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Hemophilia Ontario
Hémophilie Ontario

Hemophilia Ontario is a certified chapter of the Canadian Hemophilia Society



Outgoing President's Message

by Paul Wilton

Everyone I have ever met with a bleeding disorder and their families have dreamed of a cure. When we first meet others in our community a cure is often the first topic that comes up. When you ask parents, they say they want a cure so their child doesn't have to experience painful bleeds or traumatic episodes at the hospital where three nurses try to hold down their petrified child for an infusion. To those affected, a cure means the ability to participate in sports that others are playing, more confidence in providing for your family, reduced anxiety about potential threats in our life-saving medicines, and avoiding the sleep denying pain of crippled joints.

We don't quite have a cure, but two things are clear. First, we're closer than ever. Secondly, our contributions to research have been essential to improving our care. Whether it is recombinant factor products, for which studies prove prophylaxis is a cost-saving investment for governments, or the soon to be released longer lasting products, research has resulted in our ever increasing quality of care.

In Ontario, we need to do our part to ensure this progress continues until we find a cure. In 2013, the Alberta Chapter of the Canadian Hemophilia Society donated \$75,550 to research, Quebec donated \$10,000, Newfoundland and Saskatchewan each donated \$5,000. We need to make sure we are doing our fair share. Hemophilia Ontario has set achievable goals of donating \$10,000 to research in 2014 and \$20,000 in 2015. There are some obstacles to achieving these goals, but these can be overcome in time. Hold the Board of Directors and Executive Director accountable to ensure these desired goals are being achieved. Budgets indicate priorities, so we need to make sure we are earmarking the necessary resources to reflect the magnitude of this goal to each one of us. Think about how a cure would change your life or that of a loved one.

There are game changing developments in our care, both positive and negative, just around the corner: longer-lasting treatments, data-driven outcome based medicine, and the threat of government cut-backs. Using only the voices of a few, we will not be able to swing the pendulum towards the decisions in these areas our community needs. It will take all of us being engaged and doing our small parts to make it happen. We have a collective responsibility to those who fought before us to expand what was once the seventeen year life expectancy for people with hemophilia, and a responsibility to the next generation to engage in improving care and finding a cure. Without this engagement, we not only risk missing out on new opportunities, we risk losing the quality of care so many before us struggled to achieve.

Hemophilia Ontario must focus on achieving the desired outcomes presented in this journal. These goals are a clear directive, straight from our stakeholders. No games, no distractions, no meandering, no excuses, just results. Our Board, Staff and Volunteers need to demonstrate that we are capable of achieving results. I have no doubt we can achieve each of these goals, but it will require unrelenting organizational focus and discipline. 💧

What's in this Issue?

SUMMER 2014 Volume 5, Number 2

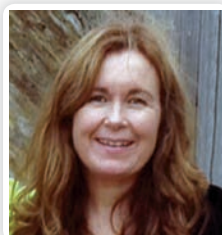
- 02 Leadership Messages
- 04 Hemophilia Ontario News
- 09 Hemophilia Ontario Youth
- 10 Bleeding Disorders News
- 12 Central Western Ontario Region
- 12 North Eastern Ontario Region
- 13 North Western Ontario Region
- 13 Ottawa & Eastern Ontario Region
- 15 South Western Ontario Region
- 16 Toronto & Central Ontario Region
- 17 Clinic Corner
- 18 HIV/AIDS & Hepatitis C News
- 21 Healthy Living with a Bleeding Disorder
- 22 Feature Articles
- 26 BleedHers
- 27 How To Get Involved
- 28 Travelling Tips

Thank you to our sponsors:

MAGAZINE and PROGRAMS



PROGRAMS



President's Message

by Julia Sek

Greetings to old friends and new! I am very happy to be a part of the Hemophilia Society once again. I am, also, very excited about being a part of the Hemophilia Ontario Board; the wealth of knowledge and experience on the Board is fantastic. As always, we are committed to improving the lives of those affected by inherited bleeding disorders. This includes the quality of life throughout one's lifespan; infancy, school years, adulthood and seniors. In our programming, you will see that we have listened to and continue to work with our community to develop programs that meet your needs. Our staff and board are diligent and dedicated to help us continue growing stronger as a community!

From camp to clinic support to our most recent event, "Aging with a Bleeding Disorder", we are supporting the programming that is important to our community. Please, always be sure to share your ideas and experiences about programs with our staff and Board members so that we provide programs that are current and relevant.

On another note, I recently participated in an Ontario Hospitals Association conference. It was well attended and the message was clear: chronic disease management, patient and family engagement is critical!

As Pam Wilton has voiced proudly many times, we do this and have been doing this well for a long time! It does not mean we are perfect or that we don't have areas we can improve on, but we are on this journey and are well along the path!

Together, let's keep building a strong, healthy community that works towards improving lives and finding a cure!

Have a safe and wonderful summer! 💧



Executive Director's Message

by Terri-Lee Higgins

The life cycle is, by definition, "occurring or persisting from beginning to end." When we are young we think there's an endless supply of days and opportunities. As we grow and mature we begin to realize that every day, life provides challenges and opportunities leading us in one direction or another. Sometimes we know how to move forward, sometimes we don't. In this issue of *Blood Matters*, you will find information that may help you to make choices that are right for you, whatever stage of the life cycle you are in. Maybe your child is considering going to camp for the first time or your teenager is thinking that there isn't a reason to keep diaries. Maybe you are about to embark on a family or personal vacation or you are preparing to retire. Every situation will have an impact and what that looks like differs from person to person.

There isn't a book that provides us with detailed descriptions of what to do in a certain situation so, we often turn to others who have life experience to help guide us. For generations, Hemophilia Ontario and its members have relied on peer-to-peer support as we have lived life. In following that trusted process, we reached out to our community, to those individuals living with and / or affected by inherited bleeding disorders and members of the HTC teams and asked them what they felt were the most important things to know / be aware of for persons living with an inherited bleeding disorder throughout the life cycle. We felt it was very important to not only provide information to those living with inherited bleeding disorders but also to caregivers. Caregivers are those people in all our lives who help us with our daily living and could be a mother, father, spouse, partner, relative or friend – without them we may not accomplish as much or live life as fully. Whether or not you choose to implement any of these ideas and suggestions is up to you.

Each new day is another chance to change your life. Will today inspire you to change? 💧



Editor's Message: The Journey – "Are we there yet?"

by Tom Beer

If you've got kids you've heard this question many times on any trip or outing. This edition of *Blood Matters* is a look at the journey that our readers are on.

I have a lot more yesterdays than tomorrows on my journey, so, each today counts. Carpe Diem? Seize the Day - Oh yeah! So what? Let me share a bit of your today.

Making the most of the day, having a good feeling about where you're going, your success on your journey, is discussed in a study of *The Factors of Self-Worth*, by Dr. S Baumrind, during her time at the University of Chicago.

1. A Feeling of Self-reliance

Successful people learn how to work most effectively – alone and/or with others to work out problems. As we get older, and as we face problems and or issues outside our comfort zones, we learn that we can rely on our past experiences and abilities, but NOT all the time. Often, we know someone who can provide enlightenment or encouragement; or "we know someone who knows someone" who can help. (Several articles in this edition are written by these people). When there is no peer who can help, the person with the good life outlook knows when to turn to the experts. (Look for the articles relying on professional input.)

2. Self-Control of Behaviour

People learn to control behaviour to suit a situation. I am reminded of a discussion in a Principal's office after a tumultuous meeting with a troubled student and a very aggressive parent, whose tactic was "in your face" confrontation, first with the Principal, and then, when a case had been made, with his child.

After the meeting, the Principal and I asked ourselves, "Did this meeting accomplish anything positive? Does this guy treat every situation like this?" (I was reminded of one of my grandmother's sayings – "We were given one mouth and two ears. Obviously, we were meant to listen twice as much as we speak" ... Hmm).

3. Positive Approach Behaviour

A person's approach to new situations or people often determines success. Using one's past experiences as a basis for judgement of a new issue is fraught with problems. Do you remember the "Beta or VHS" debate? No... well, what about the tech preferences between Blackberry and Apple? No... well, do you remember when you called the kids to dinner instead of texting them? ... Aha!

If you're not positive about change, progress is being made and you're in danger of being left behind. As I indicated last edition, remember yesterday, look to tomorrow, but live TODAY. Steve Jobs said, "Everyone here has the sense that right now is one of those moments when we are influencing the future." So, be ready. Be positive. Move ahead on your journey.

4. Good Interpersonal Relationships

We need family, friends, colleagues, experts, influencers. All these give us a sense of who we are, how we relate to the world, and more importantly, that we "fit in." Often, in my career, I encountered those who didn't know who they were, where they fit, or where they were going. Sometimes, all they needed was a responsive ear, sometimes more. When you encounter difficult situations or decisions that will influence your life journey, look to those you care for and respect to give you balance.

There are the guidelines. Now, go on about living.

Above all, have a good trip. ♦

"It's good to have an end to journey towards; but it is the journey that matters, in the end." – Ernest Hemingway

Parents Empowering Parents Program:

Parents Empowering Parents (PEP) is a program, sponsored in Canada by Bayer, designed to promote effective parenting skills to parents of children with hemophilia, and to educate and support parents through classroom discussions and exercises.

by Rachel Leslie

On behalf of CHS and the Parents Empowering Parents (PEP) steering committee, we are pleased to update you on PEP's progress over the past year.

Four PEP workshops were held in 2013, taking place in Nova Scotia, Alberta, Manitoba and Saskatchewan, and we are looking forward to upcoming events in Manitoba (a PEP reunion), Ontario and Atlantic Canada. Each event is planned to meet the unique needs of parents in that area, with some regions holding weekend workshops while others have chosen to meet on 2 Saturdays or tied-in with a clinic visit, both of which allow for childcare.

The Steering Committee meets by teleconference each month to carry plans forward, including working on a curriculum revision as

Hemophilia Ontario News



well as creating a page on the CHS website <http://www.hemophilia.ca/en/support-and-education/pep---parents-empowering-parents-program/>, and establishing an Intranet page, to collect resources and allow sharing of PowerPoints and ideas among facilitators who are preparing for their PEP event.

We are looking to not only raise awareness, but to invite you to reconnect with PEP across Canada by keeping you informed and involved. Please don't hesitate to contact us: rleslie@hemophilia.ca if you'd like more information on PEP events coming up in your area or would like to join the steering committee. ♦

Our Goals

2014 | 2015

Originally printed in the 2013 Hemophilia Ontario Annual General Report
by Paul Wilton

Care and Treatment for All:

Goal: Achieve comprehensive care for all people with inherited bleeding disorders.

Envisioned Outcomes 2014-2015

- 1.1 Nine Hemophilia Treatment Centres in Ontario will have been assessed to identify strengths and gaps in services as benchmarked with the national standards of care.
- 1.2 Nine Hemophilia Treatment Centres will have services for women with inherited bleeding disorders.
- 1.3 Ontario will have designated provincial funding for the Hemophilia Treatment Centres.
- 1.4 Those co-infected with HIV and Hepatitis C to have access to liver transplants.
- 1.5 Hemophilia Ontario will provide services to those living with Inherited Bleeding Disorders and/or HIV/AIDS and Hepatitis C and their families.
- 1.6 Access to care in less economically developed countries will be expanded.

Safe and Secure Supply:

Goal: Advocate for access to a secure supply of the safest and most efficacious therapies for the treatment of inherited bleeding disorders.

Envisioned Outcomes 2014-2015

- 2.1 Canadians with inherited bleeding disorders will continue to have access in a timely way to a safe and secure supply of the most advanced therapies with optimal quantities at no cost to the end-user.
- 2.2 Hemophilia Ontario will continue to have representation in the blood system in Canada.

A Strong and Cohesive Organization:

Goal: Build a strong and cohesive organization through the development of an engaged and informed Board and membership, while putting an emphasis on better collaboration between Hemophilia Ontario and the Canadian Hemophilia Society.

Envisioned Outcomes 2014-2015

- 3.1 Targeted sources of revenue will increase by 8% in 2014 and 13% in 2015.
- 3.2 Hemophilia Ontario's volunteer base will increase by 15% from 176 volunteers.
- 3.3 Hemophilia Ontario's membership base will increase by 100 stakeholders from 998 members. (National by-laws stipulate that members of chapters are members of the national organization).
- 3.4 25% of those stakeholders identified in outcome 3.3 will be people with von Willebrand disease, women with bleeding disorders or rare inherited bleeding disorders.

- 3.5 Young people aged 18-25 will be involved as leaders at the provincial level and in each of the five regions. Each Board and operational committee shall include at least one youth. Each Regional Council shall include at least two youths.
- 3.6 Two reviews will be completed to determine potential areas of collaboration, and to identify efforts that are unnecessarily duplicative. One review will be in partnership with the Canadian Hemophilia Society, the other with external organizations.
- 3.7 A Regional Council will be established in Northern Ontario which meets the requirements set out in the Regional Council mandate.

Research:

Goal: Promote and fund research to improve treatment and to ultimately find a cure.

Envisioned Outcomes 2014-2015

- 4.1 Hemophilia Ontario will contribute \$10,000 in 2014 and \$20,000 in 2015 to the Hemophilia Research Million Dollar Club.
- 4.2 Ontario researchers will have been able to recruit sufficient subjects to conduct their research in inherited bleeding disorders, HIV and HCV.

Awareness:

Goal: Raise awareness among people with inherited bleeding disorders, their immediate communities and health care partners.

Envisioned Outcomes 2014-2015

- 5.1 All people with inherited bleeding disorders in Ontario who are known to Hemophilia Treatment Centres will be entered in the Canadian Hemophilia Registry (CHR).
- 5.2 The number of women with inherited bleeding disorders in Ontario registered in Hemophilia Treatment Centres will increase by 5% from 1720.
- 5.3 The number of people with rare inherited bleeding disorders in Ontario registered in Hemophilia Treatment Centres will increase by 5% from 494.

Education and Support:

Goal: Provide effective delivery of information and support to patients and their families.

Envisioned Outcomes 2014-2015

- 6.1 A defined set of five core programs and services will be offered by Hemophilia Ontario annually.
- 6.2 Every person with an inherited bleeding disorder registered in a Hemophilia Treatment Centre in Ontario will be informed of the existence of Hemophilia Ontario and the Canadian Hemophilia Society and their programs and services.



Retiring Board Members

The following Ontario Hemophilia News articles are;

by Terri-Lee Higgins

Hemophilia Ontario would like to thank and recognize the following individuals for their time and commitment to Hemophilia Ontario's Board of Directors:

Mike Beck: a member of the Ontario Board for the past 11 years, he has been involved extensively provincially and regionally in TCOR. He has been a member of the Jordan Twinning initiative, assisted with planning every golf tournament, worked on the Amalgamation, on the Ontario Policy Committee and helped around the office. A strong advocate for the organization, he encouraged youth to become involved and have a voice. Mike has accepted a new career opportunity in Georgia and we wish him the best of luck.



Kristen Luszka: a member of the Ontario Board for the past 2 years, Kristen has been instrumental in guiding us with our social media and sharing her personal story of living with an inherited bleeding disorder. She worked with staff to develop the initial 6 month Facebook plan and more recently, assisted with the development of our new Twitter initiative. We have come a long way with our presence, thanks to Kristen sharing her expertise in this area. Kristen, we thank you for sharing your voice in so many ways. 💧



Remain Connected:

As of July 01, 2014 Canada's Anti-Spam Legislation (CASL) will come into effect

CASL will require express consent from the recipient of all future commercial electronic messages (e-blast, e-mails, Twitter/Facebook postings, Youtube, etc) from Hemophilia Ontario.

As a member/supporter/volunteer, The Board of Directors and staff at Hemophilia Ontario would like to take this opportunity to thank you for your interest in our organization. We value our relationship with you and would like to continue providing you with information. In order for us to do so, we require your express consent.

An e-mail outlining the process of providing your consent has been sent out to all individuals on our contact list.

If you have not received this e-mail please contact: Matthew Maynard mmaynard@hemophilia.on.ca or 519 432 2365 💧

TCOR/NWOR Staffing Change

Sarah Wood, TCOR and more recently the NWOR Regional Service Coordinator, has accepted a new position as the Executive Director for Federated Health in Toronto. Her last day in the office will be Friday June 27th. Many of you would have met Sarah at a TCOR or provincial event such as Just the Guys or Wellness for Women. She has been an integral member of the Ontario Regional Service Coordinator team helping get new provincial initiatives like the Facebook revamp up and running while remaining a resource to her peers. Sarah has been the go-to person for TCOR programs and events, meeting many members facilitating the building of new networks. Her outgoing personality, friendly manner and professionalism have earned the communities trust and support. This is an amazing promotion for Sarah. We know she will tackle this new venture with the same passion and dedication she's displayed as part of our cohesive team and will quickly establish herself as a valued employee in her new role. Working alongside of her has been an honour and privilege, and we know she will continue to succeed in this new phase of her professional career. Please join me in congratulating Sarah and wishing her well as she takes on this new chapter in her life. Sarah, we wish you all the best and will truly miss your passion and enthusiasm. 💧

Volunteer Awards and Years of Service Recognition

National Volunteer week provides the perfect time for Hemophilia Ontario's Volunteer Recognition program to thank and honour those who, by their commitment and example, inspire others to engage in volunteer service. This year's recipients were:

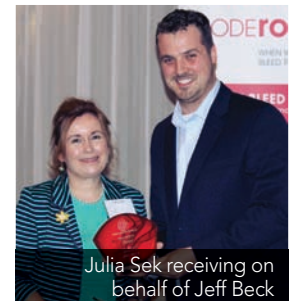
Jeff Beck: *President's Award* – Jeff's greatest achievement was defining the role of the Board and Executive Director facilitating development of the Strategic Plan to adapt the organization to respond to new challenges and facilitating moving toward more cohesive working structures. He has been a resource and mentor to many. Thank you Jeff, for leading us in this new direction.

Mike Beck: *Shawn Duford Grassroots Leadership Award* – Mike's dedication, commitment and hard work have ensured the members of the inherited bleeding disorders community had free and supportive access to Hemophilia Ontario's goal of ensuring and delivering advocacy, education, programs and services to our community. Best of luck Mike as you take on new adventures.

Lori Laudensch: *Ann Harrington Award* – Each day Lori puts every effort into ensuring the delivery of optimal care including adjusting her work and personal schedules to accommodate pre and post-surgery treatments, teaching school staff and classmates and as a resource to other community care providers. Lori diligently pursued the completion of the Service Contract to reintroduce the RSC to clinic.



Mike Beck



Julia Sek receiving on behalf of Jeff Beck

Hannah Higgins: *Leaders of Tomorrow* – in her eighth year as a volunteer, Hannah enhanced her volunteer involvement from regional to provincial as she assisted with administrative duties and as a volunteer at the Wellness for Women conference. Her favourite involvement is as staff of Pinecrest Adventures Camp where she is the crafts co-leader and in 2014 she was elected to the SWOR Council as a youth representative.

Julia Lepera: *Leaders of Tomorrow* – Julia became involved with the region attending programs at a very early age to learn about her brother's care. As a volunteer regionally, she is crafts co-leader for Pinecrest Adventures Camp, has attended the NACCHO conference twice and was selected to attend World Congress in Paris. She participated as a volunteer at the Wellness for Women conference and in 2014 was elected to the SWOR Council as a youth representative.



Hannah Higgins receiving on behalf of Lori Laudenbach

Hemophilia Ontario is pleased to recognize the commitment of our Hemophilia Treatment Center members.

This year we are recognizing the following individuals who achieved these years of service milestones:

- 5 years Jordan Lewis
- 10 years Dr. Anthony Chan
- 15 years Dr. Manuel Carcao; Donna Langen
- 20 years Diana Cottingham
- 25 years Dr. Mariana Silva
- 30 years Dr. Jerry Teitel; Dr. Doug Smith
- 35 years Dr. Irwin Walker; BettyAnn Paradis

We are honoured to recognize the commitment of these individuals, and their peers, who together bring 697 collective years of experience to our community. Thank you! 💧

Annual General Meeting

Hemophilia Ontario held its Annual General Members Meeting on Saturday April 12, 2014 in Hamilton, Ontario. Membership to Hemophilia Ontario is open to anyone with an inherited bleeding disorder, as well as anyone interested in furthering the cause of hemophilia and other inherited bleeding disorders.

The 2014-2015 Board of Directors was elected as follows:

- | | | |
|---|--|---|
| President
<i>Julia Sek</i> | Secretary
<i>Amy Griffith</i> | <i>Ashwani Kurichh</i>
<i>Samuel Leon</i> |
| Vice President Board Development
<i>David Neal</i> | Past President / Member Engagement
<i>Paul Wilton</i> | <i>Monica Mamut</i>
<i>Maia Meier</i>
<i>Mary Pedersen</i> |
| Vice President Advocacy
<i>Victoria Kinniburgh</i> | Directors at Large
<i>Raja Alami-Ammoury</i>
<i>Rob Dinsdale</i> | <i>Igor Rivstevski</i>
<i>Darlene Villeneuve</i>
<i>Moutasem Zakkar</i> |
| Treasurer
<i>Phyllis Gray</i> | <i>Maury Drutz</i>
<i>Shelley Hewett</i> | CHS Delegate
<i>Paul Wilton</i> |



Thank you to everyone who attended the AGM, our pharmaceutical sponsors and our volunteers. 💧

Just the Guys 2014

Save the Date!

Attention CWOR, OEOR, SWOR & TCOR members! Please save the date of September 19-21, 2014 for our Just the Guys Weekend.

We don't want to give away too much, but we can tell you this, it will be **OUT OF THIS WORLD!**

Official registration forms will be sent out in July.
For any further information, please contact:
Alex McGillivray, RSC
(905)522-2545 or amcgillivray@hemophilia.on.ca

We hear you ... Thank you!

Thank you to everyone who completed the Annual General Meeting survey. There was great feedback on everything from the educational speakers, to the AGM to the location and meals that has been shared with the staff and the Ontario Board of Directors to better help us plan future events. By providing both your positive and constructive comments we will be better able to provide the information you want and need. We are always open to, and welcome, your feedback. If you have anything to share at any time, positive or constructive, please do not hesitate to contact me by telephone at 519-432-2365 or by email: thiggins@hemophilia.on.ca



First Time Experience: At the AGM

by Shelley Hewett

On April 12 2014, my husband and I were pleased to attend our first Annual General Meeting of Hemophilia Ontario held in Hamilton, Ontario. Being that it was our first time to attend, we were a little apprehensive about what to expect. So, for any of you who have never been to the AGM or may have had to miss it this year, this is what took place.

The morning sessions mainly covered the business end of things including what had gone on during the year and who needed to be recognized for their hard work. I especially took note that there are many individuals who have given years, even decades, to the organization so it was a pleasure to see them recognized for their years of hard work and devotion. The afternoon sessions were very interesting. The presentation by Physiotherapist Karen Strike from CWOR and her research into the use of ultrasound imaging in the clinic setting by specially trained physiotherapists was very informative. By comparing the use of regular x-rays, ultrasounds, and MRIs she was able to conclude that ultrasounds are the best option for diagnosing joint problems. She clearly showed that even without symptoms, joint damage could be seen using an ultrasound. As this study is still in progress we will have to wait and see what changes in joint care might come about as a result.

An interactive debate between Rob Dinsdale and Matthew Maynard on the pros and cons of keeping accurate bleed journals was next. The clear conclusion was that keeping accurate records is really important, although Rob Dinsdale did put forth a valiant effort trying to prove otherwise pointing out that new joints are better than the old ones anyways! The afternoon ended with an informative presentation by Sarah Crymble on the Standards of Care in Ontario clinics. Sarah pointed out that with an ever increasing number of patients to treat, the work to establish and keep certain standards in our clinics is an ongoing process.

In summary, I found the AGM very interesting and educational and I would recommend it to anyone who has a bleeding disorder or has a family member who is affected. Being together with a group of people who have dealt with many of the same issues you have or are going to have in the future can be very comforting and up lifting. ♦

Financial Assistance

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, assistive devices (e.g. MedicAlert bracelets, crutches, brace), equipment (e.g.

protective helmets), in-hospital costs (e.g. telephone and TV) 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, ask that members attempt to have these costs covered by other social agencies including medical plans and the 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 that year. We are unable to carry claims over into the following year.

For information about the guidelines or to receive the Financial Assistance Forms to complete and submit with receipts, please contact your local Regional Service Coordinator. ♦



Save the Date!



Hemophilia Ontario
Hemophilie Ontario



Community
Camp

WEEKEND

October 3-5, 2014

CAMP WANAKITA

1833 Koshlong Lake Rd., RR#2

Haliburton, ON K0M 1S0

This two night, two day residential camping experience is for individuals, adults, or children living with a bleeding disorder and their support persons. The weekend provides participants the opportunity to experience camp and participate in educational sessions.

Friday Arrival: 7pm Sunday Departure: 1pm

For more information, please contact Susan Turner at 1-888-838-8846 ext. 21 or sturner@hemophilia.on.ca



Being Involved 101

by Amy Griffith

We hear it all the time: when you find something you are passionate about, throw yourself into it. In my experience, *wanting* to be involved and knowing *how* to be involved, are two completely different things.

It's likely that by holding this magazine in your hands, you or someone in your life is or has been affected by an inherited bleeding disorder. This common factor (no pun intended) unites us all.

Youth are the future of this already well-established and successful organization, and there are plenty of resources to explore and initiatives for our younger generation to be a part of. Here is a personal, comprehensive list of all things "YOUTH".

REGIONAL

Board Development Committees and Regional Councils: Young people aged 18-25 are encouraged to be involved as leaders at the regional and provincial level and in each of the five Hemophilia Ontario regions. Each Board committee must include at least one youth, while each Regional Council must include at least two youths. For more information, contact your Regional Service Coordinator. This time commitment is small, yet important in ensuring youth members are accounted for in governance decisions.

Regional Volunteering Opportunities: There are lots of opportunities to give back to your regional chapter and volunteer at local events and activities. Contact your Regional Service Coordinator for more information.

Pinecrest Summer Camp: A five day camp that happens once a year in the SWOR region. Youth can volunteer as camp counsellors. Contact the SWOR RSC for more information.

PROVINCIAL

Hemophilia Ontario Youth (HOY) Program: HOY is a relaxed and leadership focused community where youth between the ages of 16-26 can enjoy company of friends, who just happen to be other individuals with inherited bleeding disorders. Through educational sessions focusing on self-care, advocacy and leadership promotion, youth gain an outlet to share their own experiences and hear how others cope with the same issues they are facing.

Blood Matters Youth Section: Become a youth writer in this very magazine! Released three times per year, *Blood Matters* is distributed province wide to Hemophilia Ontario members and acts as the second largest communication piece within the organization.

Just the Guys Annual Weekend: This residential camp weekend for boys ages 4-17 that are affected by an inherited bleeding disorder along with an accompanying male 19 years of age and above, provides the opportunity for participants to gain a better understanding of their diagnosis and to connect with other families.

Wellness for Women Bi-annual Weekend: This educational weekend takes place once every two years in order to provide women affected by an inherited bleeding disorder the opportunity to learn more about their bleeding disorder and general women's health, and acts as an opportunity for women to focus on their capabilities and strengths, to ask questions, to share ideas in a safe environment and to provide support.

Community Camp Bi-annual Weekend: This educational and social weekend takes place once every two years and is open to people living with bleeding disorders, their families, and their unaffected siblings. This weekend provides an opportunity for the whole family to connect with other families with bleeding disorders and to allow all family members the chance to learn about issues related to bleeding disorders.

YMCA Camp Wanakita Summer Camp and Student Counsellor Programs: Located near Haliburton, Ontario, Camp Wanakita is open to all children and youth from 7 to 16 years of age. It provides an opportunity to participate in outdoor activities in a safe environment while meeting other children with, and without, bleeding disorders. With the help of six hemophilia nurses from across the province, children with bleeding disorders learn to self-infuse at camp.

Hemophilia Ontario youth between the ages of 15-17 who are ready to take on a leadership role and learn more about caring for campers, are encouraged to

apply for the first year Senior Counselor (SC) program. SCs work alongside camp counselors where they take on a leadership role caring for campers, leading games, building camp skills, and attaining lifesaving qualifications. For more information, contact your Regional Service Coordinator.

NATIONAL

Canadian Hemophilia Society National Youth Committee: The CHS-NYC consists of energetic individuals who represent almost all regions of Canada who are working together to support, promote and address youth involvement within the organization.

SAVE THE DATE: This year's installment of the Youth Leadership Workshop held by the CHS-NYC will be held October 2nd-5th at the ME to WE Leadership Centre in Bethany Ontario. Any youth between the ages of 18-30 are encouraged to apply. For more information and to request a registration form, contact H  l  ne Bourgaize at hbourgaize@hemophilia.ca. Deadline for applications in June 30, 2014.

James Kreppner Memorial Scholarship and Bursary Program: In recognition that a sound education is of utmost importance, the Canadian Hemophilia Society offers the opportunity for those who qualify to receive a scholarship or bursary in the amount of \$5,000 to attend a post-secondary institution of their choice. James was a lawyer and long-time volunteer and member of the CHS Board of Directors and a highly respected activist who passed away in 2009 due to HIV and hepatitis C-related complications. This fund is an on-going tribute to honour James' dedication, intelligence and commitment to the CHS and community service. For more information, visit the Canadian Hemophilia Society website.

North American Camping Conference for Hemophilia Organizations (NACCHO): This event is held annually in Tempe Arizona, and is the only camping conference dedicated to creating and enhancing summer camp experiences for youth with bleeding disorders. Participants exchange resource materials, meet with representatives from the National Hemophilia Federation and share their most successful experiences with people from camps all over the world.

GLOBAL

Karttik Shah Youth Fellowship: The CHS Karttik Shah Youth Fellowship was initiated in memory of Karttik Shah of Toronto, Ontario, in recognition of his commitment to hemophilia youth programming in Canada and abroad, and for his participation over many years on the World Federation of Hemophilia Youth Committee. In order to promote the development of its future leaders the CHS offers one fellowship to enable a Canadian youth who is committed to long-term involvement in the CHS to attend the Hemophilia World Congress taking place bi-annually in a to be determined location globally.

International Twinning Projects: Twinning is a formal, two-way collaboration or partnership between emerging (developing country) and established Hemophilia associations. As hemophilia organizations in developed countries learn more about the hardships of people living with hemophilia in developing countries they often want to offer help. Twinning is one of many WFH programs and services designed to improve hemophilia care. This help comes in the form of programs and services including healthcare development programs, humanitarian aid, and the production of publications and materials.

World Federation of Hemophilia Youth Leadership Opportunities: The WFH youth programs help foster the next generation of leaders in the bleeding disorders community and ensure that they are well prepared to take over a leadership role. The WFH youth leadership program includes fellowships/scholarships, leadership skills training, and resources for young people. ♡

Upcoming HOY Camping Trip!

The youth were sent a survey, at the end of 2013, asking what their interests in the HOY program were and were not, what education interested them, and which activities they want to see run in 2014. One thing that was clear from the survey answers was that the youth want to focus on keeping the HOY program as a provincial entity, and that there is a large interest in the great outdoors. As a result, this year, the youth will be going on a camping trip! This trip will happen over the weekend of August 15-17, and will take place at Sibbald Point Provincial Park, just outside of Barrie.

This trip will be totally free!

If you are interested in attending, please contact 2014 HOY leads, TCOR RSC Laura Tomkins at ltomkins@hemophilia.on.ca or 416-972-0641 ext. 14, or OEOR RSC Amanda Grant at agrant@hemophilia.on.ca or 613-739-3845 ♡



Safety and Security of Treatment Today

by Ryan Kleefman

A secure and safe supply usually tops the list of main concerns for those receiving products such as factor. For this reason, it is important for us to be aware of what pharmaceutical companies are doing to improve the safety of the medications we receive. As a patient with a bachelor's degree in science, this information is relevant to me and is intended to help people advocate for themselves, and is not intended to be a recommendation of products discussed.

My second instalment in this series of articles about the supply of safe products will focus on Baxter and CSL Behring. The following information about Baxter is based on a press release by the Wall Street Journal which reveals Baxter's renewed commitment to innovation as well as improving patient outcomes. This press release covers much of Baxter's involvement in the World Federation of Hemophilia conference in Melbourne, Australia. The information about CSL Behring is based on their website's content.

One of the drugs in Baxter's research pipeline is a PEGylated factor for the treatment of hemophilia A. Baxter remains focused on ensuring the safety as well as the efficacy of this new product which is designed to reduce injection frequency by increasing the length of the half-life of the factor in the body. In the late stages of research and development this drug is continually tested in order to ensure patient safety.

Baxter reported on a global study on ADVATE. The results of the study show something which has not been reported before. Past studies showed favourable safety and efficacy of ADVATE, but this decade long meta-analysis was the first study to truly show the efficacy and safety of using recombinant factor VIII in real-world settings around the globe.

There was potentially positive news for those with von Willebrand disease. Baxter is currently testing the first recombinant factor replacement product for the treatment of this bleeding disorder. This improves upon the current treatment. Though current treatments are safe, they are derived from blood. A recombinant factor would increase the safety and security of the blood supply by removing the human input which has potential for disease transmission as well as by removing the reliance on donated blood because the factor would be produced in a similar process to other recombinant factors.

While blood derived products received much negative publicity due to the Tainted Blood Tragedy and the resulting knowledge of blood-borne contaminants, some bleeding disorder treatment products utilise human proteins in the manufacture of their medications. These blood-derived products are required to treat bleeding disorders for which recombinant factors are as yet unavailable.

CSL Behring is considered one of the leading pharmaceutical companies in the world in terms of plasma protein biotherapies. It has produced plasma products for over 65 years. Its facilities in Switzerland Germany, and Illinois hold contracts for purifying blood products in several countries, including Canada.

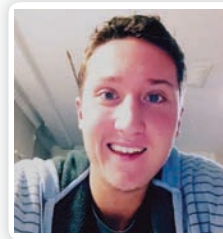
The immediate downside to the use of plasma-derived medications is the possibility of infections carried by human proteins used in the production of clotting factor products. However, the use of plasma-

derived products does reduce the cost of medications. Reduced cost does not compromise quality or safety.

CSL Behring's manufacturing is considered one of the most stringent and powerful in the pharmaceutical industry. One innovative safety measure is plasmapheresis. When a donor comes to give blood, a machine attached to the needle immediately separates a first blood sample into cells and plasma in order to ensure cleanliness and safety. Only after these initial tests are completed is the full second blood donation taken. When the blood reaches the laboratory, serum samples are tested for HIV, hepatitis, or any other pathogens. From the laboratory, samples go to a logistics centre where blood is then kept frozen and held in inventory until all the testing is completed. CSL Behring's manufacturing process uses fractionation, which separates blood into its different components. At the manufacturing facilities, therapies are packaged and lot samples are kept for further safety testing.

CSL Behring has invested much money into research and development toward safer products. Updates to manufacturing facilities, product safety measures, and process enhancements have virtually eliminated the risk of any viral transmission. CSL Behring's innovative process and commitment to product safety mean its clotting factors are among the highest quality available.

Safety of blood products, though it has improved immensely in recent years, must remain in the minds of those receiving products, whether recombinant or plasma-derived. It is important for patients and the community to be informed so that they can advocate for themselves as well as for future generations. ♦



by Zach Adams

Having been fortunate enough to attend the 2014 WFH World Congress from May 11-15 2014 in Melbourne, Australia, I felt as though I had many topics to draw from for this issue of *Blood Matters*. I narrowed my selection based on my interest, and often, the interest of others, in the development and advancement of new factor products and technologies. This is a topic that I feel

has brought with it much excitement and promise. Many decisions will have to be made by health care providers and patients; therefore, it is important to ensure awareness and understanding.

Two of the more common bioengineering principles focusing on extending factor half-life, which will be the focus of this article, include PEGylation and the use of fusion proteins. PEGylation is the use of a molecule termed polyethylene glycol that is made to bind to a specific site on the rFVIII protein thus increasing the molecular size/mass. This alteration will then increase half-life by assisting to prevent filtration, degradation and clearance. N8-GP is a PEGylated rFVIII developed through Novo-Nordisk that has shown a terminal half-life of 19 hours, 1.6 times greater than the previous product. BAY 94-9027, created by Bayer, has also shown a half-life of around 19 hours compared to the current 13 hours for rFVIII-FS. Baxter has created BAX855, which in preclinical studies on animal models has shown a 1.5-2 fold increase in half-life, with clinical studies still ongoing. When examining Hemophilia B, and FIX, Novo-Nordisk has developed N9-GP with studies showing a half-life of 93 hours, which is 5 times higher than the previous product. Secondly, fusion proteins, either Fc of Immunoglobulin G (IgG) or Albumin, are attached to the rFVIII

molecule and used to extend half-life. Using the Fc fusion, BiogenIdec has developed rFVIII-Fc, which has shown in clinical studies to maintain a half-life of 19 hours. They have also created rFIX-Fc, for Hemophilia B, which has shown a terminal half-life of 82 hours. Finally, CSL Bearing has developed rFIX-FP, in which albumin is bound to FIX and this has shown in clinical studies to have a 5 fold increase in half-life, thus leading them to suggest that “schedules involving weekly dosing or dosing every 2 weeks are feasible.”

Although these novel products are currently being tested and validated through clinical studies, they continue to provide us with a glimpse into the future of hemophilia care and prophylaxis. In an interesting article written by Dr. Carcao, he states, “With the advent of longer acting factor concentrates, prophylaxis regimen will almost certainly change. This will involve changes in what trough levels are targeted and how frequently factor is administered”¹. Therefore, continuing to remain vigilant and up to date regarding new products will facilitate knowledge and understanding for future decision-making regarding individualized treatment. ♦

All product information contained within this article was retrieved from the article titled “Novel products for haemostasis – current status” written by J. Oldenburg and T. Albert in the journal Haemophilia (2014).¹ Quote from Dr. Manual Carcao was found in article titled “Changing paradigm of prophylaxis with longer acting factor concentrates” in the journal Haemophilia (2014).



Hemophilia Ontario Advocacy for Safe Supply:

We Are Here To Be Your Voice

At Hemophilia Ontario, we are committed to making sure that all of our members have access to a safe and secure blood supply. If you ever have any issues with medication or factor access (at a clinic, whilst travelling, etc.) please contact your local Regional Service Coordinator and we will advocate on your behalf. ♦

What's Happening in the Bleeding Disorders World?

Hemophilia Ontario is not endorsing or recommending any of these findings. Please speak to your Hemophilia Treatment Centre about your own personal care and treatment.

A new “portable, noncontact, vein-illumination device,” called AccuVein, has been developed. According to Heidi Siegel, AccuVein’s director of marketing communications, this device “highlights the hemoglobin in the veins differently than the surrounding tissue, so it helps identify veins.”

“The user simply positions the device seven to 10 inches above the targeted area. Employing red and infrared light, the product then shows a real-time projection of the patient’s veins on the surface of the skin for clear vein targeting.” This revolutionary product is “engineered to be user friendly and simplistic” and is small enough to be able to fit into a clinician’s pocket.

Article source: <http://www.qmed.com/mpmn/article/vein-illumination-device-helps-clinicians-stick-it-first-time>

Many pharmaceutical companies are currently working on releasing new factor treatments this year for those living with Hemophilia A and B that will allow patients to infuse less often. These long-acting recombinant treatments will allow one to infuse half as often, if not even less.

Another benefit? According to an article found on the Reuters website, “some industry experts say these and other new treatments could help drive down the price of existing hemophilia products.” In addition, Dr. Guy Young, director of the Hemostasis and Thrombosis Center at Children’s Hospital Los Angeles, has stated that “when these drugs get on the market there will be pretty massive and quick uptake.” This article also goes on to state that “biotechnology companies...are working on methods to replace...hemophilia genes, allowing patients to begin producing their own clotting factor.”

Article source: <http://uk.reuters.com/article/2014/03/07/us-hemophilia-idUKBREA260OT20140307>

Another article [states] that by 2018 half of the hemophilia market share will be taken over by these emerging therapies. However[,] while the “developing countries of China and Argentina are anticipated to undergo significant hemophilia market growth by 2022, driven by increased rates of diagnosis and greater adoption of recombinant regimens...premium pricing opportunities for new products in these countries will still be restricted by the economic barriers that have traditionally prevented recombinant therapies from capturing substantial shares in these markets.”

Article source: <http://www.prcarbon.com/emerging-therapies-to-seize-half-of-hemophilia-market-share-by-2018-changing-landscape-says-reportstack/5216903/>



Regional General Meeting

All CWOR articles, unless otherwise noted, are by Alex McGillivray

CWOR held their Regional General Meeting on March 1st at Dundurn Castle. This year Linda Waterhouse, MSW and Alex McGillivray, RSC, presented information on financial programs and services that members can access. We also held our Volunteer Awards Ceremony to recognize volunteer efforts in the region as well as a delicious Greek lunch! Many thanks to the CWOR Council for helping to organize this event, Jane Dinsdale for organizing the delicious lunch, and Terri-Lee Higgins, Executive Director for making the trek to Hamilton. Also, a special thanks to our 'voluntold' photographer, Tyler McGillivray. ♡



Awards at the CWOR Regional General Meeting

Save the Dates

Men's Program - July 26th

Big Sale on the Little Street - September 6

Supercrawl BBQ Fundraiser - September 13 - 14

Aging Program - November 8

Winter Celebration/Camp Wanakita Registration
November 29 or December 7

****Dates are tentative and may potentially change****

Big Sale on the Little Street!

Have you done any Spring Cleaning? If you answered yes and still have some clutter hanging around, why not donate those unwanted items for a great cause? Help us raise money for programs and services in the Central West Region by donating those unwanted items to the Big Sale on the Little Street Fundraiser! This year we're looking for dishware, mugs, costume jewellery, gardening items, and household decor. We also welcome interesting knick knacks! If you have something you'd like to donate, please contact Mary Pedersen, CWOR Council Member at (905)524-2946 or dansker@cogeco.ca to arrange a drop off time. ♡

CWOR

Regional Council and Staff

Rob Dinsdale
Mary Pedersen
Igor Ristevski
Debbie Bordi
Meagan Bordi

CONTACT

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905-522-2545
amcgillivray@hemophilia.on.ca



World Hemophilia Day

April 17, 2014

All NEOR articles, unless otherwise noted, are by Stephanie Morrison

Betty-Anne, Tammy and Linda from our hemophilia treatment clinic and the RSC Stephanie were available to answer questions and hand out educational material to the public, raising awareness about bleeding disorders. Booths were set up on two separate days at Health Sciences North's main campus and the Sudbury Outpatient Clinic site. Visitors and staff of the hospital were given bandage dispensers and were encouraged to ask questions and take pamphlets. ♡



Betty-Anne, Tammy and Linda

Spring Clinic

The NEOR HTC held its spring clinic on Saturday June 7th. All who attended were invited to a "Lunch and Learn" education seminar focusing on the genetics of women with inherited bleeding disorders. The genetic counsellors from Health Sciences North gave a talk about how genetics plays a role in determining the type of bleeding disorder a woman might have and how severe a woman's bleeding disorder might be.

Our youth representative, Julia Fortunato, kept our younger members busy eating pizza and creating special crafts for Father's Day. ♦

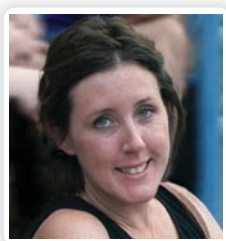
NEOR

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Betty-Anne Paradis
Joanne Beaulieu
Julia Fortunato
Tim Hewett
Shawn Morrison

Regional Council and Staff

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North Western Ontario Region



Region Changes

All NWOR articles, unless otherwise noted, are by Sarah Wood

We wanted to take this chance to say welcome to all of our new members in the North Western Ontario Region of Hemophilia Ontario, and welcome back to all of our existing members! We have seen some transition in this region with staffing and that has unfortunately resulted in a hiatus from the majority of programs and services in the region, but we are working to change that. We are committed to getting the much needed programs and services back up and running in the region and are really looking forward to connecting with all of you!

As a member, you can look forward to receiving monthly electronic newsletters from us where you will find out about what programs are coming up, educational opportunities, or just anything else happening in your region! You also have access to all of the programs and services, learning opportunities, and financial assistance that Hemophilia Ontario provides, so please get in touch with us if there is ever anything you need, or if you just want to get connected or say hi! We look forward to working with all of you :) ♦

Spring Clinic

On April 7 & 8 the North Western spring clinic was held in Thunder Bay at the Thunder Bay Regional Health Sciences Centre, and it was a big success! The next clinic will be happening in the fall so keep your eyes open for the dates. Hemophilia Ontario will be working on an education session for parents and their kids at this clinic as well, so get in touch with Terri-Lee Higgins: thiggins@hemophilia.on.ca to let us know what you would like to learn about! ♦

New Northern Council

Stephanie and I are very happy to announce that there is a new Council that has been formed to oversee activities in both Northern Regions. This Council works with both the North East and North West staff to guide and support all activities that concern the North. If you are interested in having a voice and making an impact in your region, get in touch and join the Council! ♦

NWOR

Shelley Hewett
Betty-Anne Paradis
Joanne Beaulieu
Julia Fortunato
Tim Hewett
Shawn Morrison

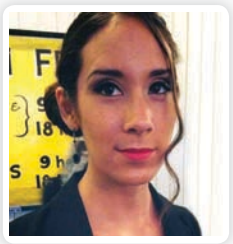
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Ottawa and Eastern Ontario Region

OEOR Welcome!

Amanda Grant joined the team late February and is the new Regional Service Coordinator in the Ottawa and Eastern Ontario Region. She is committed to helping non-profit organizations and is enjoying her work with Hemophilia Ontario and its members. ♦



Past Events

All OEOR articles, unless otherwise noted, are by Amanda Grant

Regional General Meeting

The OEOR RGM took place late afternoon at the Ottawa Police Association's beautiful location on Catherine Street. The meeting included many pharmaceutical representatives, Hemophilia Ontario registrants, Council and Ontario Board members. Pharmaceutical representatives delivered informative presentations about upcoming products and answered questions. Many of the new products have an increased half-life making the timing of the next dose later, which could substantially improve the quality of life for those with a bleeding disorder. During the meeting the new Ontario Board members were elected. The OEOR is happy to announce Raja Ammoury-Alami, Ashwani Kurichh, and Darlene Villeneuve as the voted in Ontario Board Members this year. The OEOR would like to thank all in attendance including the pharmaceutical representatives, and the accommodating staff at the Ottawa Police Association.

World Hemophilia Day

World Hemophilia Day was launched 25 years ago on April 17 by the World Federation of Hemophilia. Along with other regions, the OEOR this year set up a kiosk in the Gloucester Shopping Centre with the help of one of our new volunteers, Samara Noun accompanied Regional Service Coordinator, Amanda Grant. The general public was given resources and information on hemophilia, bleeding disorders with numerous open discussions on the protection and importance of Canada's blood supply. With the help of social media, passersby would send out a Tweet or Facebook message supporting World Hemophilia Day. Thank you Samara for your time and thanks to all that showed support. 💧



OEOR World Hemophilia Day Display

Future Events

OEOR 20th Annual Shawn Duford Golf Tournament

Summer is officially here and that brings with it the Shawn Duford Golf Tournament! The tournament has been well received over the years with over a hundred participants involved. Participants arrive during the afternoon, arriving in time for lunch. A shotgun start and best ball is how the tournament will begin. Dinner is available at the end of the tournament along with awards and prizes. It will be held at The Meadows Golf & Country Club on 4335 Hawthorne Road, Ottawa. It'll take place on August 9, 2014 at 1:00 pm. This is an event that

numerous Hemophilia Ontario members look forward to. We hope to see you there! For further information please contact Amanda Grant at agrant@hemophilia.on.ca

Parents Education Day

The OEOR is happy to announce their first Parents Education Day. This event will involve a panel of youth and a panel of parents talking about the issues around living with a bleeding disorder. This is an opportunity for parents to learn from youth about how to support someone with a disorder and struggles young people have throughout different age groups. The event is also geared toward parents of newborns with a bleeding disorder, which will provide further support to them throughout their child's lifespan. Please join us at the Heron Road Community Centre at 7:00pm on Wednesday, June 25.

Camp Wanakita

Camp Wanakita is full steam ahead with the highest youth turnout in the OEOR! Most consent forms have been sent to Laura Tomkins. If you have yet to send the consent form and any other important information please contact Laura Tomkins at ltomkins@hemophilia.on.ca. Transportation will be provided to camp on the morning of July 27 leaving the CHEO parking lot along with a parent volunteer. On August 9, transportation will arrive at Camp Wanakita along with an adult volunteer and will drop off campers at CHEO. Departure times will be announced shortly. For more information about transportation please contact Amanda Grant at agrant@hemophilia.on.ca.

Summer BBQ

August 24, 2014 will be the Ottawa Summer BBQ. The event will take place at Millennium Park in Orleans. This is a great opportunity for members to connect with each other, provide support, and enjoy the great outdoors. Join us for face painting, balloon toss, and of course, delicious food! For more information please contact Amanda Grant at agrant@hemophilia.on.ca

Look out for.:

OEOR Mild Hemophilia & Platelet Disorder Education Session

With the help of Diane Bissonnette and Lucie Lacasse, a Mild Hemophilia and Platelet Disorder Education Session will be in the works for the Ottawa region. Stay tuned for more information.

OEOR Kingston

Keep your eyes open for further information about our upcoming Aging with a Bleeding Disorder Session and the Community BBQ.

OEOR Bowl-a-thon

Ottawa is planning its annual Bowl-a-thon. The fundraiser will take place later this year with prizes to be won. The time and location of event to be announced on a later date. 💧

OEOR

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Ashwani Kurichh
Nancy Sauve
Anna Sicoli
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SWOR 5th Annual Polar Bear Dip

All SWOR articles, unless otherwise noted, are by Matthew Maynard

Mother Nature was kind to these brave dippers and gave them decent weather, but the water still was icy cold! Thanks so much to everyone who took the plunge at the 2014 SWOR Polar Bear Dip. You raised over \$6000 that will directly support programs and services in the region.

There were some great costumes and everyone got some fantastic sponsorship. The winner of most sponsorship was Hannah Higgins of London and the most donors was Mike Bondy of Lasalle. The winners of the superheros costume were Pam Cullen-Baron and Aliyah Baron.

Prizes were provided by Sport in Port Adventure Outfitters and great support from the Port Stanley BIA, Susan Tanton, Dave Jefferys, and Sharon Lomas along with all the donors and on beach supporters. We also had media support from MyFM and from Lake Erie Beacon. We are hoping that you will join us next year – our costume theme next year is Animals! 💧



SWOR Superheroes Polar Bear Dip

Upcoming Events

July 28 : World Hepatitis Day – in collaboration with Regional HIV/AIDS Connection, SWOR will be promoting testing and awareness at the Central Library, London as well as working with other service providers in the region to awareness and testing to other cities throughout the region.

August 21-24: Pinecrest Adventures Camp, Camp Menesetung Goderich, ON. This 5 day residential camping experience for children with a bleeding disorder and their siblings aged 5-15 years, offers knowledgeable and specially trained volunteer staff (medical, co-directors and counsellors) on site 24 hours per day. August 20th will be a staff training and preparation day on site.

September 27: 7th Annual Golf Tournament for Hemophilia and Inherited Bleeding Disorders, Ingersoll Golf Club, Ingersoll, ON

Education Day and Regional General Meeting

SWOR enjoyed a successful education day followed by the Regional General Meeting. Thanks to Shannon Lane, Dr. Walid Shammam and our panel of experts, Adriana, Marco, Johnny, Michelle, John and Pam for their presentations on their understanding of treating a bleeding disorder. During lunch, which was provided by Youth Opportunities Unlimited Café, a London social enterprise, we celebrated 26 years of service and contribution by Sheila Schembri to the Bleeding Disorders Program. This was followed by Zach, Eric and Pam offering unique global perspectives of camps, programs, and congresses. During the Regional General Meeting we celebrated our volunteer of the year Maureen Schaus. We would like to thank Maureen, Dawn, Ryan, Holly, and Jeff for all their compassion and work for SWOR in the past year. 💧



Maureen Schaus
SWOR Volunteer of the Year

Scrapilicious

March 22 was a wonderful day - thank you to ALL who came, donated, encouraged, it was great fun! We'll look forward to next year - maybe even getting more accomplished than we did this year - and gaining new tidbits of information and creative ways to do things in scrapbooking! We celebrated a birthday and gained new awareness of bleeding disorders that affect women, thanks Michelle, for Skyping in and presenting. Altogether - a great day! Special thanks to our organizers Kathleen, Marion, Heather and also our setup help from Ruby and the cleanup help from Eric and Laurie. 💧



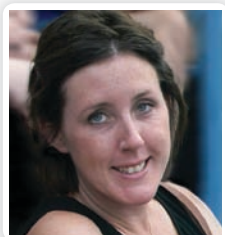
SWOR Scrapbooking

SWOR

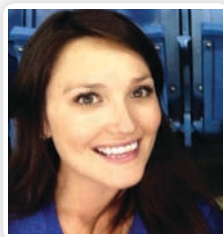
Regional Council and Staff

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Kathleen Hazelwood
Travis Hazelwood
Hannah Higgins
Julia Lepera
Michelle Lepera
Monica Mamut
Leigh McFadden
Marion Stolte
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Sarah Wood



Laura Tomkins

What's Happening in TCOR

World Hepatitis Day is Monday July 28., 2014
Stay tuned for events in your area.

TCOR Golf Tournament will be held on Friday September 12, once again at the beautiful Nobleton Lakes Golf Club. Take a day off work and come enjoy great weather, company, food, and golfing, all for a good cause! Please contact Susan Turner for more information.

Dr. Paula James will, once again, host the annual VWD webinar on Thursday September 18 at 7:00 pm. In order to not be repetitive to past years' webinars, this year's webinar will focus on women with inherited bleeding disorders and iron loss. As you don't even have to leave your home in order to participate, make sure to register with Laura Tomkins for login info!

Commemorative Event for TCOR will be held on Sunday November 9, 2014. Please contact Laura Tomkins if you have any ideas you would like to share for this event.

The Winter Families in Touch/Camp Wanakita Registration event will be on Sunday December 7, 2014 ... Our most popular event of the year! Make sure to be there for a fun time! 💧

What Has Happened in TCOR

March 1 the TCOR Regional General Meeting took place at the RINX Entertainment Centre. TCOR members networked, enjoyed lunch, learned about what Hemophilia Ontario has been up to this past year, including upcoming events and Twinning, and were able to listen to a fabulous presentation by John Schmitke on his experiences being a young man with a bleeding disorder and how he took control of his care and his life.



TCOR Volunteer Award Recipients

On Sunday March 23 almost 40 TCOR members braved the cold and came out to the annual Polar Bear Dip. Woodbine Beach was full of superheroes, with 10 of them plunging into the cold waters of Lake Ontario! A great warm up led by Lole Ambassador Angela Donovan Jackson was accompanied with music, food, and socializing, and over \$9500 being raised for research and TCOR programs and events!



TCOR Polar Bear Dip

Friday April 17 was World Hemophilia Day, and TCOR was at both SickKids and St. Michael's interacting with those in the hospitals to spread the word about bleeding disorders. The booth was a popular attraction!

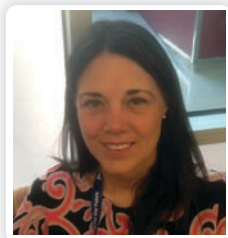
On Sunday May 4 the 2nd annual Aging with a Bleeding Disorder event was held. Based on last year's inaugural and very popular event, this year's event once again drew a crowd. A fabulous lunch was accompanied by 4 amazing speakers: hematologist Dr. Michelle Scholberg, physiotherapist Laurence Boma-Fisher, naturopathic doctor Dr. Jean-Jacques Dugoua, and TCOR RSC Sarah Wood who spoke about accessing homecare. 💧

TCOR

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Stages of Living with a Bleeding Disorder

by Linda Waterhouse, Social Worker,
Hamilton-Niagara Regional Hemophilia Centre

Adapted from "Social Work in Hemophilia Care" – a presentation by Anne Vaughan MSW RSW

Hemophilia challenges and affects all family members not only the person diagnosed with hemophilia. These challenges change as one travels over all the developmental stages. Each challenge is unique to the individual and their family as well as their medical treatment plan and bleeding disorder severity.

There is an immediate impact on parents and extended family members when the diagnosis of a bleeding disorder is made. This impact can include feelings of grief, sadness, anger, resentment and denial. Family members may experience shock particularly if there is no known history of hemophilia in the family. There may also be feelings of guilt experienced by parents as they struggle with the knowledge they may be the one whom the child inherited the diagnosis from. For some parents they may be learning of their carrier status for the first time. Many family members experience feelings of fear due to lack of knowledge about hemophilia and its' treatment. Some families bring with them a past history and experience of bleeding disorders that includes feelings and memories of family members treated with tainted blood products or left with severe disabilities from bleeds. A new diagnosis brings with it both hopes and fears for the future of their child.

During infancy and early childhood both parents and child may struggle with the fear of coming to the hospital, requiring medical procedures and receiving needles. Parents often struggle with the balance of giving their child independence and the need to protect their child from injury and trips to the hospital. As children enter school parents become the advocate and educator to school staff as they seek to ensure a safe environment for their children to learn and grow. Children share they just want to be seen as normal by their peers. They want to participate in sports and other school activities and do not want to be seen as different from their classmates. At this same time clinic staff are teaching the child more about their hemophilia diagnosis and how to recognize bleeds and causes of pain. Children are taught how to self-infuse and begin to take more responsibility of their treatment and self-care. As children move into their adolescence they strive for normalcy and to be accepted by their peer group while they recognize and learn to accept certain limitations that that may impact their choices of activities and careers.

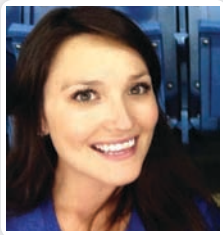
In adulthood, people with hemophilia navigate issues that might arise as they develop intimate relationships and begin families of their own. Adults must manage changes in treatment regimens and physical complications that that may force them to take time off from work or post-secondary education programs or training. Being in a career that is financially rewarding so as to be able to provide financially for themselves and their families as well as a career that has benefits and flexibility are important to people with bleeding disorders.

Through every step of the life's journey with hemophilia the Hemophilia Treatment Centre Team is there to provide education, support and reassurance that you and your family are not alone. ♦

Ontario Treatment Centres

Visit <http://www.hemophilia.ca/en/provincial-chapters/ontario/treatment-centres/> for detailed contact information for each of the bleeding disorders treatment centres in Ontario. ♦

- Hamilton Health Sciences Corporation
- London Health Sciences Centre
- Thunder Bay Regional Health Sciences Centre
- Sudbury Regional Hospital
- St. Michael's Hospital
- Hospital for Sick Children
- Kingston General Hospital
- The Ottawa Hospital
- Children's Hospital of Eastern Ontario



Paid Plasma Updates

by Laura Tomkins

This information is not provided as a reflection of Hemophilia Ontario or the Canadian Hemophilia Society's views on this matter, but rather as an educational piece aiming to keep members up-to-date on this issue.

Lots of news surrounding the possible introduction of three clinics into Ontario, two in Toronto and one in Hamilton, which will offer those who donate their plasma "payouts in the form of donations to the Hospital for Sick Children in the donor's name or \$25 Visa gift cards". (http://www.thestar.com/news/canada/2014/03/18/plasma_clinic_threatened_with_court_order_by_ontario_government.html#).

Below is a collection of news pieces that highlight where things are with these clinics. According to the Government of Ontario's website in an article titled "Preserving Ontario's Voluntary Blood Donation System":

- "On June 27, 2013, the federal government indicated that it considers payment to blood and plasma donors to be within the jurisdiction of provinces and territories."
- "Currently, there is no legislation specifically prohibiting paying for blood or plasma donations in Ontario."

Deb Matthews released a letter on March 14, 2014, which can be seen at http://www.health.gov.on.ca/en/news/bulletin/2014/hb_20140314_1.aspx, stating that she intends "to propose regulatory amendments that, if enacted, would strengthen the licensing requirements for labs and specimen collection centres to prohibit paying donors for their blood or blood constituents, including reimbursement of expenses or other forms of compensation" and to also "introduce new legislation in the coming weeks that, if passed, would clearly prohibit making payments to blood donors in Ontario. This proposed legislation would also amend the legislation governing labs and specimen collection centres to expand the public interest grounds to deny a licence for new blood collection facilities and to strengthen our lab enforcement regime so we can take quick and decisive action in case of violations." The legislation which was introduced was not passed prior to the call for election.

Some other notable facts surrounding this matter are as follows:

- Currently, the only place where it is illegal to pay for plasma in Canada is Quebec.
- Currently, the only place available where you can be paid to donate plasma in Canada is Manitoba.
- There are debates about, "if plasma needs to be collected in Canada".
- There are debates around where this plasma, if collected, will be used; within Canada or not.
- There are debates on whether paying people to donate plasma will decrease the rate of those donating for altruistic purposes.
- There are debates whether the blood collected will be safe or if it would put the blood supply at risk.

For more information, please visit these various media links. The opinions in these articles do not necessarily reflect those of Hemophilia Ontario or the Canadian Hemophilia Society. ♦

<http://diablogue.org/2014/04/25/big-pharma-backed-patient-groups-attack-bill-banning-paid-blood-and-plasma-collection/>

<http://diablogue.org/2014/04/24/will-act-banning-paid-blood-and-plasma-collection-die-in-committee/>

<http://www.theglobeandmail.com/globe-debate/why-we-shouldnt-pay-canadians-to-donate-blood/article18123479/>



<http://www.ctvnews.ca/health/ontario-vows-to-shut-private-clinics-that-pay-people-for-blood-plasma-donations-1.1734926#ixzz2wMcGYE8E>

<http://www.lfpress.com/2014/03/14/ontario-health-minister-deb-matthews-opposed-to-paying-for-blood-and-plasma>

<http://www.theglobeandmail.com/news/toronto/proposal-for-paid-blood-plasma-donations-prompts-concerns/article16640008/>

http://www.thestar.com/news/queenspark/2014/03/14/ontario_pulls_the_plug_on_private_blood_clinics.html

<http://impactethics.ca/2013/08/06/policy-laundering-and-payment-for-plasma/>

http://www.thestar.com/news/canada/2014/05/02/key_liberal_legislation_dies_with_rejection_of_ontario_budget.html



Access Delayed is Access Denied: Regulatory Challenges Regarding Hepatitis C Treatment

by Paul Sutton
Former Policy Researcher, Canadian Treatment Action Council (CTAC)

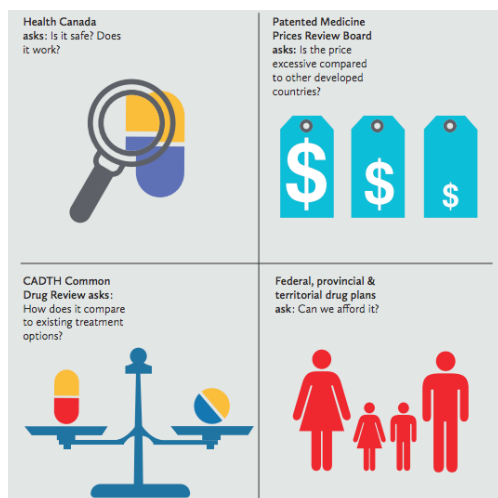
Currently, the most pressing issue in hepatitis C treatment access relates to how new medications are recommended and funded on public pharmaceutical plans. Because hepatitis C treatment is very expensive (the current standard of care of pegylated interferon, ribavirin and boceprevir or telaprevir costs around \$70 000), most people living with hepatitis C access treatment through a public plan – either as part of class action settlement benefits following the tainted blood scandal, through disability health plans, or through catastrophic drug coverage (like the Trillium Drug Benefit in Ontario).



Because they are publicly administered, these plans are required to make treatment listing decisions with a finite set of resources in mind. Public health plan managers and their staff look at the comparative clinical benefits of new medications, the associated costs (in terms of actual treatment expense as well as upstream and/or long-term financial savings to the health system), as well as what can fit in the budget in a given year. Financial limitations result in hard decisions, and it's important that we, as people either living with or with a vested interest in the health outcomes of people living with hepatitis C, ensure these decisions don't have negative impacts.

In order to make best use of financial resources, prior to being listed on public plans, new medications approved for use in Canada (such as simeprevir and sofosbuvir) are assessed by the Common Drug Review (CDR). The Common Drug Review is what's known as a health technology assessment; in other words, it's a body that makes evidence-informed recommendations on whether new treatments

are safe, effective, and cost-effective, keeping a variety of factors (like broad health system expenditures, such as decreased hospital visits) in mind. Important to note, all public pharmaceutical plans including the 6 federally administered drug plans, participate in the Common Drug Review, with the exception of Québec.



This graphic shows the four steps by which new medications are reviewed and come to market on public plans in Canada. Source: Canadian Agency for Drugs and Technology in Health (cadth.ca)

The amazing advances that we're seeing in hepatitis C treatment are coming at an inopportune time. There are three major pressures mounting on the Canadian public drug coverage: multiple new drug submissions (outside of hepatitis C and HIV) are straining regulators' abilities to make quick decisions; a new inter-provincial and inter-territorial scheme to bulk purchase brand name drugs (the Pan-Canadian Purchasing Alliance or PCPA); and ongoing funding freezes or cuts to public services.

The Common Drug Review, which reviews evidence about new medications approved by Health Canada before provincial, federal and territorial drug plans (outside of Québec) agree to list them, has been overrun lately by new submissions. Because the CDR has limited resources (it's financially supported by its member drug plans), it made a decision midway through 2013 that it can only assess 2 new medications at each meeting of its Canadian Drug Expert Committee (CDEC) – the advisory body that approves new medications.

Because of this limitation, the CDR has "queued" many new medications waiting to be assessed, and is tackling new files on a first come, first served basis. While this approach may seem fair, it means new, life-saving medications are being considered after less clinically important drugs. A good example of this is how a new indication for botox is going to be considered by the CDEC before they consider simeprevir.

Because of these delays, the CDR is not expected to make recommendations on either simeprevir or sofosbuvir prior to late summer or fall 2014. Considering all the people who have been patiently waiting these important advances in treatment, this just isn't acceptable.

Added to this, a new interprovincial bulk drug purchasing scheme (the Pan-Canadian Purchasing Alliance, or PCPA) also stands to delay access to hepatitis C treatment. While many of us recognize the need for governments to get control of rising health system costs, including brand-name and generic treatments, a lot of uncertainty exists around how the PCPA operates.

What we currently know is that the Government of Ontario administers the PCPA, informing manufacturers whose medications have been recommended by the CDR that the PCPA plans to enter negotiations to list the new drug on their plans. From there, provinces and territories can decide whether they want to "opt in" to the group negotiations. From there, the per-unit cost of a medication is negotiated by the governments and the manufacturer.

While this process may sound wise, there are some potentially drastic consequences for patients. First, all provinces and territories are allowed to "opt in", but are allowed to "opt out" at any time; they are not compelled to list the drug when negotiations conclude. Further, once a province or territory has opted out, they are forbidden to negotiate with the manufacturer for another two years.

This is a concern because provinces and territories with fewer resources have no disincentive to join in the negotiations – after all, they're likely to get the best possible price through collective bargaining. However, if a provincial or territorial drug plan manager then decides that they just can't afford the new medication at the negotiated price, patients (including people living with hepatitis C) won't be able to get access to the new medication for at least two years. On top of all of this, there's currently no patient input mechanism for the PCPA, and negotiations take place in secret; the PCPA doesn't even have a website that announces negotiations completed or in progress.

This is especially bad considering the barrage of news reports all of us are seeing on a daily basis on spiralling health system expenditures and the need to get costs, including pharmaceutical costs, under control. These pressures are expected to combine with the PCPA's strict limitations on future negotiations to spell bad outcomes for patients – and especially, people living with hepatitis C who are awaiting innovative and costly therapies.

Taking Action! CTAC's Hepatitis C Work and How You Can Help

CTAC, as Canada's civil society organization taking the lead on access for HIV and hepatitis C treatment, is engaged in a number of activities to speed up availability of new treatments and ensuring they're available to all in need.

Our organization is engaging closely with our colleagues at the Canadian Agency for Drugs and Technology in Health (CADTH), the organization that runs the Common Drug Review, to address some of the delays that have emerged. We are encouraging the CDR to assess life-saving medications (such as those to treat hepatitis C and HIV) by prioritizing medications based on quality of life data instead of on a "first come, first served" basis.

Further, we are currently updating our position paper on the CDR in light of the Pan-Canadian Purchasing Alliance. Available later this spring, we will be consulting with people living with HIV and hepatitis C across the country to deliver recommendations to reform the CDR, making it more efficient and ensuring it can react quickly when much-needed new drugs emerge.

Additionally, CADTH is undertaking a Therapeutic Review on new hepatitis C treatments.

The goal of the review is to help participating drug plans make evidence-informed decisions about which new treatments are expected to help patients the most, while remaining cost-effective. We have provided guidance to CADTH on this review, encouraging them to recommend hepatitis C treatments to become available for all who need it. After all, we won't be able to cure hepatitis C at the population level if they are only offered to people who already have significant liver scarring – especially considering recent evidence shows the earlier a person is treated, the more likely they are to achieve a sustained virological response and cure their hepatitis C. To learn more about CADTH's Therapeutic Review, please visit their website at <http://www.cadth.ca>

We're just *beginning* the fight to ensure a safe, effective and highly tolerable cure for hepatitis C is available to all who need it. And in order to win, we're going to need your help.

Please visit www.ctac.ca to learn more about our work in this area, and to join us in action opportunities over the coming year to take action on getting access to a hepatitis C cure. 💧

Hepatitis C and HIV/AIDS News Flashes

People with HIV and HCV co-infection experience more rapid liver disease progression, on average, and do not respond as well to interferon as those with HCV alone. But direct-acting drugs may help reduce this disparity.

The hepatitis C protease inhibitor faldaprevir added to pegylated interferon and ribavirin cured hepatitis C in nearly three-quarters of people with genotype 1 hepatitis C virus (HCV) and HIV co-infection... equaling response rates for people with hepatitis C alone.

Article source: <http://www.aidsmap.com/page/2832775/>

Not only do people with HCV have a 30 times higher risk of death from liver cancer, compared to those without the virus but a new study released has found that they "also have a higher risk of dying early from non-Hodgkin lymphoma, pancreatic, rectal, and oral or pharyngeal cancers".

Researchers reported; 'persons with chronic hepatitis C died an average of 12 years earlier than the general population from 12 different cancers - i.e., bladder, breast, colon, esophagus, leukemia, liver, lung, non-Hodgkin lymphoma, oral, pancreatic, prostate and rectal cancers.'

Article source: <http://hepatitisnewdrugs.blogspot.ca/2014/03/hcv-weekend-reading-hepatitis-c-and-non.html>

A new report has been released stating that "hepatitis C is 'under-documented'" with "only about 20% of people with HCV-related chronic liver disease had this listed as a cause of death."

Even if we exclude other diseases associated with HCV infection such as diabetes and non-Hodgkin lymphoma, it appears that most are dying not just with HCV but... possibly from HCV.

Article source: <http://www.hivandhepatitis.com/hcv-epidemiology/4531-deaths-due-to-hepatitis-c-likely-undercounted>

To read an article comparing different types of herbal and dietary supplements and their impact, in combinations with medications, on those living with hepatitis C. The supplements being reviewed include items such as vitamin D, antioxidants, green tea extract, and traditional Chinese herbal medications , please visit:

Article source: <http://hepatitisnewdrugs.blogspot.ca/2014/02/2014-complementary-and-alternative.html>

Researchers in British Columbia performed a study from 1996-2011 to see "how well people living with HIV are being engaged in the continuum of services needed to achieve an undetectable viral load—including testing and diagnosis, care and support, and treatment." As a result while 67% "had been linked to care" in 2011, only 53% were receiving care and only 51% had actually started antiretroviral treatment (ART). As well, only 35% who started ART had an undetectable viral load. ART "can suppress HIV replication in the body and lower the viral load (amount of virus) in a person's bodily fluids to undetectable levels." As a result, the researchers concluded that "interventions are needed to improve services at every stage of the cascade—HIV testing and diagnosis, linkage to care, retention in care, access to treatment and adherence to treatment. Such efforts have the potential to improve the health of people living with HIV and reduce the number of new HIV infections."

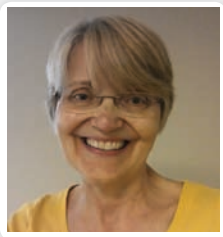
Article source: <http://www.catie.ca/en/catienews/2014-02-19/gaps-british-columbia-s-hiv-treatment-cascade>

25% of Canadians who are HIV positive do not know it, and "people who are unaware of their infection status may only seek care when they are very ill." As a result, researchers in Winnipeg offered rapid HIV testing to 501 adults seeking care in hospital emergency rooms. In turn, "the vast majority of people (96%) who underwent rapid HIV testing and counselling reported satisfaction with the test" and "agreed that they would be willing to have rapid HIV testing in a hospital's ER should they be offered the opportunity again in the future." As well, "93% of participants stated that such testing and counselling were appropriate for the ER."

On top of this, while these researchers did not target specific HIV risk groups, 7 cases of HIV were uncovered through this study.

These "seven cases were quickly linked to an HIV specialist," and, as seen in a recent study done in San Francisco, "being in the hospital and having access to thoughtful, caring and sensitive staff provided newly diagnosed patients with emotional support and education about the many benefits of modern ART and the likelihood of surviving for several decades after initiating therapy. This education helped to build trust with the medical-healthcare system and according to researchers, 'instilled a sense of hope about the future, as their response to an HIV diagnosis remained characterized by fear of death, even 30 years into the epidemic."

Article source: <http://www.catie.ca/en/catienews/2014-02-04/most-manitoba-patients-satisfied-hiv-testing-emergency-room>



Lifespan of Support in HIV and Bleeding Disorders

by Gloria Aykroyd,
Social Worker, Infectious Diseases Care Program, St. Joseph's Hospital

Since 1991, I have worked at St. Joseph's Hospital's Infectious Diseases Care Program, (formerly called the HIV Care Programme), in London Ontario. The scope of the program includes working with anyone living with HIV or co-infected with HIV/HCV. When I started at the clinic I quickly gained an understanding of the complexities of what it meant to live with HIV that was so stigmatized and discriminated against. There was so much anger among so many people with a focus on how people got it ..."blaming" was a predictable response. There were hardly any treatments available back then.

I remember my introduction to the Hemophilia Program at our hospital. Dr. Martin Inwood and Liz Clegg helped me learn very quickly about bleeding disorders, and of the great loss of many lives from HIV within the hemophilia community. Parents of children and adults living with hemophilia felt let down by the system, the one that gave them their 'life saving' blood, tainted blood. They questioned if they could trust product after what happened.

I remember the sounds of laughter and friendships that were made at the monthly children's IVIG clinic; the nurses and the play therapist in their midst. I would meet with the parents to help them work through their thoughts and feelings and gain support from one another. Some parents felt angst... would they see their child grow up or would they die? Over time, with the advent of new treatments and longevity becoming more of a reality, we no longer needed those IV treatments or the group. There was hope, but as these children grew, they were filled with questions. "Will I really grow up? How can I tell people? Will anyone want to date me... be with me? I not only have hemophilia but have HIV (and for some Hepatitis C) too". Some weren't told for a very long time about their diagnosis as they were too young. Some did die. Some lived. Some went on to adulthood, living a full life. Others have struggled with fear of taking the risk to find someone, to be in a relationship. As Nelson Mandela has said, "Courage is not the absence of fear, but the triumph over it." I hope one day they can feel that way.

We have come a long way in the fight against this illness and the accompanying stigma and discrimination. People are living longer and there is hope like never before. But, until there is a cure, I hold dear to my heart what Melinda Gates (Bill Gates' wife) has said:

"But above all, and unlike so many other great works, ending AIDS will not be the success of one great scientist, one great community worker, or one great leader; it will be an accomplishment of the whole human family working together for one another." ♦

New Hemophilia Ontario Collaborations in the HIV/AIDS and Hepatitis C Communities

Stephanie Morrison, NEOR RSC, recently had the opportunity to meet with Richard Rainville, Executive Director of Reseau Access Network, the HIV/AIDS Access Centre in Sudbury. In the coming months she will be meeting with all of the staff at the centre, learning how the services provided help members of the Sudbury and district community as well as bleeding disorder members who may have been affected by the tainted blood tragedy.

On April 23, Amanda Grant, OEOR RSC, had the opportunity to meet Shelly Terkuc event coordinator of Ottawa HIV Primary Care Group. The group's focus is around "education, discussion and local information-sharing for primary care physicians and allied health care workers who are involved in HIV care in the community." Primary Care meets every 3rd Wednesday of every month between September to June to discuss upcoming treatments and to network. All meetings are chaired by Dr. Len Moore at OASIS in the Sandy Hill Community Health Centre. Before the guest speaker begins, the group often takes a couple minutes for attendees to mention community announcements, including Public Health warnings, and trends, etc. As part of Hemophilia Ontario's objectives, by providing services to those living with bleeding disorders and/or communities in need of support with public health, RSC Amanda Grant will throughout the year encourage protection against sexual transmitted infections by handing out resources and attending future community forums. ♦

Healthy Living with a Bleeding Disorder



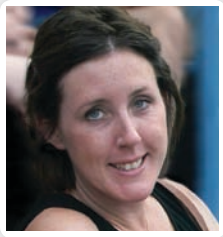
Now Experience Wellness

A New Program

by Terri-Lee Higgins

The NEW program provides funding for youth 17 years of age and under living with an inherited bleeding disorder to participate in first time physical activities, or other activities toward promoting healthy lifestyles. Together with the Ontario Physiotherapists we are working on the brochure and program details and plan to introduce the program by the summer.

For brochures and further details contact your Regional Service Coordinator. ♦



Let's Get Physical: Finding What's Right For You

by Sarah Wood

Summer is quickly approaching and that means people, especially children, are going to be participating in more sports and activities and maybe even trying something new. Previous *Blood Matters* articles have discussed the importance of physical activity in terms of weight management, joint care, and flexibility, but now we will discuss which activities have the highest and lowest risk levels. In general, people with bleeding disorders should steer clear of activities that involve contact or are high impact as they drastically increase the chances of bleeding and injuries. Regardless of its risk level, what may be a good sport or activity for one person may not be great for someone else – there are many things to consider. Before starting any new activity a person should always check with their Hemophilia Treatment Centre and ensure they are using the required protective devices and treating accordingly. The following list can be found in the National Hemophilia Foundations Playing It Safe book. 📖

Article source: <http://www.hemophilia.org/NHFWeb/Resource/StaticPages/menu0/menu2/menu35/menu204/PlayingItSafe.pdf>

SAFE

- | | |
|--------------------|-----------------------|
| Archery | Golf |
| Aquatics | Hiking |
| Elliptical Machine | Martial Arts/ Tai Chi |
| Stationary Bike | Snorkelling |
| Fishing | Swimming |
| Frisbee | Walking |

SAFE to MODERATE

- | | |
|------------------|----------------------------|
| Bicycling | Spinning Classes |
| Rowing Machine | Frisbee Golf |
| Ski Machine | Pilates |
| Treadmill | Resistance Weight Training |
| Circuit Training | |

MODERATE

- | | |
|---------------------|----------------------|
| Aerobics | Indoor Rock Climbing |
| Bowling | Roller Skating |
| Stepping Machine | Rowing |
| Dancing | Cross Country Skiing |
| Recreational Diving | T-Ball |
| Cardio Kick Boxing | Tennis |
| Ultimate Frisbee | Yoga |
| Jumping Rope | |

MODERATE to DANGEROUS

- | | |
|---------------------|-----------------|
| Baseball | Racquetball |
| Basketball | River Rafting |
| Canoeing | Scuba Diving |
| Cheerleading | Skateboarding |
| Gymnastics | Track and Field |
| Horseback Riding | Downhill Skiing |
| Ice Skating | Snowboarding |
| Inline Skating | Soccer |
| Jet Skiing | Softball |
| Kayaking | Surfing |
| Kung Fu/Tae Kwan Do | Volleyball |
| Mountain Biking | Water-skiing |

DANGEROUS

- | | |
|--------------------|-----------------------|
| BMX Racing | Power Weight Lifting |
| Boxing | Outdoor Rock Climbing |
| Competitive Diving | Rugby |
| Football | Snowmobiling |
| Hockey | Trampoline |
| Lacrosse | Weight Lifting |
| Motorcycling | Wrestling |

Feature Articles

Bleeding Disorders Across the Lifespan:

Patients & Caregivers Perspectives

Living with a bleeding disorder looks different for every person, at every age, during every stage of life. While we all may share similar experiences and that can help connect us at times, each of our own journeys is unique to us and those around us. With the advances in treatment and care in the bleeding disorders world, we now have patients that are living from infancy through to old age, and while this is a fortunate advancement, it also adds chapters to everyone's unique story. So often we focus on the person living with the bleeding disorder and their experience, but some of the most compelling and powerful stories also come from the caregivers of these people, the loved ones who do the infusions, who drive to medical appointments, who hold our hands when we get our initial diagnosis, and who care for us throughout our lives and our health struggles. These people are our support, our backbone, our team, and too often, their stories go unheard. In the next pages you will see small parts of the incredible stories and experiences of patients and their loved ones as they share a bit about what it means to live with a bleeding disorder through the lifespan.



"I think he has Hemophilia, but we need to run some tests first"

– the doctor said

We were in the hospital's emergency room with our one week old son soaked in blood and this was the first time we heard about Hemophilia. I had no idea what it was or where it came from as there was no history in the family.

Hi, my name is Ayeh and I am

the mother of a little boy with severe Hemophilia A. He was diagnosed after a post-circumcision bleed. It was confusing enough to be first time parents trying to learn how to take care of a new born and the diagnosis of Hemophilia made things even more complicated. Being a young immigrant couple with no family members and few friends, we started our journey on the bumpy road of living with a bleeding disorder. I was diagnosed as the carrier and felt extremely guilty for passing the gene to my child. It was very hard to get over that part.

Little by little we started to learn and adapt to the new situation and soon we discovered that we were living a totally different life than other parents. Things that were taken for granted by them were serious issues for us, like a new born scratching his face, a toddler struggling to stand up on his feet, or a little runner bumping into furniture or walls. Each of these "little" accidents could turn into serious issues. As a result, it was extremely stressful to go on long trips, camping out, or even attending crowded parties. Finding a baby sitter was also another issue so I ended up giving up on work to be able to be a 24/7 on call emergency responder. Even though it was hard, it helped with overcoming the feeling of helplessness and guilt.

One day when he was 11 months old, he held on to the coffee table and stood up, then let go and landed on his bum to a sitting position. This simple natural move caused him a soft tissue bleed. This particular bleed had two outcomes for us, first we found out he had developed an inhibitor, and second, we realized how his injuries may look to the public. We were told to be careful changing his diapers in public because if someone were to see that big bruise, they might call the police accusing us of beating our baby!!!

People who have no idea what bleeding disorders are play an important role in our life. They are all around us and it's a challenge to try to have a "normal" life when most people around you don't treat you as "normal!" Living with a bleeding disorder for 10 years taught us how important it is to educate others.

Along with all the hospital visits, blood tests, surgeries, and countless number of needles, it was extremely hard and frustrating to deal with kindergarten and school when he was younger. Over the years I started developing an allergy to my cell phone ringing! The only time I didn't mind getting a call on my cell is when he was right in front of my eyes and I knew, it wasn't someone from school calling to say he had a bleed. In his first school, they were mostly supportive and his homeroom teachers started to learn how to deal with the situation pretty quickly. Unfortunately it was a challenge to get the other staff to be educated. Even though we were there for 4 years, I never succeeded in persuading them to have an educational session for staff. In the second school, we only lasted 5 months!!! The only thing they were willing to do was pulling him out of any kind of activities at gym and separate him from other kids. They totally rejected the offer to be part of the "comprehensive care-parent-school" circle. It was one of the most stressful and challenging periods of our life and emotionally affected us all pretty seriously. His current school is

fantastic though. They are extremely supportive of our situation and very open to learn about it. Hemophilia is not a problem for us here and for the first time it feels like we belong.

Of course it is not a lasting "happily ever after" ending and he will eventually be out of school and out in the world again. All this has made me realize how important information is and how different life could be if others around us are educated and informed. I've learned that supporting our not so large community and spreading awareness makes life much easier for my kid, to us as parents and caregivers, and also the next generation of bleeders to come. ♦

Ayeh Hamidan, mother of a son with hemophilia



"Caring is universal. There are only four kinds of people in the world, those who have been a caregiver, those who currently are caregivers, those who used to be caregivers and those who will need caregivers."

– Rosalind Carter

While considering this topic recently, I found this quotation. Clearly Mrs. Carter is trying to

convey that we all will be affected one way or another and for many of us, in more than one category. The recipient is almost always someone who cannot look after him/herself, a child or adult with considerable medical needs, terminal illness, disability or dementia to name a few. Caregivers spend a significant amount of time caring for their family member or friend: some studies suggest at least 20 hours a week but for many, particularly parents of severely disabled children, it is a twenty four hour a day responsibility with negligible assistance or relief, accompanied by the worry of who will carry on when they are gone. Most caregivers don't consider their own needs, including rest and personal health, not acknowledging that their ability to care for someone else depends on their own well-being.

This is an uncomfortable realization following our family's experience nearly 18 years ago, which I doubt differs much from that of many families in the hemophilia community at the time. Struggling to maintain some semblance of normalcy, working, fitting in appointments, treatments etc. sometimes was overwhelming, complicated by my own stubborn conviction that I could do it all, something common to caregivers, I have learned from my recent readings. I usually said we were "fine," not recognizing the good it would do just to see a fresh face, hear the news – not just for us but for our son who was not well enough to go out socially. It took a while, but we learned to acknowledge that no one cared if the house was dusted or if I had any cookies to offer with a cup of tea, to be gracious and simply say "thank you" when offered a break, a casserole or a visit.

It takes a while but eventually one realizes that the airlines are right! Put on your own oxygen mask before assisting others because you must look after yourself if you hope to give the best care to another.

"Because no one can walk this path alone, and in this country, nobody should ever have to." – Laura Rosen Cohen, in *Crushing the Caregiver*, National Post, May 2014. ♦

Jennifer Crump, community supporter and surviving mother of affected son



My name is Kathleen Cruse and I am the caregiver to my 44 year old husband, 13 year old daughter, 12 year old son and sometimes my 70 year old father-in law who all have von Willebrands disease Type 2B. Talk about keeping it in the family. Does this present some challenges and issues in our daily living? Absolutely. Would I have it any other way? No!

My father in law was diagnosed in 2003 following hernia repair surgery. My husband was diagnosed in 2007 following surgery which led to severe results and almost loss of life. Following this occurrence we pushed to get our kids tested and they were diagnosed in 2008. Initially I was not sure what this was all about and what this meant for my family moving forward. How would this affect us on a day to day basis and what did it mean for the kids were some of the questions that came to mind. Through this initial period of finding answers and looking for guidance the staff at London Health Sciences Centre, SWOR Hemophilia Ontario, were very helpful and full of knowledge and explained everything at a level that even the kids would understand. The kids have been fortunate to attend various camps where they have met other kids with the same and different bleeding disorders. Through our kids we have been able to meet many other families coping and dealing with similar issues.

My family is fortunate in that our form of treatment is by oral meds used as needed throughout a bleed or following an episode. My children take Tranexamic Acid as follows: 2 tabs, 3 times daily for 3 days to assist the body in repairing the loss.

At first my thoughts were to protect my children from hurting themselves in any way. I soon realized that this was not the right mind set and that kids get hurt no matter if they should have a bleeding disorder or not. So with more education it was easier to let my kids be kids and if an incident arose we would deal with it. It was a real eye opening experience to take my children to the Emergency Room and be completely baffled at the lack of understanding and/or compassion for whichever of my family members was hurt. To have to be an advocate for care was extremely frustrating at times, but again further investigation led to more knowledge of how to cope and deal in the future. Each trip to the ER became a learning experience for each of us.

My son suffers from nose bleeds and has become his own best care provider. He did his science project on vWD this year and was very proud of the knowledge base that he had prior to researching more information. My daughter did her public speaking speech on vWD a couple of years ago and was one of the finalists picked to go to the gym in front of her school, and she spoke quite elegantly about this bleeding disorder. My daughter has now started to see a pediatric hematologist and gynecologist approximately every 3 months at Kingston General Hospital. My husband suffers from a very low iron count and this means a lifelong interaction with hospital staff at different points in time to receive blood transfusions.

I would say that most of the time living with von Willebrands disease does not affect our day to day lives. When an issue should arise it can cause some distress in the short term but we manage. Extended family members have now learned how to cope as well. 💧

Kate Cruse, caregiver for a family with von Willebrands disease



*"Family!
What does it mean to me?"*

Basically, a family is made up of parents and kids, brothers and sisters, loving one another, caring for each others well-being and happiness. Some families have to deal with things that others don't.

My family deals with a health issue. I have an older brother with a bleeding disorder and

it makes my family a little bit different from most others. We have factor in our refrigerator, needles and syringes in our cupboard and tensor bandages here and there around our house. We have spent a lot of time at Sick Kids hospital and we are sometimes late going places on factor treatment days.

My brother gets a lot of extra attention from my parents, other family members, friends and even some teachers. There are times that he would get special things-almost like rewards-for making it through a rough 'bleed' day. Sometimes I feel jealous but deep down I understand why there is more attention focused on him than on me.

Sick Kids clinic days are never my favourite days. I often tag along because it is easier for my parents but at times I miss being at school hanging out with my friends. I remember one time we had to go to Sick Kids for my brother on my birthday which was not so fun; although, my parents made it special for me afterwards. Even though I don't prefer to tag along on clinic days, when I do go there everyone is happy to see me and I don't feel left out.

There are times that our family plans, trips and outings get cancelled because of a bleed. I understand that my brother needs to be healthy before we have fun! Pain can't be fun. I don't think any kid should suffer through pain and have to get needles to help them heal. I think my brother is a tough guy.

If I hear people say that my brother can't do things because of his bleeding disorder I will tell him it's ok and try to cheer him up. Sometimes I wish my family didn't have to deal with a bleeding disorder because of all the stress and pain but then thinking about it on the positive side we have met a lot of families that are just like ours which feels good! It's cool to know that I'm not the only kid in a family with a sibling who has a bleeding disorder.

I think my brother has shaped me into a better person because of his bleeding disorder. I have more compassion towards others because I am use to showing compassion and empathy a lot at home!

My family may not be a typical family but we're not defined by a bleeding disorder. I love my family and wouldn't want them any other way! 💧

Jenna Reid, sister of patient with von Willebrands disease



I was 17 the first time it hit me, and I remember it well. I was standing in the bathroom of a Chicago hotel, where I'd just finished a long day at a college conference and was preparing to infuse (I've since gotten smarter and treat in the mornings now!). As I struggled to find a vein, I took a long look in the mirror and realized even at 17 that my body wasn't going to get younger. That

sounds like a silly thing for a teenager to say, but I suspect most of you understand exactly what I mean. I realized that the scarred veins and stiff joints I was dealing with at 17 were the same ones I would have for decades to come, and I needed to look after them as best I could. That day, my mission for my body became one of self-preservation. No matter what I did physically, my primary goal was always the same - keep whatever I've got.

I've been saying for years that I plan on seeing 100. That's an astounding feat for anyone, especially with a bleeding disorder, and I'm deeply aware of how privileged I am to even be able to make such a statement. Yet with the latest advances in medical technology, and the continuing improvements in treatment, I actually think it may

be possible. To me, 100 is an incredible goal, to be able to look back on a rich full life full of the proudest accomplishments and the simplest joys.

It won't happen though without a whole lot of self-preservation. Living until 100 is one thing, but the ability to move around at 100 is something else altogether, and that's my true goal. From every centenarian I've seen, and I've been lucky enough to meet a few, the best thing you can do is to keep moving. The latest studies of people 90+ indicate that just 45 minutes of exercise a day, even if it's broken down into smaller chunks, may be the key to a healthy longevity.

So I keep moving. I'm blessed with joints that cooperate most of the time, and I accommodate them when they're less cooperative. I've never been a natural athlete, nor have I really wanted to be, but I understand that the only way to reach my goal is to get up and keep moving in one form or another. I continually give my body new challenges, recently that's included lifting weights, but I do so on my own terms, and at my own speed, in a way that I won't jeopardize my progress by doing more harm than good. I can't say I always make the smartest choice, to be fair. That said, I realize that the worst choice I could make for getting to my goal is doing nothing.

Go ahead, finish the rest of the magazine (they're doing an incredible job of it lately), then start moving, however you can. You'll be glad you did. 💧

Shaun Bernstein, living with hemophilia



If I Knew Then What I Know Now

by Matthew Maynard

So if you are young and have a bleeding disorder you might want to read this. If you are older please treat this as the opening to a discussion, I would love to know what you would say! If you are a parent of someone with a bleeding disorder you might want to have a read before your children are asking if the latest *Blood Matters* is here yet.

I was asked this question: living with a bleeding disorder, what advice would you give to someone just starting out? I do not have any children of my own so my only voice is as someone who has lived their life with a bleeding disorder so this is about the three things that have worked for me and might work for you.

- 1. Listen to your body!** Being in the middle of a joint bleed and noticing, that really hurts! Being in the middle of nose bleed and realizing, this is embarrassing! Or even when it is a great feeling, like you just finished climbing the hill on your bike or finished 3 laps of the pool! The more you can pay attention to your body and listen to when it feels good, the better you will be able to listen to when something is not quite right like when you took the jump on your bike hard or smacked your hand on the pool side.
- 2. Ask lots of questions!** Of your parents, your teachers, even your nurse or doctor or service coordinator. Lots of times you might have a question about your disorder but it is your parents asking all the questions when you are in the clinic - don't forget to ask your own questions every chance you get. The more you know about what is going on or what you are supposed to do or what happens when, etc., the more prepared you can be.
- 3. Take the advice of your team!** Did not know you lead a team? Well you do! The team I am talking about are the ones helping you with your bleeding disorder. They know about treatment, products and you are the leader of this team (I know they think they are) and if you listen to your body and ask lots of questions you will be able to get their best advice for your own care. What you do with it is up to you, always is. So if you are on prophylaxis follow the schedule, if you are supposed to take one thing for a nose bleed and something else when your knee hurts get their advice and follow it.

So, regardless of how often you think about your bleeding disorder, make sure you listen to your body, ask lots of questions and take the advice of your team - it won't keep you out of trouble but it might get you out of some trouble. 💧



Letter to my Teenage Self

by Amy Griffith

Looking back on my teenage years I am thankful that today I have no regrets. However, with the knowledge that I have now, there are a few things that I would have done differently. I hope that any young women reading this magazine affected by a bleeding disorder can learn from my inevitably awkward teenage experience in hopes they can get a head start in their bleeding disorder care.

1. Period. Just say it. Out loud, with confidence. The lengths that we as young women go to in order to conceal the largest part our lives still astounds me to this day. I remember trying to discreetly move a tampon from my backpack to my hands, hiding it in my sleeves before heading to the bathroom at school. Or choreographing a strange walking arrangement so that friends could check the back of my pants when I walked. When did having a period start requiring Level Five CIA training?

Ladies, the secret is out. Any red blooded human with the lowest level of sexual education will be well aware that women menstruate, a reality since the dawn of time. How others react to finding a pad in your purse, or seeing you browsing the feminine aisle at your local drug store, is completely up to you. Be confident, and don't let anyone give you reason to be embarrassed. There is absolutely no reason to live your life as a double agent.

2. Start seeing your OBGYN early. As a young teenager, I thought that I was getting a full comprehensive check up every time I went to see my family practitioner. For the most part, I was. I found that I was treating OBGYN as a "specialist" practitioner, one that I only needed to see when something wasn't right.

As women, our OBGYN is an essential member of our wellness team, even more so as young women moving into adulthood. Your OBGYN specializes in and focuses on solely your reproductive needs, and as a developing young woman, especially one with a bleeding disorder, it is important that you get the attention you need for preventative care. Don't be like me: waiting until I was missing days at school from heavy periods, bottoming out in iron stores and exhausted all the time. Establishing a relationship with an OBGYN early is a great way to be prepared for anything Mother Nature decides to throw your way.

3. Be vocal. The hematology field has come leaps and bounds in the past decade when it comes to comprehensive care for women. Hemophilia Treatment Clinics across the province are dedicated to providing resources and services to women with bleeding disorders, and outreach programs such as **CODERouge** advocate tirelessly for our voices.

But like many things in life, nothing is perfect. As women, we are still the minority and it is imperative that we have a voice. Don't be afraid to speak up. My reality check came back in 2008, in the emergency room of a new city, where I was brushed aside with a nosebleed because "women can't have bleeding disorders". I learned that I needed not only be a patient, but a teacher and where necessary, a fighter. In order to see a change, women need to take an active role in raising awareness for female bleeding disorder care.

Don't be discouraged! Be empowered. 💧



A Teenager in the 1980s

by Michelle Lepera

I am a **CODERouge** ambassador for the Canadian Hemophilia Society. I wanted to share one of my experiences with my own bleeding disorder (carrier of Hemophilia A) so I could raise awareness for women with bleeding disorders.

I was 17 years old in 1985 when my wisdom teeth came in. I was in grade 12, graduating year! I had to have all 4 wisdom teeth taken out. No problem! The procedure was done, I went home with my aspirin for the pain and I was healing just fine. A week later I had gone back to school. I was sitting in class and all of a sudden I felt a warm gush of something in my mouth. Puzzled I went to the bathroom to see what was happening. By the time I got to the girls room I felt another sensation; it was blood. This was only the beginning of a month of agony. No one knew what to do with me. My bleeding baffled my teachers, my parents, even the dentists! I went back to the dentist 3 times, each time they had to freeze my mouth and sew my gums closed, but they kept bleeding. Busting open by morning, waking to clots of blood choking me. I was in so much pain they gave me aspirin. This contributed to the problem. I remember hearing a Dentist mentioning hemophilia but waving his theory off because "she's a girl" Finally at the fourth attempt to stop the bleeding they had to burn my gums shut. I had lost a lot of weight, I was most likely anemic, I had no energy but by the grace of God I graduated!

It wasn't until my son was one year old and diagnosed with Severe Hemophilia Factor 8 deficient that my questions about my bleeding were FINALLY answered. I also had a bleeding disorder.

Today if I need any kind of medical procedure done, I contact the bleeding disorders program in London and they advise me on the proper way to handle my situation. There are many different treatments for the many bleeding disorders women have. You are not alone and it's not just in your head.

We have come a long way since the 1980's but I know we still have a long way to go. I don't look back and wish things were different because experiences like this have made me the advocate I am today.

If you have any questions or think you or someone you know may have a bleeding disorder, please contact the Canadian Hemophilia Society and the code rouge program, both can be found on Facebook! 💧

Do you have any questions?

If you have questions or comments after reading the articles in this section and want to connect with our ambassadors directly, they can be reached at coderouge@hemophilia.on.ca.

Both Amy & Michelle would love to hear from you!

Do you have a story to tell?

Would you like to share a story about your experiences as a female with an inherited bleeding disorder? It could be featured here in our next edition!

Contact Alex McGillivray, RSC at amcgillivray@hemophilia.on.ca

How to Get Involved:




Hemophilia Ontario
Hémophilie Ontario

Hemophilia Ontario welcomes the interest of individuals in our organization. The Board of Directors is elected at our Annual General meetings for a 1 year term. Each region elects a Regional Council at their Regional General Meeting.

For further information please contact:

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

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Your generosity is the key to providing programs and services to individuals with inherited bleeding disorders. No other organization in Ontario offers these supports to those living with and / or affected by inherited bleeding disorders. With your passion, commitment and dedication we know we can make a difference.

Here are some of the ways you can help:

DONATE

Make a donation, please visit:

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

Donate monthly through direct debit or on your credit card

If your employer has a charitable donation program, have an amount taken off each pay cheque

Leave a bequest in your will

FUNDRAISE

Volunteer at a fundraising event, such as bingo

Join an event, such as the Polar Bear Dip, and obtain sponsors

Nominate Hemophilia Ontario as your company's charity of the year

CAMPAIGN

Become a Hemophilia Ontario campaigner. Tell your family, friends and colleagues about our work

VOLUNTEER

Become a Hemophilia Ontario volunteer. Each and every one of our nine regions across Ontario are always looking for volunteers to become active and involved. Give a little bit of time, or give a lot. Whatever time you can give will be greatly appreciated.

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www.hemophilia.on.ca

TIPS FOR TRAVELERS



ALWAYS WEAR YOUR
MEDICAL ID



BRING
YOUR OWN
TREATMENT

AVOID A SHORTAGE OF PRODUCT

Products abroad could be different from what you are used to and potentially very expensive.



HAVE A
LETTER

FROM YOUR DOCTOR

Explaining to security why you are carrying treatment products. Include the serious implications of not having them immediately to hand.



HAVE A LETTER IN THE LOCAL LANGUAGE

Outlining your condition and the treatment you need.



GET YOUR MEDICAL
INSURANCE
IN ADVANCE

Be able to deal with any issues that might come from having an existing medical condition.



FIND LOCAL
TREATMENT CENTRES
OR NATIONAL
HEMOPHILIA ORGANIZATIONS

DO YOUR
RESEARCH!



KEEP THEIR CONTACT
INFORMATION AT HAND

See the WFH website for our worldwide Treatment Centre directory.



CONTACT THEM IN ADVANCE

Learn about the availability and cost of treatment products.



TRAVEL WITH
FRIENDS!



Ease any stress that arises from travelling somewhere new and have someone nearby in case something goes wrong.