

A publication of



Hemophilia Ontario  
Hémophilie Ontario

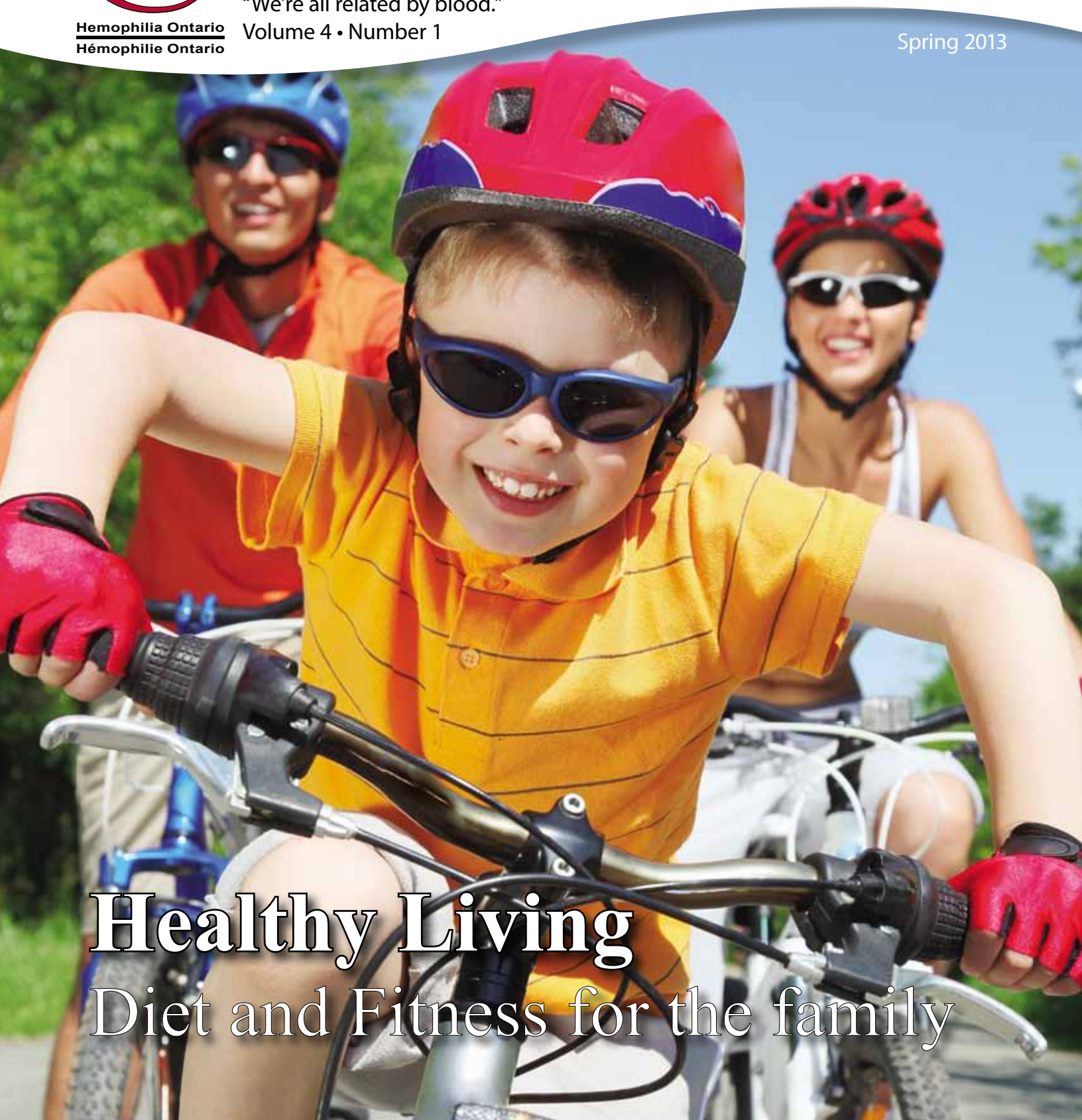
# BLOOD

*matters*

"We're all related by blood."

Volume 4 • Number 1

Spring 2013



## Healthy Living

## Diet and Fitness for the family

## Hemophilia Ontario

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**Hémophilie Ontario**

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of the Canadian Hemophilia Society.

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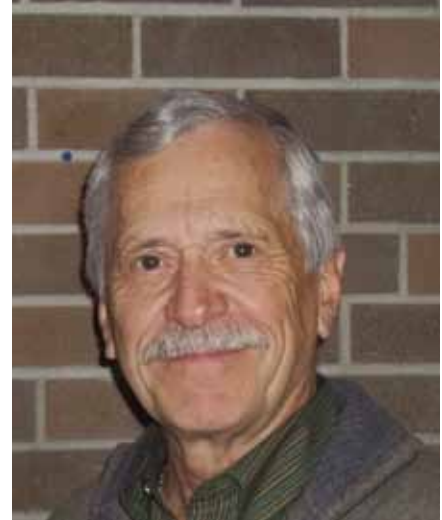
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or 1-888-838-8846.

## Leadership Messages



Terri-Lee Higgins



Tom Beer

### EXECUTIVE DIRECTOR'S Message

by Terri-Lee Higgins

**LIVING HEALTHY** sounds so easy, yet if you live a busy life it can be incredibly challenging. There are days when my energy levels are in my toes, but like every other day, I have to find ways to get up and going and get through the day.

I love to walk but I am a fair-weather walker and don't see much of the outdoors in winter. My friends who walk year round encourage me to purchase better garments to keep me warm; I am giving this serious consideration. Until then I have dusted off the treadmill and spend time each week walking to music, staring out at the snow in my back yard waiting for spring and gardening.

I have tried "dieting" only to put weight back on. The key for me has been making positive lifestyle changes that I can manage. I am a carb queen; however I have reduced my intake to about four days per week and am finding that I don't crave them like I did. We have a few meatless dinners a week and lots of homemade soups for lunch. Sweet potatoes really are delicious baked. We bought smaller dinner plates and about two-thirds of every meal are veggies. I drink about 10-12 glasses of water throughout the day which has lessened my snacking—the jelly bean jar in the office still is about half full.

Healthy living is more than just watching what I eat. I also find that there are many things I do day to day that help me feel positive and able to accomplish my healthy goals:

- Put worry into perspective—only eight percent of what we worry about ever really happens
- Exercise, eat right and get enough sleep
- Do something for someone else—it will boomerang back to you
- Learn to say no—we have limits to our time, energy and interests
- Find people who will challenge you, believe in you and inspire you to improve
- Discipline yourself today and you will enjoy life more tomorrow.

A positive attitude and appreciating what we have can be very good starts toward healthier living. Living healthy and our reasons for being healthier will be different for every person. Some will jump in with both feet and others will take baby steps. Move from awareness to action at your own pace and know that what you do today will change your future. ♦

### Message from the EDITOR

by Tom Beer

**"IT'S EASY TO FORGET** what's important, so don't!" (Colonel Potter, *M.A.S.H.*)

"Age is mind over matter. If you don't mind, it don't matter." (Satchel Paige.) Being well becomes more significant as we age.

I was reminded, just over six months ago of the truth of this line. At about age 9, I broke my wrist. Since that time, except for an occasional sprain, I'd been spared any major health problems. Then, the weekend before Labour Day, 2012, I broke my ankle, badly enough that I needed major corrective surgery.

Nine weeks later, when my orthopaedic surgeon said to "Lose the boot(cast)," I realized that I'd need to learn how to walk all over again. It had been so natural for so long that I'd never consciously thought about "the process of walking." Imagine my surprise and chagrin when I heard lines like, "You know your gait will never be the same." "Guess this ends your touch football career." "S'pose you'll be able to skate again.?"

I'm not a pessimist, but I can see that if I were, the changes might cause me to become dejected. I can't watch those Heart and Stroke commercials that tout the "fact" that for many Canadians the last 10 years of their lives

will be spent with illness. For me, my injury means life's different—not over. Like many of you, I get up every day, give thanks that I've got today, and get on with life. I walk nearly as much, thanks to an older dog whose control is better than mine but needs to be walked. I look down at the surface now; icy, snow-covered, uneven. I look ahead more than ever. (Not a bad philosophy for life, eh?) My pace may not be as assertive, but, I've managed to walk lots in Acapulco, and I'm walking the dog, even in snow storms. Now, best of all, there are whole walks that go by without me really thinking about my ankle.

I'm eating better, feeling more energetic, and I'm even looking forward to taking a couple of swing lessons while I'm in Myrtle Beach next month.

So, forget the old saw about lemons and lemonade. Life is what it is. Your best way to live it is one day at a time, taking what comes, and getting on with living.

If, as some say, we only come this way once, I've still got a lot of territory to cover, a lot of places to see, and a lot of people to meet.

So, if we pass one another on one of our walks, say "Hi!"

Then, as they say in the musical, *The Wiz*, "Move on down the road," 'cause that's where I'm heading.

Being well is the focus of this volume of *Blood Matters*.

Being well matters—a lot.

How about you? Any "being well" stories you'd like to share? ♦



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## Hemophilia Ontario News

### Hemophilia Ontario FINANCIAL ASSISTANCE POLICY

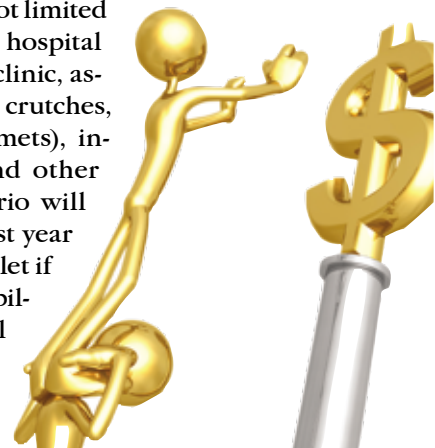
**THE GOAL** of the financial assistance policy is to provide exceptional financial support to people with bleeding disorders and their families to reduce the burden caused by their condition. To be eligible for financial assistance, these individuals must be members of Hemophilia Ontario, or if not,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

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

Hemophilia Ontario is the payer of last resort and will first of all attempt to have these costs covered by other social agencies including government.

When an individual's costs are to be reimbursed by a social agency at a later date, Hemophilia Ontario can enter into an agreement whereby the funds are advanced and then later recovered.

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



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### CELEBRATING our VOLUNTEERS

#### Igor RISTEVSKI

*by the CWOR Council*

**THE CENTRAL WESTERN ONTARIO** Regional Council would like to recognize Igor Ristevski for his participation and contributions to CWOR and to Hemophilia Ontario. Igor joined CWOR in 2009 as a volunteer and has since taken on a more engaged role within the community. He contributes his time to Council meetings, represents our region as a delegate to Hemophilia Ontario, attends fundraising events such as The Big Sale on the Little Street, and has spent countless hours shopping for gifts for our annual Holiday Celebration. More recently, Igor spent his time helping with the move of the CWOR office, for which we are sure Alex McGillivray is most grateful! Igor also serves at the national level as a member of the Canadian Hemophilia National Membership Committee.

Unaffected by a bleeding disorder himself, Igor became a volunteer with CWOR because he wanted to get more involved in the community. We are so glad that he joined us and we look forward to continuing to work with him in the future. Igor, many thanks for all you do. ♦

**DARLENE VILLENEUVE  
and NANCY SAUVE-  
CHARBONNEAU**

*by Alex McGillivray*

**IF YOU'VE ATTENDED** a program in the Ottawa Region, chances are you've met both Darlene and Nancy. The sisters can often be found dedicating their time to organizing the region's annual bowl-a-thon, or working diligently towards making the OEOR Holiday Celebration a great success. From sitting on the Region's Council, to putting together crafts, to shopping for gifts, these two women live and breathe for helping the inherited bleeding disorders community. It is because of their strong devotion to their community that they are being recognized as wonderful volunteers. Thank you for all that you do. ♦

**NEW PHOTOGRAPHY  
and Video Policy**

**PHOTOGRAPHS AND VIDEO** for Hemophilia Ontario and family individual use are a source of pleasure and pride. Participants are not required to comply with laws and legislation when taking photographs for their own private use of their children at an organized event. However we must always be mindful of the need to safeguard the welfare of children in our programs and the privacy of our members. As a result Hemophilia Ontario has a new Photo/Video Policy designed to prevent harm to all participants and will apply to all forms of publications; print, film, mobile devices, video, DVD on websites and professional media.



Provincial Staff will review the new policy at every program or event including completion of a Consent form. Individuals over 18 will be required to answer yes or no to three specific questions and then sign the form confirming the use of the photo as identified on the form. The back of the form clearly identifies the parameters around Hemophilia Ontario's potential use of the photo/video. The completed form allows us to use the photo up to one year from the date taken. Should we wish to use the photo after this timeframe, we would contact the person/family explaining the use of the photo/video, seeking explicit permission. Program and event participants will be provided with a handout identifying that the use of personal photos is permitted; however selling or uploading photos to the internet with anyone other than you/your family without that person or parent's permission is illegal.

In today's world of exploding social media, Hemophilia Ontario works with its members and partners to respect privacy and build a supportive, respectful practice that everyone can work with.

Should you have questions or concerns around this new policy, contact Terri-Lee Higgins, Executive Director at [thiggins@hemophilia.on.ca](mailto:thiggins@hemophilia.on.ca) or 519-432-2365. ♦

**Send Us Your Pics for  
WORLD HEMOPHILIA  
DAY**

**THIS YEAR WE HOPE** to put together a little project for World Hemophilia Day. We're looking for people to submit their photos of living with an inherited bleeding disorder for us to post on Facebook on April 17—World Hemophilia Day.

If you're interested in submitting your photos, please send them to Alex McGillivray, Regional Service Coordinator at [amcgillivray@hemophilia.on.ca](mailto:amcgillivray@hemophilia.on.ca). ♦



# We're All Related by Blood



**Hemophilie Ontario**  
**Hémophilie Ontario**

## HEMOPHILIA ONTARIO

### 57<sup>th</sup> Annual General Meeting Agenda

#### Schedule of Events

**9:00 - 10:00 am** — Registration and breakfast

**10:00 am** — Welcome and Annual General Meeting

#### Agenda

1. Call to Order — Paul Wilton
2. Approval of the Agenda
3. Approval Minutes of Saturday April 21, 2012 Annual General Meeting
4. Volunteer Recognition throughout meeting
5. President's Report — Paul Wilton
6. Financial Report
  - i. 2012 Audited Financial Statements
  - ii. 2013 Membership Fees — Paul Wilton
7. Executive Director's Report — Terri-Lee Higgins
8. CHS Report — David Page
9. Appointment of the Auditor 2013
10. Submitted Reports
  - i. Youth Committee
  - ii. Hemophilia Provincial Coordinator
11. Election of the 2013-2014 Hemophilia Ontario Board
12. Other Business
13. Adjournment

**12:00 - 12:55 pm** — Lunch (for those attending the afternoon sessions)

**1:00 pm** — Dr. David Lillicrap, *Hemophilia Treatment Advances; Prospects for the next Decade*

**2:00 pm** — Amy Griffith, Michelle Lepera, Women and Bleeding Disorders, CODERouge Ambassadors

**2:30 pm** — HERO Study report—a multinational study on the psychosocial issues surrounding hemophilia.

**3:00 pm** — Closing Remarks

**3:30 pm - 6:00 pm** — Hemophilia Ontario Board of Directors Meeting

**Saturday April 27, 2013**

**10 A.M. - 3 P.M.**

Ramada Hotel  
300 Jarvis Street  
Toronto, Ontario  
M5B 2C5  
416-977-4823

**RSVP to: Susan Turner**

**1-888-838-8846 or  
416-972-0461 ext 21  
sturner@hemophilia.on.ca**

**NO later than:  
April 13, 2013**

Regional representatives  
requiring overnight  
accommodations, please  
contact Susan no later than  
Friday April 5, 2013 to make  
these arrangements



◀ L to R: Karen Plater, Margaret Plater and the Federal Minister of Health, the Hon. Leona Aglukkag, MP

## JOHN PLATER AWARDED Queen's Diamond Jubilee Medal by CANADIAN AIDS SOCIETY

by Bill Mindell

**JOHN PLATER** was always a very special person for me and the other parents of young boys with hemophilia of my generation. He was the tall, handsome, active and smart teenager who would drive the hay wagon, ride his horse and talk to any of our small children as if he were their best friend. He was the model that we as parents wanted our young sons to grow to emulate: a gracious, kind and friendly young man; later a university graduate, a lawyer and a loving husband. His character, strength and optimism alone gave us hope in the darker days of the 1980s, even before he became so much more.

Although everyone in the CHS, and especially Hemophilia Ontario, is aware of and grateful for the decades of contributions and leadership that John Plater gave to the hemophilia community, we are not alone. On November 27, 2012 he was awarded (posthumously) the Queen Elizabeth II Diamond Jubilee Medal by the Canadian AIDS Society (CAS) at their Fifth Annual Gala Dinner held at the Chateau Cartier Hotel in Gatineau,

Quebec. The Gala is timed to coincide with the celebration of World AIDS Day on December 1. Medal recipients were honoured with this distinction for their exemplary work and service in the field of HIV/AIDS in Canada.

The CAS noted how fortunate it is to have so many accomplished leaders who help improve the lives of people living with and affected by HIV/AIDS. It was granted the privilege of sharing the medal with 30 members of the HIV/AIDS community, who are among the 60,000 outstanding Canadians selected to receive this distinction in recognition of the 60th anniversary of the accession of Queen Elizabeth II to the Throne.

John's wife, Karen, accompanied by his mother, Margaret, attended the Gala to receive his medal. Karen and Margaret were seated at the front table with the Master of Ceremonies and other dignitaries including the Hon. Olivia Chow, MP.

A nice surprise for Karen and Margaret came when the Federal Minister of Health, the Hon. Leona Aglukkag, MP, addressed the group on behalf of the government and, in the course

of congratulating all the recipients, singled out John for special mention. He was the only recipient whom she specifically named and described his particular contributions in some detail.

This is not John's first Queen Elizabeth Jubilee Medal. Ten years ago he was recognized for his many years of outstanding contributions to the betterment of the lives of those with hemophilia when he was among those select few who received the Queen Elizabeth II Golden Jubilee Medal from the CHS.

*Editorial Note: Hemophilia Ontario nominated John for a 2012 Casey Award and we are honoured to announce that John was the successful nominee. The Casey Awards annually celebrate individuals and organizations across Canada that demonstrate leadership in the fields of HIV/AIDS and social justice and were created in tribute to June Callwood. Karen will accept the award on John's behalf at their ceremony in March, 2013. ♡*

<http://www.youtube.com/watch?v=ZDRIF4jMigc&feature=youtu.be>



Hemophilia Ontario Youth in front of the Commemorative Tree at Camp Wanakita.



## Wanakita: A PLACE OF DISCOVERY

by Amy Griffith

**I HAD THE PRIVILEGE** of attending Camp Wanakita for 10 summers before I finally immersed myself into the “real world.” For anyone who has never attended camp, you may think that I’m being melodramatic by referring to everyday regular life as the “real world.” However, if you have attended camp, you know exactly where I am coming from.

During my first summer as an Intermediate camper, I was the only one in my cabin with a bleeding disorder, and the only girl that I knew of at camp with a bleeding disorder. As I spent consecutive summers at Wanakita, I discovered much about myself that I truly believe I would not have learned anywhere else. I learned that if you want things to change, you need to advocate for yourself. That if you want people to understand what you’re going through, you need to tell them. I learned to network and have made lifelong friends in return. I learned how to self-infuse and how to safely test my limitations so successfully that after six summers as a camper and then an SC, I spent four more summers at Wanakita as a staff member. Wanakita inspired me to advocate for youth, and to help them realize all they are capable of, which most of the time, when realized, will absolutely blow you away. ♡

## Celebrating **COMMUNITY CAMP**

by Terri-Lee Higgins

**CAMP WANAKITA** was selected again as the location to host our Community Camp on a great October 2012 weekend. Ninety-eight participants shared the weekend with an array of speakers including Adult Hematologist Dr. Minuk on Aging with a Bleeding Disorder; Pediatric Hematologist Dr. Klaassen on Children with a Bleeding Disorder: Using the Latest Treatment Approach to Improve Quality of Life; Physiotherapist Mary Jane Steele talked about staying active; Social Worker Denise Labreque helped parents understand ways of speaking with their HTC teams. Diane Bissonette and Betty Ann Paradis were our onsite nurses and presented Passport to *Well-Being*. The Kids on the Block puppets from the Thames Valley Children’s Centre in London entertained everyone with their skit on living with Hemophilia, and Nancy Thomson worked with the HOY youth on speaking publicly. On Sunday the youth held an open question panel for parents to ask their burning questions.

We also celebrated a milestone—our 20-year partnership with Camp Wanakita. YMCA Camp Wanakita opened their doors in 1992 to offer boys with hemophilia a residential camp experience. Unlike other camps that were approached, Camp Wanakita was willing to accept the fact that some of these children were infected with HIV through receipt of tainted factor concentrates. To remember, honour and celebrate the individuals infected and affected by the tainted blood tragedy, a commemorative tree planting ceremony took place around the newly-planted maple tree at Camp Wanakita. We closed the celebration by enjoying an amazing cake prepared by the Camp Wanakita Chef.

Hemophilia Ontario programs such as Community Camp are designed to provide participants the opportunity to meet new families, re-establish friendships, share togetherness stories and learn new things. It is a powerful thing when our community comes together to share ideas, stories and hope. We can’t wait to see what the next 20 years offer. ♡

## Wanakita: A PLACE TO PLAY

by Dan Ignas

**IT'S NO SECRET** that hemophilia can be time consuming. It's also no secret that it has forced some of us to grow up faster than our peers, causing us to become more responsible and, for better or worse, "serious." That time invested in your health is directly taken away from those precious years typically allocated to an uninterrupted childhood.

We've all heard that "all I really need to know I learned in kindergarten," and I fully agree. I'd like to add to that statement with my realization reflecting on 15 years of experiences—camps are a place—like nothing else I've seen—where anyone can go, for any amount of time to practice, refine and further develop those beautiful fundamentals we learned in kindergarten.

As I ground my way through a tumultuous undergrad in the left-brained world of engineering, what literally kept me alive, balanced and sane was working at camp each summer. It was the sticky nine-week marshmallow, sandwiched by two rigid four-month semesters that made up the year that was my s'more.

Maintaining the ability to play, keeping a light-hearted sense of humour, and learning to relinquish responsibility where appropriate, were some of the most useful lifeskills that I learned to cultivate and eventually teach. For me the most precious aptitude was developing the ability to create moments of pure joy with others and within myself.

It was a supreme privilege to attend and then be on staff at Camp Wanakita for eight and seven years respectively. I am beyond proud to say that I left on my own terms five summers ago and am already a "grand-counsellor" because the kids/teens/youth I helped bring through the ranks have already done so with their own people. I am so very proud to have helped replenish that wonderful place in Haliburton I love which allowed me to truly catch up on my childhood. ♡

## CAMP Wanakita

by Trevor Reid

**CAMP WANAKITA** says it's "a place to have the time of your life!" and I totally agree.

The past five summers at Camp Wanakita have been a great experience for me. I get to be "just another kid" at camp and most of all I get to be away from my parents!

I have met a ton of awesome people at camp and look forward to seeing some familiar faces when I go back next summer. I also look forward to camp activities like sailing, kayaking, air adventure, camp fires and hanging out with the other campers (including the girls) at the dance.

The nurses at the Bayer Den are awesome too. They have been super patient when teaching me to self-infuse which really helped me focus and learn.

I'll be returning to Camp Wanakita this summer and I will be very disappointed when I am too old for camp. Wanakita truly is a home away from home! ♡

## NORTH AMERICAN CAMP CONFERENCE of Hemophilia Organizations (NACCHO)

**NACCHO:** Building Today for Tomorrow

Camp staff, counselors and volunteers from all around the world descended on Phoenix Arizona recently for the annual North American Camping Conference for Hemophilia Organizations, or NACCHO as it's known. Representatives from Hemophilia Ontario were among this group to present the amazing work our camps do, as well as learn a ton of new strategies to ensure that our campers have the best camp experiences possible. We were able to send a group of youth leaders who are involved in our Pincrest, Wanakita and/or Just the Guys Camps to learn



The Hemophilia Ontario Group @ NACCHO

new skills and to network with other counselors from across the globe and they had such a great time, they learned a lot, and they really showed people what a dedicated and hard working group of people Hemophilia Ontario has involved in their camps. Here are some of the highlights of their experiences:

*“Throughout the weekend, ideas about everything from staff manuals to assessing campers to managing a health but were shared. Networks were formed between many individuals, leading to a flow of information. Through my attendance at the conference, I was able to glean many ideas for our own camp which I will now try to implement to make camp even better next year. The theme was Building today for tomorrow. That is what I will attempt to do now, so that our camp becomes even more amazing in the future.” – Ryan Kleefman*

*“I feel that I gained quite a bit of experience and was able to get myself out of my comfort zone and meet a lot of new people. I enjoyed the sense of pooling information that the seminars offered and the sense that everyone was there not just to gain experience but to put their experience out there so others could take from it too.” – Josh McCormack*

*“This weekend provides an incredible opportunity for youth, directors and nurses to gain extremely valuable knowledge regarding all aspects involved in running a bleeding disorders camp. Right from the beginning of the conference you feel a sense of inclusion and connection with everyone in attendance, all striving for the same goal, an improved camp experience. I was able to learn tons of new information about how to improve myself as a counselor and how I may improve my communication skills with other staff and campers. By participating in this weekend conference I am able to bring back great information that may build upon the already fantastic Hemophilia Ontario camp programs.” – Zach Adams*

*“The information I learned will definitely benefit my leadership and interpersonal skills. Every single person that attended had a positive attitude and there was a sense of community right from the beginning. All the sessions taught me something different but were all similar in teaching me new ways to better myself as a staff member and a counselor. I learned a variety of information that I can share with the other counselors at Pinecrest so we can make Pinecrest even better than it already is.” – Julia Lepera*

*“NACCHO is the only camping conference dedicated to summer camps that serve youth of the bleeding disorders community. However, the focus of the conference was not*

*solely devoted to bleeding disorders, but rather how to provide the best experience possible to all campers. No camper deserves any less of an experience than the other, and through various meticulously planned breakout sessions, all attendees learned tricks and tools to help ensure that our campers have the time of their lives. I was able to learn what programming other Hemophilia camps had successfully implemented in order to meet the needs of the bleeding disorders community. Furthermore, I learned valuable skills about teamwork, time management, burnout avoidance and programming organization that I truly value as an educator of all youth.” – Amy Griffith ◊*



Zach Adams

## Canadian Hemophilia Society News

### CHS Rendez-vous 2013

**THE CANADIAN** Hemophilia Society is pleased to invite you to attend *Rendez-vous 2013* which will be held May 23-26, 2013 in Winnipeg.

This significant event will feature the Medical and Scientific Symposium: Perspectives on Personalization of Care, the CHS Annual General Meeting, informative community workshops and annual meetings of four healthcare professional groups.

*Rendez-vous* is jointly organized by the Canadian Hemophilia Society (CHS) and the members of the Association of Hemophilia Clinic Directors of Canada (AHCDC), the Canadian Association of Nurses in Hemophilia Care (CANHC), the Canadian Physiotherapists in Hemophilia Care (CPHC), and the Canadian Social Workers in Hemophilia Care (CSWHC). *Rendez-vous 2013* is presented by Bayer HealthCare and sponsored by Baxter, Biogen Idec Hemophilia, CSL Behring, Novo Nor-

disk, Octapharma and Pfizer.

This year the Medical and Scientific Symposium will present sessions on **Medical Perspectives** (*Pharmacokinetic vs. weight-based dosing; Longer-acting concentrates: lower frequency or higher trough levels... or both?; Gene therapy vs. longer-acting concentrates in hemophilia B; and Discussion of impact of new technologies on care*) and **Psychosocial Perspectives** (*The psychology of prophylaxis; Vocation, vocation, vocation: The impact of bleeding disorders on career choices; Obesity in hemophilia—physical and treatment implications of increased body mass; and Sport and activity selection: Exercise is a drug.*)

This biennial conference will explore state-of-the-art advances in treatment and research benefitting people with inherited bleeding disorders. Attending this invaluable meeting is a unique and rare opportunity,

in only one weekend, to gain new knowledge at the medical and scientific sessions and community workshops, to network with peers and friends, to visit the pharmaceutical industry exhibits and to participate in your organization's Annual General Meeting. Community workshops will feature a fascinating look at our past, our present and our future with a presentation on 60 years of care, an update on our strategic plan and what lies ahead for the next 10 years.

On this 60<sup>th</sup> anniversary, the CHS hopes to bring together as many people as possible from the bleeding disorders community. To achieve this, chapters are strongly encouraged to sponsor their members to attend.

For more details, consult the CHS website at [www.hemophilia.ca](http://www.hemophilia.ca) or contact your local chapter. We hope you can join us. ♡

## Why is CHS Membership **IMPORTANT TO YOU?**

by Helene Bourgaize

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

In addition, the CHS invests close to half a million dollars each year in

Canadian research to improve care and find a cure.

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

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

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

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

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

World Federation of Hemophilia News



**WORLD HEMOPHILIA DAY 2013**  
50 Years of Advancing Treatment for All

**THE WORLD FEDERATION OF HEMOPHILIA (WFH)** and the global community have worked together for the past 50 years, to improve care and treatment for inherited bleeding disorders. World Hemophilia Day 2013 will take on a special significance as we mark 50 Years of Advancing Treatment for All.

In spite of the tremendous progress made over the last half century, the vast majority of people with bleeding disorders living in developing countries do not have access to proper care. In fact, 75 percent of people with bleeding disorders still receive very inadequate treatment or no treatment at all. The percentage is even higher for those with von Willebrand disease and rare factor deficiencies.

It is important that we reflect on where we have been, where we want to go, and that together, we can Close the Gap. **Join together on April 17 to mark World Hemophilia Day.** Connect with the global online community, on the WFH's Facebook page at [www.facebook.com/wfhemophilia](http://www.facebook.com/wfhemophilia) and share your hopes and wishes for the next 50 years.

“One of the greatest benefits of participating in World Hemophilia Day is the recognition that our community is more powerful when we work together,” says Alain Weill, WFH president. “People from around the world will mark this day and raise awareness about the need to achieve treatment for All.” ◊



WHERE WE HAVE BEEN

**WORLD HEMOPHILIA DAY 2013**

APRIL 17

**50 YEARS OF ADVANCING TREATMENT FOR ALL**

Join us on Facebook and leave your 50<sup>th</sup> anniversary messages



WHERE WE WANT TO BE



TOGETHER,  
WE CAN CLOSE  
THE GAP  
[www.wfh.org/whd](http://www.wfh.org/whd)






## DON'T FORGET TO "Like Us" on Facebook

by Alex McGillivray

**OVER THE** past few months Hemophilia Ontario has been actively working on maintaining the organization's Facebook page. Fans have enjoyed Mission Mondays, Trivia Tuesdays, Worldly Wednesdays, Thankful Thursdays, and the best of all, Fan Fridays.

We also award a fan with the title of "Fan of the Month" and accompany that with a prize. December's winner was AyeH Hamidian, and January's winner was Venus Reid. Congratulations! If you are already a fan, we encourage you to engage with us every day, and if you're not a fan yet, we urge you to join the community.

We look forward to connecting with you. Find our page using the following link: [www.facebook.com/pages/Hemophilia-Ontario/192391854132304?ref=hl](http://www.facebook.com/pages/Hemophilia-Ontario/192391854132304?ref=hl) 



## Pharmaceutical News

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

## HEALTHY LIVING and Hemophilia Baxter


**YOUR HEMOPHILIA CARE TEAM** has probably told you that physical activity is recommended for you, since exercise can help strengthen your joints and muscles. In fact, healthy joints can actually help reduce your risk of joint bleeds!

There are a variety of sports, activities and exercises that can be right for you. By taking part in these activities you will be able to stay fit, improve your joint health and feel great. It is important to take your factor prophylactically to help protect you while you are active, and to choose activities that can provide you with a safe environment.

Swimming is an example of sport that is less stressful on your joints and can be a great workout. There are a variety of ways to get active in the water, one of which is running. The resistance from the water actually burns more energy than running on land and can help strengthen your muscles while preventing damage to your knees. Doing laps in the pool, swimming with your friends or joining a water aerobics class are also fun ways to exercise in the water.

If swimming is not for you, there are numerous exercises that you can participate in at your local gym. Spinning classes, circuit training and weight lifting allow you to increase your endurance and build muscle. Yoga classes can help with flexibility, improve your balance and decrease stress. Did you know that most professional athletes do yoga for these exact reasons? Not only will these activities keep you fit, but you can do them with your friends and family. Encourage them to join you.

Outdoor activities are an excellent way to maintain a healthy lifestyle, as they allow you to stay fit while getting fresh air and sunlight at the same time. Cycling, throwing a Frisbee®, going for a hike or playing golf are all fun activities that you can do with your friends and family. We all know there are rainy days when you are not able to go out and enjoy the weather. On days like these you can burn some energy with Nintendo®Wii™ or XBOX®Kinect®. Whether you want to dance, bowl or play soccer, there is an activity for you.

Remember, keeping your joints healthy by exercising will allow you to remain physically fit and continue with your daily activities. Not only will you help your joints, but exercising can have a positive effect on your emotional well-being and prevent heart disease and diabetes. Talk to your hemophilia care team today to see what fun and exciting activities are waiting for you. 



Bigstock Photo: 17176589

## STEP UP. REACH OUT. International Leadership Program for Youth Bayer

**ARE YOU A YOUNG PERSON** with hemophilia who wants to make a positive difference in your community? Step Up Reach Out (SURO) can help you reach that goal. SURO is an international leadership program designed to help build tomorrow's leaders in the bleeding disorders community.

The program was created by the University of Texas Health Science Center, Gulf States Hemophilia and Thrombophilia Center (UTHS) in 2007 and is administered by the Lone Star Chapter of the National Hemophilia Foundation, with support from Bayer HealthCare. To date, the SURO program has trained nearly 90 individuals from more than 20 countries.

Young people selected for the program will join others from all over the world in receiving specialized, hands-on training and coaching to foster their leadership skills. There is no cost to participants or their families for Step Up Reach Out travel, accommodation or program expenses, other than obtaining passports and visas (if applicable).

To find out more about the program and how to apply, please visit [www.stepupreachout.net](http://www.stepupreachout.net). Information and applications for the 2013-2014 session are available on the website. ♡



## VWD FOCUS GROUP Findings

### An Update from Octapharma Canada

**TO BETTER UNDERSTAND** the needs of von Willebrand Disease (VWD) patients, a VWD focus group was conducted on January 19, 2013. This VWD research session was funded by Octapharma (a company dedicated to the improvement of patients with bleeding disorders including VWD), but conducted by a third party to ensure that there was no direct involvement or influence by the company. Octapharma was recently granted a Health Canada approval for a new generation, alternative VWF/FVIII concentrate for VWD patients. Participants attending included adults and adolescents with VWD and parents of children with VWD, all of whom had type III VWD or required factor concentrate to treat bleeding episodes. The insights obtain during the session will help Octapharma enhance the programs and services that are available for the bleeding disorders community.

- The main topic was centered on prophylaxis. Although the majority of individuals acknowledged the benefit of being on prophylaxis, they felt that not much information was provided to them by the clinics when they first began treatment. Perhaps the development of educational material focused on this aspect of VWD management would be useful for parents and families to have to take home.
- Parents of children with VWD and VWD patients want better communication between them and the clinic with regard to new products available for VWD. It was clear that information obtained at the Hemophilia Treatment Centre (HTC) is the most trusted source and therefore participants would like to see an increased level of communication from the HTC regarding new products available for their bleeding disorder.

- Participants were concerned with the lack of medical knowledge of staff outside the clinic (i.e. community hospitals) and with school educators. They would like to see more educational materials developed to help with this.

Octapharma's commitment to the bleeding disorder community is to partner with the patient organizations and the HTC not only to help provide the highest value of care but to improve the overall treatment of their bleeding disorder. Octapharma's goal is to utilize the feedback received to enhance our understanding of the issues faced by VWD patients and parents. Octapharma appreciates the time and willingness of the participants to share their thoughts and opinions. Octapharma would like to thank those individuals who attended as these efforts will strengthen our work and help us better serve the bleeding disorders community. ♡

## Central Western Ontario Region

### Big Sale on the **LITTLE STREET** Fundraiser

**IT'S BACK!** Save the date of Saturday September 7 for the Big Sale on the Little Street. Remember, this fundraiser takes place during the Locke Street Festival, so come on down and show your support while enjoying live music and entertainment on Locke Street.

If you would like to donate any items to the sale, please contact Alex McGillivray, Regional Service Coordinator at 905-522-2545 or [amcgillivray@hemophilia.on.ca](mailto:amcgillivray@hemophilia.on.ca) for more information. Please note that clothing and electrical items will not be accepted at this time. ♡

### **PARENTS**

#### Education Day

**ON OCTOBER 27**, parents of children with bleeding disorders attended CWOR's Annual Parents' Education Day program at Pillitteri Winery in beautiful Niagara on the Lake.

The program was designed for parents to ask affected youth that are currently in college/university what it was like for them growing up with a bleeding disorder. Supported by the Hamilton Treatment Centre's social worker, parents were able to ask questions, and were able to share experiences in a safe environment. One parent's response was, "It was great and very informative. I enjoyed listening to the youths' experiences growing up and it helped me to understand what my child is living with." ♡



### Aging with a **BLEEDING DISORDER**

**IN 2012**, CWOR created a new pilot program based on feedback from CHS' 2011 *Rendez-vous* Symposium in Calgary – the Aging with a Bleeding Disorder Program.

Members from the community, as well as from other parts of the province gathered at Dundurn Castle on November 3 to listen to presentations from the local treatment centre's medical team. Presentations were given by Dr. Iorio, Adult Hematologist; Kay Decker, Nurse Coordinator; Karen Strike, Physiotherapist; Linda Waterhouse, Social Worker; Sarah Crymble, Hemophilia Provincial Coordinator and Michel Long of the CHS all on the topic of aging with a bleeding disorder.

The program was very well received, and will be used as a model for other regions and chapters to use. The Toronto Region and the Ottawa Region are slated to hold events in 2013.

We'd like to thank all of the medical team members who attended this event, as well as Rob Dinsdale, CWOR volunteers and Co-Chair of planning this program for their time and dedication to making this program a great success. In addition, we'd like to thank all the volunteers who assisted in the set-up, take down and overall support of the program. ♡

### **HOLIDAY CELEBRATION** and Camp Wanakita Registration

**CWOR HELD** its annual Holiday Celebration and Camp Wanakita Registration event on December 8, 2012 at the Stoney Creek United Church. Everyone enjoyed a delicious potluck meal and the kids had a blast playing games and getting creative at the colouring table. Everyone also had a chance to register for camp this summer too.

Families enjoyed a special visit from Zach the Elf and Robin the Reindeer as they swooshed in straight from the North Pole with gifts for everyone. Robin the Reindeer also brought bags of special reindeer sprinkles to put out on the lawn on Christmas Eve to help guide Santa to their homes.

Many thanks are extended to Mary Pedersen for raising the funds to hold this event through her Big Sale on the Little Street fundraiser, and for all the effort she put into making sure the day went smoothly. Thank you to Rob and Jane Dinsdale, Paul, Debbie and Meagan Bordi and Igor Ristevski for helping out with the day's activities. A special thank you is sent out to Zach Adams and Robin Pedersen for bringing some extra joy to each child's face with your elf and reindeer skit. We'd also like to thank all of the members for bringing in the delicious food and for continuing to make this event so special. ♡



**We've MOVED!**

**THE CENTRAL WESTERN** Ontario Regional office has moved. We now share office space with The AIDS Network of Hamilton. Our new office address is:

101 - 140 King St. E.  
Hamilton, ON L8N 1B3

We encourage you to come visit us in our new space. Hope to see you soon. ♡

**LIAM BARBOUR** Scholarship Award

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

**Scholarship Requirements:**

- To qualify for this award, the applicant must reside in the Central Western Ontario Region, be an active member of CWOR, and have a bleeding disorder.
- The applicant must provide proof to CWOR of their enrolment at a post-secondary institution.
- CWOR has been empowered with the selection of the award on an annual basis. The award will be paid in/around the first week of October of the first year the student is enrolled in post-secondary education.

The deadline for receipt of scholarship applications is August 1, 2013. Faxed or late applications will not be accepted. For more information or to obtain a Liam Barbour Scholarship Award application, please contact Alex McGillivray, Regional Service Coordinator. Applications may be mailed to Hemophilia Ontario CWOR, 101-140 King St. E, Hamilton, ON, L8N 1B2 ♡



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

**Regional Board/Council and Staff**

Rob Dinsdale, Mary Pedersen  
Igor Ristevski, Debbie Bordi  
and Meagan Bordi  
Alexandra McGillivray –  
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101-140 King St. E  
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amcgillivray@hemophilia.on.ca

DATE	WHAT AND WHERE?	<b>Events Calendar</b>
September 20-22	<b>Just the Guys Weekend</b>	

## Northern Ontario Region

### Well WISHES

**SINCE OCTOBER, 2012** Teresa Genereux, Regional Service Coordinator has been off on a leave of absence from work. Please join us as we wish her a speedy recovery, and a quick return to work. We miss you Teresa!

Should anyone have any questions or concerns, please contact Terri-Lee Higgins, Executive Director at **519-432-2365** or **thiggins@hemophilia.on.ca**. ♡

### SPRING Clinics

**SPRING CLINICS** are just around the corner. Keep your eyes peeled for more information, and don't worry—a representative from Hemophilia Ontario will be on site to answer any questions you may have about programs and services. We look forward to seeing you there. ♡

#### Regional Board/Council and Staff

Betty Ann Paradis

Sarah Wood, Acting Regional Service Coordinator  
416-972-0641 Ext. 12  
swood@hemophilia.on.ca  
501 - 65 Wellesley St. E.  
Toronto, ON M4Y 1G7

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

DATE	WHAT AND WHERE?	Events Calendar
June 8	<b>Sudbury Clinic</b>	

## South Western Ontario Region



### WREATHS, SWAGS and Patio Pots

**WE HAD 89 WREATHS, 52 swags and 68 patio pots** delivered to Maureen's driveway as part of our holiday fundraiser. Thanks to our supporters and everyone from Woodstock to Goderich to London, these all got delivered. Special thanks to volunteers and members who got involved in the program. Special thanks to Maureen and her team in London, Karen in Chatham and Michelle in Windsor for helping to make this program a great success. We have a great supplier, De Goeys Flowers, and many of these wreaths, swags and patio pots are being enjoyed right into March. ♡

#### Regional Board/Council and Staff

Dawn Harman  
Kathleen Hazelwood  
Travis Hazelwood  
Ryan Kleefman  
Michelle Lepera  
Maureen Schaus  
Marion Stolte  
Holly Valenta  
Paul Wilton  
Moutasem Zakkar  
Leigh McFadden  
Monica Mamut

Matthew Maynard, Regional Service Coordinator  
Terri-Lee Higgins, Executive Director  
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London, ON N6A 1C7  
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mmaynard@hemophilia.on.ca  
thiggins@hemophilia.on.ca

DATE	WHAT AND WHERE?	Events Calendar
April, 2013	<b>Pinecrest</b> Camper Applications will be mailed out	
August 21 - 25	<b>Pinecrest Adventure Camp</b> , Goderich, Ontario	
September 14	<b>6<sup>th</sup> Annual Golf Tournament for Hemophilia and Inherited Bleeding Disorders</b> , Bear Creek Golf Club, Strathroy, Ontario	
September 20-22	<b>Just the Guys Weekend</b>	

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



## POLAR BEAR Dip 2013

### TAKE THE PLUNGE!

Join us on Sunday, April 14 at Little Beach in Port Stanley and celebrate World Hemophilia Day with us by jumping in the lake to raise awareness and pledges for the programs and services in South Western Ontario. It will be fun!

Pledge forms are available online at [www.SWORpolarbeardip.com](http://www.SWORpolarbeardip.com)  
To register, or for more information or directions, contact Matthew at 519-432-2365 ☺

## Toronto and Central Ontario Region



Jeenetha Kulasingam

### Regional Board/Council and Staff

David Neal, Maury Drutz, Mike Beck, Mojtaba Khezry, Samuel Leon, Victoria Kinniburgh, Sheila Coad, Ayeh Hamidian, Maryam Naji

### Staff

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

### Contact Information

Hemophilia Ontario - TCOR  
501 - 65 Wellesley St. E.  
Toronto, ON M4Y 1G7  
416-972-0641  
Toll free: 1-888-838-8846

## A GREAT HOLIDAY

Indeed!

**TCOR KIDS HAD** a great time at our holiday party making crafts and exploring the Pioneer Village as parents listened to Vanessa Bouskill talk about homecare and self-infusion. Overall, the event was a great success and we're looking forward to the next FIT event in June. A special thanks to Justin El-Rassi for sharing his first-time Wanakita experience, and Kristen Luszka and her friend Jon for watching over the kids and organizing activities for them. ☺



Sarah Wood

## TAKE THE PLUNGE with TCOR... AGAIN

**TCOR DOUBLE DARES** you AGAIN to put on your craziest costume and jump into chilly Lake Ontario for World Hemophilia Day! Collect pledges from your family and friends over the next month to support programs and services for people with inherited bleeding disorders in your area.

It's a simple way to raise awareness and funds for your community. Register online at [www.events.hemophilia.on.ca](http://www.events.hemophilia.on.ca) and collect pledges online or download the paper form. Just bring all your pledges on April 13 to Woodbine Beach at 2:00pm and take the plunge. The more the merrier, so bring your family and friends. Everyone will enjoy snacks and hot chocolate to warm up afterwards. ☺

## THANK YOU to OUR SPONSORS

### 13<sup>th</sup> Annual Hemophilia GOLF CLASSIC

#### Masters Sponsors



Bayer HealthCare

CSL Behring  
Biotherapies for Life™



Sponsor a Camper for One Week at Wanakita – 3 camper spots



#### Hole Sponsors

Arlene Atlas\Jan Drutz, Captain Printworks, Martine Celej, Maury Drutz, Dr. Julian Geller, Marinucci & Company, Strype Barristers, Neal and Smith Barristers & Solicitors, Adventure Aviation

TCOR

DATE	WHAT AND WHERE?	Events Calendar
September 20-22	Just the Guys Weekend	

# Ottawa and Eastern Ontario Region

## A MAGICAL Celebration

ON DECEMBER 9, 2012, the Ottawa and Eastern Ontario Region held its annual Holiday Celebration and Camp Wanakita Registration event. This year's festivities were a great success. Held at the Police Association in Ottawa, 65 participants came together to celebrate the holidays and to register their children for the upcoming camp year.



The kids enjoyed making crafts, playing games with a clown, and an awesome show filled with acrobatics by Jon the Cow Guy. Santa also made a special appearance bringing gifts for all the good girls and boys.

Many thanks are extended to the Suave-Charbonneau family, Darlene Villeneuve, the Kurrich family, the Van Dusen family, the Cabral family and to all the youth volunteers who came and helped out for the afternoon. Also, a very special thank you is extended to Doreen Rotar (also known as Aunt Doreen), for her generous \$500 donation towards this program. Without the organizational efforts of Nancy Suave and Darlene Villeneuve, as well as all the help of the volunteers and Aunt Doreen, this celebration would not have been as magical as it was. ♡

### Regional Board/Council and Staff

Raja Ammourey-Alami  
Jordan Cabral  
Lyanne Cabral  
Ashwani Kurrichh  
Nancy Sauvé  
Darlene Villeneuve  
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All articles in this section, unless otherwise indicated, are by Colin Patterson.

## OEOR's Aging with a BLEEDING DISORDER PROGRAM

SCHEDULED FOR THE FALL of 2013, the Ottawa Region will hold its first Aging with a Bleeding Disorder Program. At the present time, OEOR is looking for presentation ideas, as well as for any individuals wishing to get involved in the planning. If you have ideas, or are interested in participating in the planning, please contact Colin Patterson, Regional Service Coordinator at 613-739-3845 or [cpatterson@hemophilia.on.ca](mailto:cpatterson@hemophilia.on.ca). You can also contact Lucie Lacasse, Nurse Coordinator at [llacasse@ottawahospital.on.ca](mailto:llacasse@ottawahospital.on.ca). ♡



## 19<sup>th</sup> ANNUAL Shawn Duford GOLF TOURNAMENT for Hemophilia

MARK SATURDAY, August 10, 2013 in your datebook and join OEOR for the 19th Annual Shawn Duford Golf Tournament for Hemophilia. This tournament features a shot gun start at 1:00pm at the Meadows Golf and Country Club in Ottawa. Registration, as always, is on a first-registered basis, so don't delay.

For more information on the tournament, please contact Colin Patterson, Regional Service Coordinator at 613-739-3845 or [cpatterson@hemophilia.on.ca](mailto:cpatterson@hemophilia.on.ca). ♡

DATE	WHAT AND WHERE?	Events Calendar
Aug 11	<b>18th Annual Shawn Duford Golf Tournament</b> The Meadows Golf & Country Club, Ottawa, ON	
Sept 7-9	<b>Just the Guys</b> OEOR, YMCA Camp RKY in Parham, ON	
Oct TBA	<b>Bowl-a-thon</b>	

# Bleeding Disorders News

## The “WEAR AND TEAR” of Obesity

by Jeenetha Kulasingam

**OVER THE YEARS** we have become aware of secondary health issues associated with obesity. Whether through media, school, work or informal conversations, we all have heard about the direct correlation between obesity and diabetes, high blood pressure, high cholesterol, asthma, heart disease and sleep apnea. However, the one factor that is often not shared is the impact obesity has on joints.

Several studies indicate that obesity accelerates the wear on joints three-fold due to biomechanical stress (that is the weight-bearing stress upon joints when we undergo certain activities that apply force). For example, the force on one knee is about three times your body weight when you are walking (Makk, 2007). Therefore, if you weigh 200 lbs., the force on your knees alone when walking is 600 lbs. More strenuous activities such as running, climbing and squatting can lead to forces that are 10 times your body weight. Over time, these forces will lead to wear and tear of major joints, a condition called osteoarthritis which eventually could lead to the need for joint replacement surgery.

This correlation between obesity and joint pain is even more pronounced for those living with an

inherited bleeding disorder prone to joint damage. Studies have revealed that almost all individuals living with severe hemophilia suffer from arthropathy in at least one joint.

That’s why it’s even more crucial to manage your weight and have a healthy diet if you are affected by an inherited bleeding disorder.

A recent study has shown that for every pound of weight lost, there is a four-pound reduction in knee-to-joint-load per step. This means roughly that the accumulated reduction in knee load is more than 4,800 lbs. for every mile walked. This is a significant indicator about the role that extra fat tissue plays on our joints.

There is still a wide range of physical activities that one can do with joint problems. Here are a few low-impact activities that may be done by those who are obese or experiencing joint pain:

### 1. Walking

Doing this at least 30 minutes a day can keep your joints flexible, burn calories and promote weight loss.

### 2. Biking

This is a great aerobic exercise that improves cardiovascular health, and the best part is that there is very little force applied on your joints as

you are not pounding down on the pavement like you would if you were to run.

### 3. Swimming

Most HTC staff recommend swimming as a physical activity as the water provides a nice cushion resulting in no impact on the joints. Swimming also helps burn calories.

### 4. Yoga

This is great for the mind as well as your joints. Studies have shown that consistently practicing yoga relieves muscle tension and stress, increases muscle strength and promotes flexibility. This is easy to do in the comfort of your own home.

### 5. Strength Training

Lifting weights and/or doing Pilates increases your range of motion and promotes flexibility.

To summarize, managing weight has a positive impact on your heart, your mind, your joints—on every organ/cell/tissue in your body. However, for those living with an inherited bleeding disorder, maintaining a healthy lifestyle and a healthy weight should be top priority, as the negative effects are much more prominent. ♡

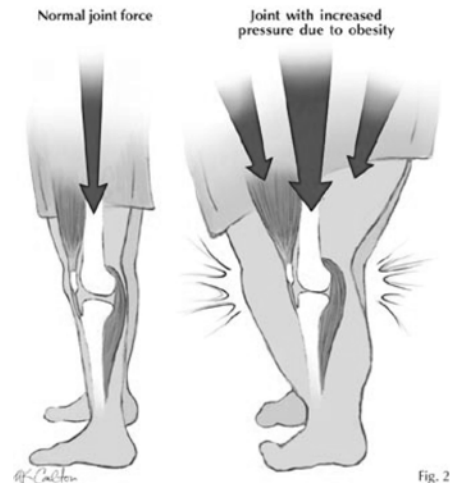
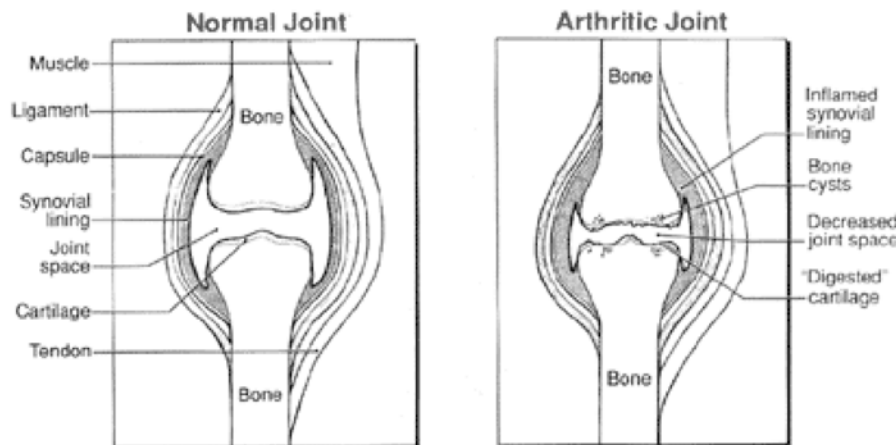


Fig. 2

## Hemophilia Ontario Youth Section



### Get ACTIVE

by Amy Griffith

**THIS YEAR I MADE** one New Year's Resolution, which was not to make a New Year's Resolution. Other than perhaps the morning after the infamous Victoria's Secret fashion show, New Year's Day is when many decide that it's time to make a change. For most of us, this means bullying ourselves into committing to a long-term goal with no idea how to achieve it, simply because we feel like it's the "thing to do."

The motto that I live by is that if you're serious about living a healthier, more active lifestyle, you are ready to start *today*.

From personal experience, I find that the "yellow brick road" to a healthier lifestyle has a three way stop:

1. Eat
2. Sleep
3. Sweat

Eating well is something that we all *want*, but likely have the most trouble achieving. Let's be realistic. A slice of pizza looks way more enticing than a vegetable platter, and I have yet to meet someone who ever ate "responsibly" over the holidays. Realistically, life is fast paced, and we tend to cater our eating habits to the same mantra. Something that I've personally found really helpful, and now live by, is juicing. Blend all of your favourite fruits and vegetables with some plain Greek yogurt, skim milk or water and have it for breakfast

or a light snack between meals. I've found that I'm more likely to snack when I'm at work, and I find it easier to drink my veggies than eat them—not to mention that there are so many combinations to try, and they're super filling.

Sleep is easy—spend six-eight hours between the sheets every night.

Exercise is a commitment all by itself, especially in the winter. Finding time to get at least 30 minutes of physical activity can seem daunting, and we can be really hard on ourselves if we fail to do it. Personally, I've tried lots of different forms of exercise, and through trial and error have concluded that if you don't enjoy doing it, you're less likely to want to keep it up. For me, this exercise is running. Long distance running can be particularly hard on your body, and as a young woman with a bleeding disorder, I am acutely aware of the risks associated with this sport. Nonetheless, with the help of my personal trainer (also known as my dedicated mother), I have found a training regime that works for me, meets my needs, and caters to my long-term goal of running the 2013 Toronto Marathon.

I believe goal setting is an essential part of successfully living a healthier lifestyle. Examples of this are:

- I'm going to run/walk for an extra minute today than yesterday
- I'm going to add another repetition to my weight set today
- I'm going to eat four servings of vegetables today
- I'm going to be asleep by 10:00pm every day this week
- I will be able to swim 500 meters in my pool by this time next month, without stopping.

No matter how large or small your goals are, so long as they are realistic, attainable and have a timeline, they will be successful. Find something that you love to do (Zumba, Tai-Chi, swimming, walking in a group, playing tennis, etc.), make time to do it, and just do it. If you love it, you will find yourself looking forward to it rather than needing to fit it into your already busy schedule. ♡



## 52 DOWN, More to Follow

by D'Marc Lewis

For those of you who know me, healthy living is not something that comes to mind quickly. Yeah, I love food. I love it more when I don't have to add sauce to it (that's a hint for all of you who invite me to dinner!).

Recently, in an earlier edition of *Blood Matters*, I discussed how my life was improving with the advent of using my bicycle for commuting. Yes, it was a time and money saver as I did not have to rely on two bus fares per direction (four fares per day). Yes, it was a deterrent when it was warm to give up and throw in that second ticket. However, it also allocated more time for me to sleep which is also necessary towards healthy living. (Didn't you know?)

My job, in short, was a daily run-you-down-to-the-ground operation. Essentially you needed to have the stamina and endurance for an eight-hour day of non-stop tiresome production. As a consequence of that job, I lost 52 pounds, mostly from exertion, and I kept my cycling to a minimum. My job today is only part time, but requires me to be on my feet for about 11 hours. I'll tell you, it's a lot of walking!

Somewhere in that year that I lost the 52 pounds, I began feeling...different. I felt with this exciting change that it was necessary to take on a new challenge and responsibility. So I embarked on two things in the hype of it all—a search for a dietician (she's actually a few yards away from the nurse coordinator's desk), and keeping my caloric intake below 1,500 calories a day. You may also find a dietician in your treatment centre. Just ask your hematologist or family doctor for a referral.

I also started making a few small changes. I take Vitamin B and multi-vitamins. I choose whole grain instead of white, organic instead of gluten-filled, olive oil instead of canola, apples and bananas instead of cookies and moon-pies, and homemade salads instead of \$5 pizzas. I think you get it, but who says it's easy for someone to make these changes over time? Never mind rapidly. Sometimes you must indulge a little now and then, and give your backside something to be naughty about even for just a couple days to work off again. If you don't, unless you're a champ, you may end up nuts. Or just straight out, you're nuts already.

I don't have any personal recipes, but if you want to try something different along this topic, I suggest giving a Google search to: Peanut Butter Whoopie Pies. A Pennsylvanian delight—one word—DELICIOUS! If for some reason, you think a recipe like this is on-point for healthy living, you're crazy – but I love you! Go on with your fine self.

Hate me or love me, it's now in the back of your head, fellow Hemos' and others. This story doesn't quite have a happy ending, but that's because it's not done yet. So you'll have to stick around to find out my progress in another article. ♡



## STAYING HEALTHY at School

by Zach Adams

As a university student, it hasn't always been easy to stay active, not to mention the difficulty of eating the right foods. These are just several of the challenges that I have had to face, so I want to mention a few tips I use to make sure I'm living an active lifestyle.

Breakfast. I've learned over the years that this is the most important meal of the day. Making sure you eat in the morning will prevent you from starting to doze off during your first class. I like to try and plan ahead, making sure I have organized the night before what I'll be eating the next morning. I also try to include at least one fruit, while staying away from sugar-filled fruit drinks. Packing some easy-to-eat snacks in a few Ziploc bags is also another great way to get constant energy throughout the day. I recommend almonds, fruits and veggies as things that keep your brain working during a long school day.

Now, exercise. Many people dread even hearing the word, never mind all of the stuff associated with what you have to do, and even worse, what happens if you don't do it. However, it doesn't have to be difficult and there are many strategies I use to make sure I'm staying active. Time management

is a big obstacle that needs to be overcome to remain fit and achieve the grades you want.

Waking up an hour before class so I can run the track or use the treadmill is something I incorporate into my day so I can get the activity I need. By simply eating right and making sure you incorporate daily physical activity into your school schedule, you may have more energy and possibly even improved grades. You can do it! ♦



## En GARDE!

by Trevor Reid

Fencing is my way of keeping physically active. Fencing also teaches self-control and discipline and is great for posture, flexibility, balance and coordination.

Fencing is a moderate contact sport. As long as I wear the correct uniform and equipment, including a protective chest plate, my chances of being injured are low. My fencing club has strict rules for warming up and stretching which improves flexibility, and for me, it reduces my chances of getting a bleed.

I enjoy fencing because it doesn't matter how old you are or how big or small you are. Fencing is a cool sport for anyone. *En garde!* ♦

## HEALTHY LIVING

### Affordable and Healthy Nutrition

by Zachary Templeman, Hepatitis C Coordinator; Regional HIV/AIDS Connection

**IT CAN SEEM** impossible for healthy food to be affordable and accessible for people living on a limited income. Buying a month's worth of groceries for under \$150 while properly following the Canada Food Guide recommendations can be done, though not without difficulty. I decided to take on this challenge and purchased the groceries listed here. I spent \$128.45; I already had olive oil, lemon juice, garlic and spices, so I didn't add those to the bill. "Healthy" doesn't have to mean bland and boring. Being a bit adventurous and trying new recipes can turn a few staples into a variety of delicious meals. I was usually able to substitute ingredients with what I had on hand in the recipes that I wanted to try. One difficulty that I didn't foresee was my ability to eat as much as the Canada Food Guide recommends. It felt like I was eating all the time! Eventually, I got used to it, but I probably could have comfortably stretched this amount of food to last two months. Creativity and time to prepare food made mealtimes much more enjoyable. All in all, this experience was positive. Cooking healthy foods on a budget can be challenging, but it is possible. ♦

ITEM	Cost*	ADDITIONAL SUGGESTIONS
8Kg bag Rice	\$ 10.99	Cinnamon
900g bag Pasta	1.15	Lemon Juice
2.5Kg bag Oats	4.49	Cumin Powder
1 loaf (reduced 50%) Bread	.99	Chili Powder
2Kg bag, dry Black Beans	3.54	Olive Oil
900g bag, dry Lentils	2.39	Garlic
12 thighs Chicken Thighs	10.52	Salt
Large jar Peanut Butter	7.97	Pepper
2.5Kg bag Skim Milk Powder	24.47	Italian Herbs
500g block Cheese Brick	5.49	Sugar
2, 2Kg bags Frozen Mix	9.58	Gelatin
750g bag Frozen Peas	2.99	Hot Sauce
2Kg bag Frozen Corn	4.79	
4 cans Frozen Juice	5.96	
2 bundles Celery	2.96	
1 big box Spinach	4.99	
3lbs bag Carrots	1.77	
4lbs bag Apples	4.98	
5lbs bag Oranges	4.99	
2 heads Cabbage	3.84	
3 large cans Canned Tomato	2.67	
1 large can Tomato Paste	.99	
2 Spanish Onions	2.65	

*This grocery list is an example of one month's supply of grains, one month's supply of fruits and vegetables, two months' supply of meat and alternatives and two months' supply of milk products according to the Canada Food Guide. This list may not work for everybody, but it can serve as a guide. Adjustments can be made to suit your preferences and needs.* ♡

## How to Make **HEALTHY LIVING** a Family Affair

by Sarah Wood

**IN A TIME** of ever-increasing technology options, emphasis on fast and easy foods, and increasingly busy lifestyles, it can be harder than ever to work in basic healthy living strategies. While options such as gyms or the latest fad diets are always available, there are also some simple everyday practices that families can do to make healthy living a part of their lifestyle and to make it something fun to do as a family. Here are a few suggestions of how to do this:

- **Take your kids to the grocery store/market and let them help pick out fruits and vegetables.** Use this as an opportunity to teach them about different produce, where it comes from, what it can be used for, etc. Allowing them to choose what they want makes them more excited to eat them.

- **Make healthy meals fun.** Come up with creative names such as Smiley Face Pizzas (let them decorate pizza as faces with vegetables), or Bananas in a Blanket (tortilla wraps with peanut butter and bananas in them), or Veggie Mush (shredded vegetables such as zucchini and carrot that can be added to other recipes). By making it fun, you'll have your kids requesting these foods while



also getting some good nutrition into them.

- **Cook together.** If children take part in the process they not only learn the skill of cooking, but chances are you will have to fight with them less to eat their food since they had a role in preparing it. Alter the tasks you give them depending on their age and skill level; small children can stir, sprinkle and spread, while older kids can chop, blend, etc. This is also a great way to get in regular quality time with your family.

- **Make treats special by having them only at certain times.** You don't have to ban all sweets or junk food from your family's lives, but you want to teach them that these things are treats and not part of a regular diet. Make a routine that Friday night is take-out night, or Sunday afternoons you bake cookies.

- **Do healthy living-based crafts with your kids.** Create an exercise and meal plan chart for your kitchen wall, or create ceramic healthy portion plates. By making these fun crafts, your children will learn something about healthy living as well as have fun together.

- **Schedule regular family exercise time.** Make it a regular occurrence and something you do together as a family. Plan Sunday afternoon hikes or bike rides, or a nighttime walk after dinner each night. By leading by example and making exercise and activity a regular part of their lifestyles, this will become their routine and create habits that children will carry on as they get older.

- **Plant a garden together.** If space permits, plant a family garden. This serves dual roles—teaching your kids about produce, as well as ensuring that you have healthy food options available at your fingertips. Extras from the garden can also be used for another family activity at the end of summer—jarring and preserving.

- **Make outdoor time a priority.** With computers, televisions, video



games, etc., there are many reasons to stay inside, but try your best to make being outdoors a regular occurrence for your family. Even if it is eating your summer meals outside, or sitting on the porch after dinner, the benefits they get from the fresh air and sunlight will be huge. ♦

## Self-Care IDEAS

by Sarah Wood

**STRETCHING HELPS** combat the natural tightening of muscles and range of motion as we age. It can help lengthen muscles, increase range of motion of joints, increase blood circulation, and increase energy levels.<sup>1</sup>

Pilates lengthens and stretches all the major muscle groups in the body. It can be used for rehabilitation or prevention of injuries of the muscles.<sup>2</sup>

Yoga brings the body and mind together through exercise, breathing and meditation. This improves

muscular and postural strength.<sup>3</sup>

Journaling—increasing evidence shows it has a positive effect on well-being. Writing about stressful events helps people come to terms with them. It also helps to clarify thoughts and feelings, know one's self better, solve problems more effectively and reduce stress.<sup>4</sup>

Art Therapy bridges the gap between the conscious and unconscious, bringing light to feelings that one wasn't aware of. It opens up new avenues of communication and self awareness that might not be present through speaking.<sup>5</sup> ♦

<sup>1</sup> Heart of Healing

<sup>2</sup> Better Health Channel

<sup>3</sup> Better Health Channel

<sup>4</sup> Psych Central

<sup>5</sup> GoodTherapy.org



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## HIV/HCV News

### Nutrition for HCV

by Sarah Wood

**WHAT KIND OF DIET** should be eaten is a common concern for people with Hepatitis C. The general answer is that you should try to eat a relatively healthy diet. The detailed answer is that if you have moderate liver damage you don't need to be as strict with your diet, but you should still try and eat a balanced diet that doesn't include a lot of harmful foods, but if you have serious liver damage (cirrhosis) then you should monitor quite closely the foods you are eating so as not to cause further damage to your liver.

Generally, someone with Hep C should try to eat a diet that is low in fat, with plenty of vegetables, fruits and whole grains. Also you should try to eat foods that are low in sodium, iron and simple sugars and high in protein, particularly if you have cirrhosis.

#### Fat

The liver is responsible for digesting fats and it has difficulty doing this when there is liver damage, so you should try to be careful with your fat intake. You don't necessarily want to cut all fats and oils out of your diet because some are needed by your body in order to function properly, but you should try to eat reduced fat

foods, including dairy products, and lean meats with the fat trimmed off. It is important to avoid processed foods that are high in saturated or trans fats. Omega-3 fatty acids should be the main type of fat that you eat. Salmon, walnuts, flaxseed and fish oil are great sources of Omega-3.

#### Sodium

Too much sodium (salt) is very damaging to the liver, and if you have cirrhosis a high salt diet can lead to ascites—an abnormal accumulation of fluids in the abdomen. People often aren't aware of just how much sodium there is in different foods. Some foods that should be avoided are canned soups, crackers, tomato sauce and soy sauce, just to name a few. It is very important to get into the habit of reading labels at the store to see how much sodium is contained in the food. Limiting salt also means that fast food should be avoided as well as processed food. Red meat should also be restricted because it is high in sodium.

#### Iron

The liver is responsible for metabolizing iron since it is the primary organ in the body that stores this metal. People with Hep C can sometimes have trouble getting this iron out of the body and this can result in an overload of iron in the liver, blood and other organs. Excess iron in the liver can be very damaging. This isn't to say that you should entirely elimi-

nate iron-rich foods such as red meat. Just make sure that you are eating small portions with the fat removed. Other foods with high iron content that you will want to watch how much you eat are liver and cereals fortified with iron. Studies have also found that high iron levels are particularly harmful to people with Hep C who are undergoing treatment, as it can decrease the response rates to the drug Interferon.

#### Sugar

It is important to try to avoid eating too much sugar or to avoid becoming overweight when you have Hep C. Sugars are sources of energy and can be very tempting to eat, but they are not a source of essential nutrients. It is much better for you to get your energy from foods such as whole grains, meats, fruits, cereals and vegetables, which are all rich in nutrients.

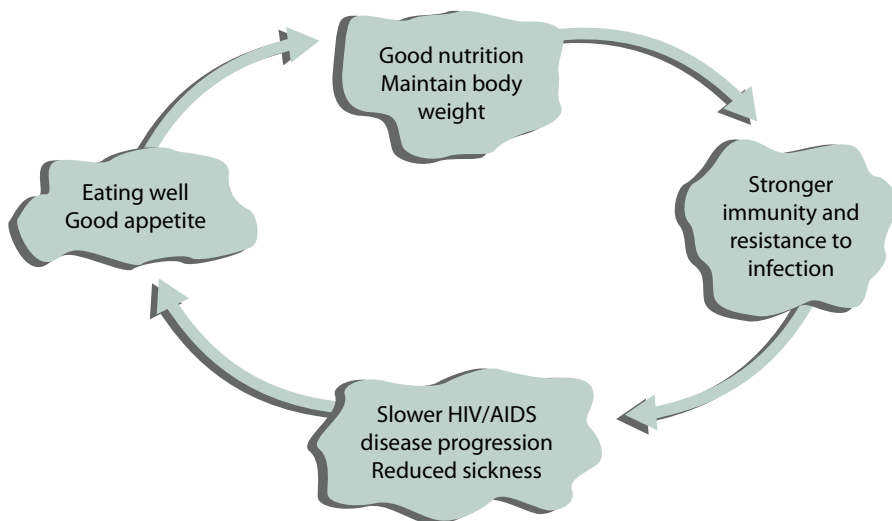
#### Protein

Protein is a very important thing for someone with Hep C as it helps to repair body tissues, including liver tissues. People with liver damage or



cirrhosis should ingest an adequate amount of protein. You don't want to go overboard as too much protein can cause other health complications with your Hep C. It is recommended to take proteins from vegetables, such as beans and lentils, and dairy products, such as eggs, milk and yogurt, instead of from meat. If you are getting some of your protein from animal products, you will want to ensure that you monitor how much you are eating of it. ♦

Written by Sarah Wood for Regional HIV/AIDS Connection Hep C News Winter 2011 Edition



## HEALTHY Recipes

by *Tristan McLaurin*

### Nutty Fruit Cookies

- ½ cup brown sugar
- ¼ cup olive oil
- 3 egg whites
- ¼ finely chopped dried figs
- ¼ cup dried cranberries
- 1 tsp vanilla
- 1 cup whole wheat flour
- 2 tbsp flax seed
- ½ tsp baking soda
- ¼ tsp cinnamon
- ¼ cup slivered almonds (chopped works too)

#### Directions:

1. Preheat oven to 350°F
2. Combine sugar, oil and eggs into bowl. Mix in dried fruits and vanilla.
3. In separate bowl, add the rest of the ingredients and mix.
4. Pour contents of one bowl into the other, mixing well.
5. Drop by tablespoonfuls onto pan or baking sheets.
6. Bake for 12 minutes

### Blueberry Smoothie

- ½ cup milk
  - ½ cup water
  - ½ cup blueberries (frozen is fine)
  - 1 tbsp flax seed
  - ½ cup unsweetened applesauce
  - ½ cup plain, non-fat yogurt (optional)
  - 2 scoops protein powder
  - a few ice cubes
- Blend. ♦

## The Cycle of Nutrition in PEOPLE LIVING WITH HIV/AIDS

by *Sarah Wood*

**NUTRITION IS IMPORTANT** for everyone, but it is especially important for people living with HIV/AIDS. Along with HIV/AIDS come many symptoms that vary from person to person. A couple that are commonly seen are weight loss, lack of energy, and insufficient dietary needs such as vitamins, fiber and protein. Doing your best to maintain adequate nutrition can have a positive impact on these symptoms. There are plenty of practical and informative resources available to assist you in planning healthy meals that will provide you with the nutrients that your body needs to maintain its strength, increase energy and either maintain or gain body weight. Being in control of these symptoms can improve your body's ability to fight other symptoms that the virus and medications can cause. The diagram below (taken from *Living Well with HIV/AIDS: A manual on nutritional care and support for people living with HIV/AIDS*) illustrates the cycle that having good nutrition can create in people living with HIV/AIDS. Take the time to find out what a good diet is for you, one that will work with your lifestyle, and take control of some of your symptoms. ♦



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Southern Ontario

# Just the Guys 2013

Save the Date!

Friday September 20—Sunday September 22

The Just the Guys program is a weekend residential camp for boys ages 4-17 who are affected by an inherited bleeding disorder, and an accompanying father/male role model aged 19 and above. The weekend provides an opportunity for participants to gain a better understanding of the diagnoses, as well as to connect with other families through a series of education sessions, activities and networking opportunities.

\*Note: 4-year-olds will be given individual consideration for participation, and 17-year-olds have the option of attending as a participant with their father/accompanying male role model, or attending as a regional Just the Guys Youth Volunteer (one volunteer position per region).\*

**OCTOBER 25-27, 2013**

YMCA Geneva Park  
6604 Rama Rd, Orillia, ON  
L3V 6H6



**This is YOUR time!**  
**This is YOUR weekend!**

**Wellness:** The quality, and/or state of being healthy in body and mind.

Being a woman living with, or affected by an inherited bleeding disorder presents its own unique set of circumstances. Achieving wellness in today's world is a constant pursuit.

W2 brings together dynamic guest speakers, provides practical tips, lessons, and advice. Conference topics may include raising a child with a bleeding disorder, living well with a chronic illness, navigating the ER and much more.

Come build your skills and knowledge and meet others who know what you're going through!

We invite ALL women living with or affected by an inherited bleeding disorder to engage in making wellness a priority.

*Set aside October 25 -27 to take part.*

Save the Date!



**MARK  
THIS  
DATE**

# Hemophilia Ontario Calendar 2013

DATE	WHAT AND WHERE?
April 27	<b>Hemophilia Ontario AGM</b>
September 20-22	<b>Southern Ontario JTG (CWOR, SWOR, TCOR)</b>
October 25-27	<b>Wellness for Women: W2 Conference</b>

*\*Dates are tentative and may be subject to change\**



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