



Hemophilia Saskatchewan

August 2016

Summer Newsletter



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CHECK OUT THIS EDITION OF THE HEMOPHILIA SASKATCHEWAN NEWSLETTER!

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- ⇒ **What is a National Tender System?**
 - ⇒ **Point of Care Ultrasound**
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Want to see this in colour?

Check us out online at

www.hemophiliask.ca

President's Message

Greetings to you all!

Well there is nothing better than summer time in Saskatchewan...we know how cold it can be so we savour these long sunny days because eventually it will be gone with the change of season. I believe that we have that ability to appreciate what others in the world might take for granted because we have our warm weather for just a small part of the year. While we long for warmer days, our bleeding disorder family in other parts of the world may be longing for something else - access to comprehensive care and treatment. Canada is a leader in this area and the Saskatchewan Bleeding Disorders Programs continues to meet the high standards of care. The opportunity to see what the world is doing became possible when we were able to send one of our active hemophilia families to take part in the WFH world congress. Please see Angie Bedard Haughn's experiences with the congress, it will enlighten you.

One of the major changes that is affecting our bleeding disorder community is the change of Factor replacement product namely Kogenate - Kovaltry, and Xyntha replacing Advate. We are hoping the transition processes are going well and if there are any issues we would like to hear about it. The pharmaceutical representatives are working closely with us to ensure that there are smooth transitions, your feedback would be valued.

We continue to be active in our work and are looking forward to providing resources to the Queen City Marathon this year. We were not able to run a water station due to lack of volunteers, so if you are in the Regina area and would like to volunteer for this in the upcoming year that would be great. Keep an eye out for our yearly fundraising event - the Grey Cup Pool raffle coming in the fall.

As always, thank you for taking the time to read our newsletter. We welcome as much as involvement as you can give, you are all incredibly valuable to us. Now go out, put on your shades and sunscreen and enjoy what's left of this beautiful Saskatchewan summer!!!

Wendy



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Hemophilia Saskatchewan?**

Check us out online at

www.hemophiliask.ca

Factor VIII and IX: CBS tender results announced

OTTAWA, April 6, 2016 - Canadian Blood Services (CBS) announced the results of the tender for recombinant factor VIII and IX for the April 1, 2016 – March 31, 2018 period for Canada, excluding Quebec.

It is important to note that the decision surrounding these contracts was a unanimous one by the selection committee, involving experts from CBS, the Association of Hemophilia Clinic Directors of Canada, the Canadian Association of Nurses in Hemophilia Care and the Canadian Hemophilia Society. The evaluation was based on safety, efficacy, quality and cost.

The new contracts for recombinant factor VIII and IX will result in an estimated 40 to 50 million dollars of savings for the health care system annually. These savings are in addition to significant savings realized in the 2013-16 period over previous years.

A large number of patients with hemophilia A will be switching products as Advate, manufactured by Shire (formerly Baxalta) is phased out over the next several months. Following similar tender processes in recent years in countries such as Ireland, the U.K. and Australia, resulting in massive product switching, no negative outcomes were observed. The province of Quebec went through a similar mass switch in rFVIII products (Helixate FS to Xyntha) one year ago, and the process went very smoothly.

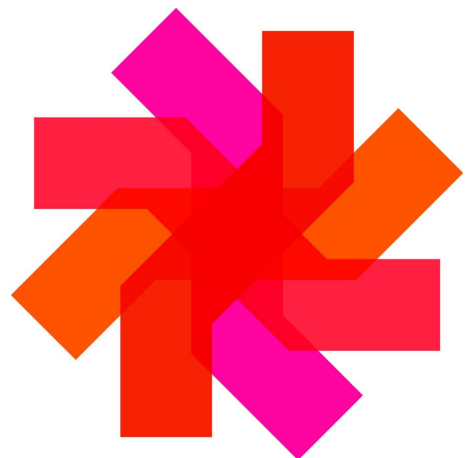
In addition, Bayer's Kogenate FS will be replaced by the company's new recombinant FVIII product, Kovaltry, also over the next several months.

While supply factors suggest that many patients using Kogenate FS will switch to Bayer's new product Kovaltry, and that many users of Advate will switch to Pfizer's Xyntha, such decisions are made jointly by the physician and patient/caregiver, and should not be imposed.

There are now four rFVIII products available for use in provinces served by CBS: Xyntha, manufactured by Pfizer; extended half-life Eloctate, manufactured by Biogen; Kovaltry, manufactured by Bayer; and Nuwiq, manufactured by Octapharma.

With regard to factor IX, Pfizer's Benefix remains the predominant product. Biogen's extended half-life Alprolix is also available. The plasma-derived FIX product, Immunine from Shire-Baxalta, while not part of the tender process, remains available.

The product switchovers will take place progressively across the country this summer and fall. Treatment centres will be in touch with their patients at the appropriate moment.



Saskatchewan Bleeding Disorders Program



Factor VIII and IX: CBS tender results. What is a national tender system?



As many of you are aware on April 6, 2016 the Canadian Blood Services (CBS) announced the results of the tender for recombinant factor VIII and IX for the April 1, 2016 – March 31, 2018 period for Canada, excluding Quebec. Many of you may have questions about what is a tender and what are the advantages and disadvantages of the tender process. The following information has been quoted directly out of the Document the World Federation of Hemophilia has developed entitled: *“Guide to National Tenders for the Purchase of Clotting Factor Concentrates.”* The following will highlight those questions and then discuss how it affects Canada, excluding Quebec.

What is a national tender system?

A national tender system, or unified procurement system, is a cost-effective system for the purchase of products or services. Instead of each organization purchasing its own supply of a particular product or service, the government purchases what is needed for the entire country or population. A national tender can bring together the key experts in a country and lead to a more rigorous and effective analysis of the criteria used to decide on which products should be purchased. This system can achieve cost savings by buying large volumes and soliciting competitive bids called tenders from suppliers, with the contract awarded for a period of time to the bidder or bidders who best meet those criteria.

An increasing number of countries are using national tenders for the purchase of clotting factor concentrates for their bleeding disorders population. Since the quantity of factor concentrates needed in a particular country in any given year can be predicted within defined margins, it is possible to purchase the entire supply for a population and period of time at once. However, there are many variables that affect the safety and efficacy of a product. Therefore, it is key to ensure that the clinicians, hemophilia organizations, and regulatory authorities with expertise in this area are directly involved in the tender process and that decisions are not made solely by officials or procurement officers with inadequate knowledge of the products.

To work effectively, a national tender system should be open, objective, and transparent. To ensure that tenders are carried out properly, certain rules and principles should be observed.

Advantages of a national tender system

National tender systems for the purchase of factor concentrates have a number of distinct advantages:

Hemophilia is a relatively high-cost condition to treat. In many countries, factor concentrates and **bypassing agents** for the treatment of **inhibitors** are among the top 10 most expensive medicinal products purchased. This has led to an increased interest in hemophilia by government health economists and an increased tendency to evaluate hemophilia therapies using **health technology assessment (HTA)** or other economic evaluation methodologies. National tenders can be cost effective as large quantities of products are purchased relative to the amount purchased by individual hospitals or areas of the country. Countries such as Ireland, the United Kingdom, and Australia, which have well established national tender systems for factor concentrates have benefitted greatly by virtue of lower cost of factor concentrates and a corresponding ability to increase per capita factor use, thereby moving toward optimal treatment. The survey of tender and procurement systems in 38 European countries, carried out on behalf of the European Haemophilia Consortium (EHC) in 2015 and published in *Haemophilia*, clearly demonstrated that tender systems with a legal framework and appropriate clinician and patient organization involvement are more cost effective. The demonstrated **cost effectiveness** of national tender processes with rigorous selection criteria argues for the replacement of HTA or other assessments in countries with well-developed tender systems. Furthermore, an adequate tender process may increase the probability of access to newer products and newer generations of products.

Saskatchewan Bleeding Disorders Program



Factor VIII and IX: CBS tender results. What is a national tender system? Continued part 2



The national tender process can lead to a more uniform, higher standard of care nationally as the safest and most efficacious products can be purchased for the use of all people with hemophilia or other inherited bleeding disorders. It can help to prevent the situation where some people with hemophilia in some regions of a country get substandard treatment, due to inadequate health budgets for their local hospital or health authority. This can be greatly assisted by concurrently ensuring that a good system for distribution and utilization of products is developed and implemented nationally.

Involvement of clinicians, hemophilia organizations, and regulatory authorities in the tender process brings an appropriate range of expertise together. The collective wisdom of the constituents will usually lead to better award criteria; better analysis of the various safety, efficacy, and supply considerations; and better decision making than that which would normally be made by individuals, clinicians, hospitals, or health insurance companies operating on their own.

The process can lead to an improved assessment of the products, based on collection of comparative data and meetings with the pharmaceutical companies over the defined time period allocated for the tender process. The process does not rely on marketing or advertising materials for the various products, or on meetings with companies. The individual views of the experts on the **tender commission**, when taken together utilizing a clear and unambiguous set of selection criteria, will usually lead to a better, more rigorous, and more representative decision.

National tenders can lead to an increased use of factor replacement therapy, up to the point where treatment is optimized. For example, in Ireland, where the current tender system was established in 2002, FVIII usage increased from 3.7 to 8.2 **international units (IU)** per capita between 2002 and 2014 despite an economic downturn from 2008 to 2012. In Brazil, FVIII usage has increased from 1.0 to 3.3 IU per capita between 2004 and 2014. It is highly unlikely that these very significant increases would have occurred without a national tender system as patients would have had to rely on the provision of treatment and tendering by individual hospitals or health board areas. These increases occurred independently of the general economic development in the country. In the last 10 years, the Brazilian economy has grown significantly, and in the last five years the Irish economy and health budget have contracted. The major reasons for the increased per capita factor usage were movement to more optimized treatment protocols driven by the presence on the tender commission of key clinicians who understand hemophilia, as well as more competitive prices for the products driven by a competitive tender process.

A national tender system allows for prediction of national demand and use, and allows planning for a national budget for the provision of factor replacement therapy. A national budget brings clarity to the total cost of factor concentrates and prevents individual hospitals from subjecting people with hemophilia to a lower standard of care than available elsewhere in a country in an effort to restrict their own hospital expenditure.

The involvement of clinicians and national hemophilia patient organizations in the process can lead to a more cost effective process. The EHC survey of tender and procurement systems for factor concentrates demonstrated a clear link between clinician and patient organization involvement and the achievement of lower prices.

A variation in the amount to be supplied can be built into the contract so that it allows for contingency planning in case the actual requirement is more or less than that planned for.

Saskatchewan Bleeding Disorders Program



Factor VIII and IX: CBS tender results. What is a national tender system? Continued part 3



In the event of a product shortage, having a contract to purchase significant quantities of factor concentrates from specified companies may be an advantage towards ensuring supply of product. The existence of a national database and stock monitoring and distribution system can also help minimize the impact of a shortage.

National tenders can increase the range and choice of products available to clinicians and patients in a particular country. In developing and emerging countries where hospital, social security systems, or insurance providers purchase relatively small quantities of factor concentrate, it has often been noted that very few companies register their products and compete for the market. This is partially due to the fact that the amounts being purchased are not deemed significant by the companies. If these disparate purchases are combined into a national tender (or even into a multinational tender such as those in Central America or the Gulf States), then the quantity purchased increases significantly and it becomes more attractive for companies to register their products in those countries and submit bids for the tender.

Disadvantages of a national tender system

There are a few potential disadvantages with national tenders for the purchase of factor concentrates:

A national tender might limit the availability of different products. However, the tender can specify that more than one factor concentrate will be chosen, thereby giving some availability and access to different products.

National tenders have the potential to limit clinical freedom. However, clinicians are not generally restricted to using only the products purchased through the national tender. In Canada, any factor concentrate that is licensed by Health Canada can be prescribed by a clinician, and indeed 5-10% of the factor concentrates used are not necessarily provided through the national tender. Restrictions to clinical freedom can also be avoided if the leading clinicians with expertise on these products are directly involved in the selection process.

A company that is unsuccessful in bidding for a tender may decide not to continue operating in a particular country and may not bid for future tenders, thereby decreasing the future availability and choice of products. This situation is more likely to occur where the volume of product being purchased or the financial value of the tender is low.

If a national tender results in lower total cost of factor concentrates for a country on repeated occasions, the health authorities may recalibrate their fiscal expectations of the cost of hemophilia care and may always expect a downward trend in cost. This has the potential to limit access to new and possibly more expensive generations of products. Lower costs may also result in reduced funding being available from pharmaceutical companies for the additional supports required by hemophilia treatment centers (HTCs) and patient organizations.

The standard tender model may be more difficult to apply if the country is assessing prolonged half-life recombinant factor concentrates or if they are comparing prolonged to normal half-life recombinant factor concentrates. This requires some new potential approaches and this is dealt with in a later section of the *"Guide to National Tenders for the Purchase of Clotting Factor Concentrates."*

Saskatchewan Bleeding Disorders Program



Factor VIII and IX: CBS tender results. What is a national tender system? Continued part 4



These potential disadvantages are largely theoretical and rather minor, and as the following discussion demonstrates, any downside they present can usually be improved.

Canada has two tenders for the purchase of factor concentrates, one for the province of Québec and one for the other nine provinces and three territories. In 2015 it was estimated that Canada purchases annually approximately 200 million IUs of recombinant FVIII, 48 million IUs of recombinant FIX, and 55 million IUs of plasma derived FVIII-VWF.

The national tender process specifically for Canada (except Québec)

In the nine provinces and three territories, the tender is held under the sponsorships of a Selection Advisory Committee appointed by the Canadian Blood Services (CBS) Board of Directors. In order to be eligible for the tender, the product must be licensed by Health Canada. Demand is estimated based on historical trends. The FVIII contracts have historically been for five to seven year periods.

The contract holder is Canadian Blood Services. It issues the request for proposals (RFP), manages the information, communicates with bidders, and seeks supplementary information when required. The Selection Advisory Committee advises the contract holder, who ultimately makes the tender decision. The committee considers criteria including safety, efficacy, range of products, consumer and physician preference, mix of products, value added in research and development, fiscal health and reliability of the potential supplier, and price. Initial bids are received in writing. This is followed by meetings with the tenderers, usually on several occasions. Additional information may be sought in writing by Canadian Blood Services between meetings. Score sheets are used for each product and, where possible, at least two suppliers are chosen for major products.

Interestingly, licensed products that are not chosen for the tender can still be prescribed by physicians as long as the company registers the product in Canada. The tender tends to provide 95% of the national FVIII concentrate requirement, the additional 5% comprises products that are licensed by Health Canada but not purchased under the tender process.

For more detailed information on the national tender process you can go the World Federation of Hemophilia website at <http://www.wfh.org/>. Look under the resources tab and select find a resource. You will find the PDF version of “*Guide to National Tenders for the Purchase of Clotting Factor Concentrates*”, 2nd edition.

Nancy Hodgson, RN BSN, Clinical Nurse Coordinator
Saskatchewan Bleeding Disorders Program

Hemophilia Saskatchewan “Physical Activity” Bursary Program

The Physical Activity Bursary program is available through Hemophilia Saskatchewan. It is a great program which helps financially assist members of Hemophilia Saskatchewan to stay active in recreational or sporting activities. It is available to children 18 years and younger, but also, youth and adults who are members of Hemophilia Saskatchewan.

This chapter funded program promotes a healthy lifestyle through safe physical activities. It gives you the opportunity to discuss your sports or recreational activity involvement with the Physiotherapist, therefore addressing any questions or concerns you may have in regards to preparation for each type of physical activity. I look forward to assisting anyone interested in applying for this beneficial program.

Give me a call, JoAnn Nilson, Physical Therapist, SBDP, 306-655-6628



Reminders to Those with a Bleeding Disorder Who Will be Undergoing Surgical or Dental Procedures

Our goal is to always provide our clients with a safe and effective plan of care while also keeping your optimal health and recovery in mind. In order to prevent bleeding complications, we ask that you remind your physician or dentist of your bleeding disorder on each visit. Take ownership and be proud to share with healthcare professionals what you know about your condition! Become familiar with your bleeding disorder and know the name of products you need to prevent a bleeding episode. Show your physician and/or dentist your Factor First / Treat First card on a pre-op visit/assessment. Ensure these professionals are aware to call us directly with any questions that arise.

Always ensure that you let the Saskatchewan Bleeding Disorder Team know well in advance of the procedure: **We need at least 2 weeks' notice of a date booked for surgical or dental procedures.** A phone call discussion with the nurse coordinator ahead of time can provide you with clarity on details for your surgery and hospital stay.

Any clients on home infusion should not have to bring in their product from home if their product is administered in hospital. Preparing yourself and family should be all that is expected of you.

The Nurse Coordinator will:

- Ensure coagulation product orders are prepared and reviewed with the Hematologist familiar with you.
- Process the orders by mail/fax once the nurse educator and staff nurses have been educated on how to mix and administer the product.
- Alert the transfusion lab staff to arrange for appropriate coagulation product to be ordered in from CBS (Canadian Blood Services), and be available.
- Alert the coagulation lab staff of lab work details to ensure they have adequate staff to process the factor level results requested, and report these to the Hematologist/nurse coordinator.
- Provide ongoing support to ward staff unfamiliar with factor concentrates and/or specific lab work requests.
- Ensure clarification prior to your discharge on the number of follow-up doses of factor to be given at home and/or a local hospital setting. (Also determine who will be administering these doses).

Any questions or concerns that arise please don't hesitate to call the nurse coordinators at (306) 381 - 4185.

We will be happy to assist!

Submitted by: Nancy Hodgson
Clinical Nurse Coordinator
Saskatchewan Bleeding Disorders Program

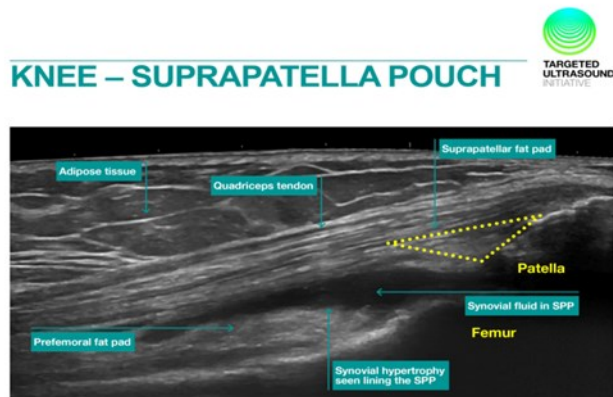


Point of care ultrasound could be a part of your next clinic visit!!

Saskatchewan Bleeding Disorders Program has purchased an ultrasound machine which will be used for point of care to help assist to answer the clinical questions: Is it a joint bleed? Or is there a synovitis? JoAnn Nilson, PT, received training in point of care ultrasound in Hemophilia joint assessment from Mohawk College in Hamilton, Ontario, Dec. 14-15, 2015. We have acquired the machine for our program in June 2016.

This will not be a diagnostic exam but to enhance the ability to identify if a joint is bleeding or if there is a synovitis present. Benefits for the use of point of care Ultrasound in Hemophilia care:

- Fast, effective, safe and readily available
- Real-time, dynamic, comparative study that can confirm or clarify (Querol & Rodriguez-Merchan, Haemophilia (2012), 18,e226.)
- Improve adherence to treatment for children and adolescent (Milan et al. Haemophilia (2014) 20 (suppl 3)66.)
- Assist in decreasing the confusion between hemarthrosis pain and arthritic pain (Aznar et al. Haemophilia (2015),21,e150.)



Ultrasound technique for knee and the picture you may see

You could experience the use of this technique as an adjunct to your physiotherapy assessment at your next clinic. Don't hesitate to ask about it.

This is how it looks and it is portable so will be used at Regina and PA clinics



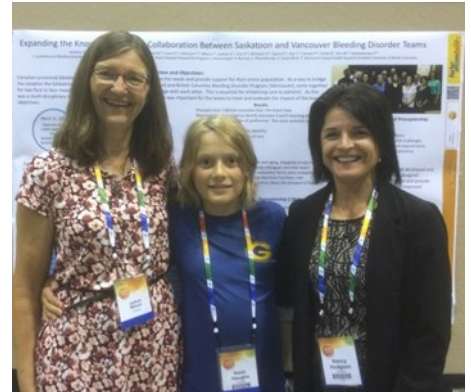
Submitted by JoAnn Nilson 306-655-6628

World Federation of Hemophilia Congress, Orlando Florida, July 24-28, 2016

Dr. Card, Nancy and JoAnn had the opportunity to attend this congress. It was an exciting and informative time. We were also excited to meet up with the Bedard-Haughn family from Saskatchewan, Isaac, Angie and Dean.

Our SBDP program had a moderated poster which was presented by Nancy and JoAnn. It was called "Expanding the knowledge base: Collaboration between Saskatoon and Vancouver Bleeding disorder teams". *Come see the poster in our SBDP hallway!!*

JoAnn, Isaac and Nancy with poster



JoAnn's highlights: the use of point of care ultrasound to enhance physiotherapy assessment, updates on ankle management, patient partnerships (Vincent Dumez), empowerment through self-care (Patrick James Lynch: check him out on youtube). JoAnn also presented a poster on the outcome of the **HIRT?** (Hemophilia Injury Recognition Tool) an injury self-management app for young men with mild hemophilia.

Nancy was one of three other CANHC nurses that had the opportunity to be a part of the Bayer Ambassador Program. The main objective of this WFH Ambassador program is to provide the Canadian Hematology nurses with emergent scientific information that will ultimately assist us in making informed decisions towards improved patient care. One of the outcomes of being part of this program is that as a group we are working on a scientific summary presentation of sessions attended at the WFH that can be utilized in an education setting such as our next upcoming regional or national meetings.

Nancy's highlights: Clinical trial results on extended half-life factor products, use and results of new pro-longed half-life products, update on gene therapy, new era for hemophilia focusing on personalized prophylaxis dosing, genomics of platelet disorders, excessive bleeding in women: spotlight on hemophilia carriers, and better screening tools for von Willebrand disease.

Bob Card's highlights included ongoing discussions regarding long acting factors and inhibitor risks of various products. Networking with colleagues (majority of Clinics represented by at least one of their Directors). Informative sessions included spotlight on carriers and bleeding (Michelle Sholzberg, chaired by Pam Wilton) and session on rare blood disorders from patient perspectives (most notable platelet function disorder and factor ten deficiency). All presentations available on line, by the way.



Our cultural night took us to the Epcot Center, we did meet a few Disney characters, experienced some international culture and viewed a fabulous fireworks display!!

The next WFH Congress will be in Glasgow – May 20-24, 2018. Weather should be better than Orlando in July!

Don't hesitate to ask us about it.

Photo: JoAnn, Goofy and Nancy



Photo: Dr Card

Submitted by Dr. Card, Nancy and JoAnn

Family perspective:

For us (Isaac, Angie, and Dean), Orlando 2016 was our first WFH Congress – it was a great experience, one we would recommend for anyone in our bleeding disorders family. As Isaac said after the first day, “it really makes [you] feel like [you’re] part of a bigger community”. Each evening, as we relaxed in our air-conditioned hotel room (Orlando in July is HOT), we talked about what we learned that day. Ultimately, there were three big take-aways for us:



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Gratitude for the level of care we have here in Canada and at this point in history. At congress, you see individuals from all over the world who are still suffering from debilitating joint issues and hear heartbreaking stories of loss and pain, many of which could be prevented if everyone had the same kind of access to medication, information, and care that we receive. It is quite different to read in Hemophilia Today about the global hemophilia community and the goal of “treatment for all” versus hearing the stories first hand.

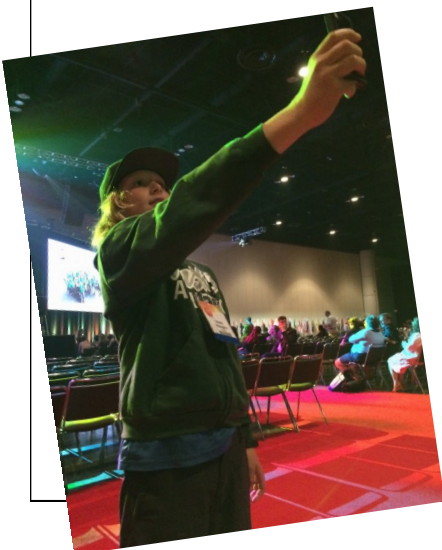
Knowledge of the ongoing efforts worldwide, both to provide innovative treatments (including those that are accessible for all) and to continue to strive towards improved products (extended half-life factor) and potentially a cure (including great strides being made with gene therapy). Isaac

particularly enjoyed the musculoskeletal sessions, which he sat in on with JoAnn. This included a whole session on the ankle – his most problematic joint – and a talk on the use of ultrasound in understanding and evaluating joint bleeds. Like JoAnn, we all enjoyed Patrick James Lynch’s talk and are looking forward to checking out more of his Believe Limited videos on YouTube. We were also encouraged by the many youth leadership opportunities available for the 18+ crowd – Isaac kept asking, “How old do I have to be to do that?” Hopefully there will be more programs developed for our younger teens soon, to help bridge that gap between local programs for kids and international programs for 18+.

Pride, as in proud of our SBDP team. One of the recurring themes at congress was personalization of care, including tailoring prophylaxis for an individual’s trough

level and activity level. This was mentioned as the next big thing coming down the line in international care – and our team is already doing it, right there at the leading edge! Likewise, with using ultrasound in physical assessment, JoAnn’s HIRT app, and collaboration between bleeding disorder teams to enhance the knowledge base. We always thought our SBDP team was pretty amazing, but now we know that’s true not just locally and nationally, but internationally as well!

On top of all of this, there was plenty of just plain fun: the opening ceremony had a live band and lots of delicious food, several exhibitors had fun games (and great coffee), and the fireworks at Epcot were a definite highlight. Isaac is already petitioning to attend the next WFH Congress in Glasgow in 2018!



Photos: Isaac, Dean and Ange

Submitted by Angie Bedard-Haughn

HEMOPHILIA SASKATCHEWAN

2016 Grey Cup Pool



Tickets are now available for purchase. If you are interested in buying or selling tickets please contact us at hemosask@hemophilia.ca

	Correct Score	Reverse Score
End of 1st Quarter	\$200.00	\$100.00
End of 2nd Quarter	\$200.00	\$100.00
End of 3rd Quarter	\$200.00	\$100.00
Final Score	\$1000.00	\$100.00

\$25 will be paid for the correct score every score change

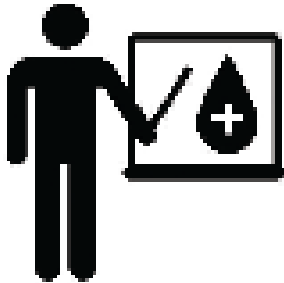
For Just \$5.00/ticket... You could be a Winner too!!!

25% Of All Proceeds Will Go Towards Research
Serving The Bleeding Disorders Community

A Guys' Day

2016 September 10th, 2016 Saskatoon, SK

If you have hemophilia and you are between the ages 6-18 then join us for:



Hemophilia
educational
sessions!



Fun
activities!



Great
friendships!

*There is
nothing
stronger than
the heart of a
volunteer.
With it
beats the
spirit of
generosity,
service and
compassion.*

**“Hemophilia
Saskatchewan thanks
all our volunteers for
their ongoing support”**

RSVP to justinjaewonhur@gmail.com by September 1st

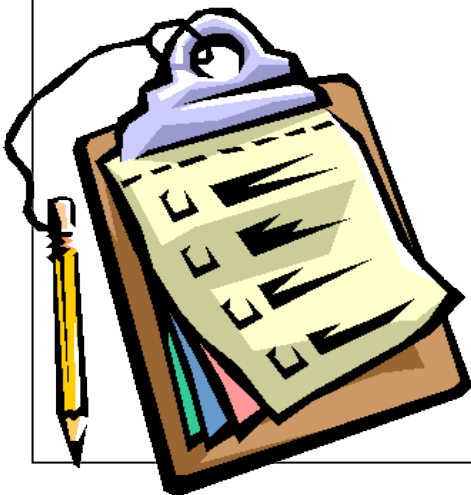
CLIENT SERVICES

Did you know Client Services are available to registered members of Hemophilia Saskatchewan (HSK) who are cared for by the Saskatchewan Bleeding Disorders Program (SBDP).

Client Services and Additional Programs are intended to help our members to defray expenses related to living with bleeding disorders.

Services associated with medical treatment (outpatient or inpatient) must be directly related to treatment of bleeding disorders: either the treatment of a bleeding episode or a surgical procedure that requires extended care due to a bleeding disorder.

To be eligible for reimbursement email hemosask@hemophilia.ca or go online to www.hemophiliask.ca for details. Forms can also be accessed at your next SBDP clinic visit.



Louise Paisley Memorial Bursary Application

\$500.00 to be awarded to student with a bleeding disorder or family of a person with bleeding disorder enrolled in a post secondary education program.

Eligibility Criteria

Student enrolled in a post secondary education program

Student could be:

Diagnosed with a bleeding disorder

Family of a person diagnosed with a bleeding disorder

Family is defined as siblings, children, parents or grandparents of a person diagnosed with a bleeding disorder

Student must be a member of Hemophilia Saskatchewan

Bursary Application must include:

Current resume

Transcript of high school marks if applicable

Acceptance letter to post secondary institute

2 letters of reference

Personal Information:

Surname: _____ First Name: _____

Permanent Address: _____

Email: _____ Telephone: _____ Cell: _____

Bleeding disorder diagnosed: _____

Name of Family Member with diagnosed bleeding disorder: _____

Check one: _____ Sibling _____ Parent _____ Grandparent

Bleeding disorder diagnosed: _____

Education Information:

Name of Program: _____

Length of Program: _____

Year of Study: _____ Date Program Complete: _____

Bursary will be reviewed annually, this year the **application deadline is November 30, 2016**. Successful applicants will be notified within 4 weeks of review.

Declaration:

I certify that all the above statements made by me are true. If it is found that I have given false information in this application, such falsification will constitute full and sufficient grounds for rejection of this application.

Student's Signature: _____ Date: _____

Please submit application and supportive documentation to:
Hemophilia Saskatchewan
2366 Ave. C North
Saskatoon, Saskatchewan
S7L 5X5

Hemophilia Saskatchewan "200 Club"

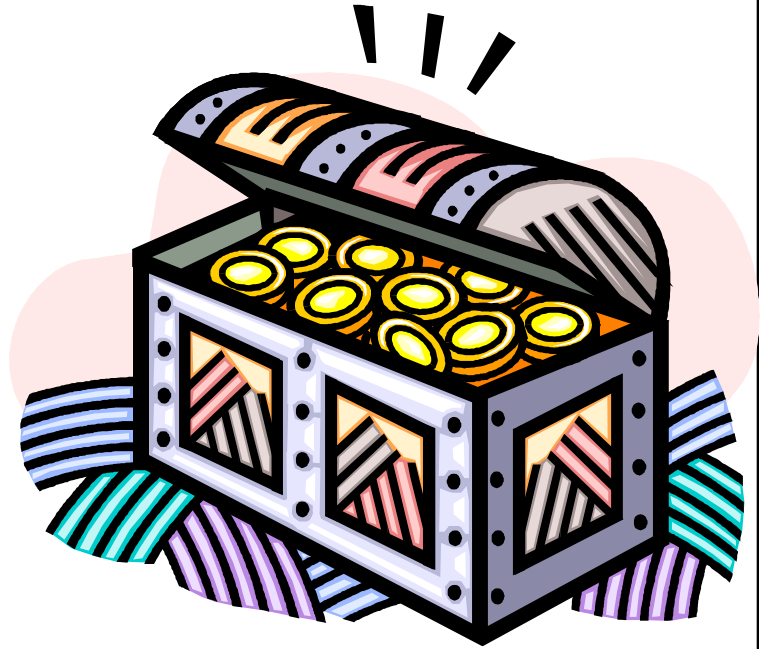
Purpose: To provide a stable, reliable, predictable, ongoing and adequate source for funding. If we can find at least 100 families, groups or individuals who will pledge a minimum of \$200 per year on an ongoing basis for the foreseeable future, Hemophilia Saskatchewan would be assured of a minimum income of \$20,000 per year.

The 200 Club is different from a one-time financial campaign, because it is ongoing, every year for the foreseeable future.

The fund would be administered by the treasurer, who would issue receipts for income at year end. Note that the government allows a 43% tax credit for donations over \$200.

A commitment to the 200 Club is made on the understanding that if the contributors' financial situation changes, the yearly commitment could be discontinued at any time.

The 200 Club is not meant to be an elite, exclusive club. It is a group of concerned committed people who want to see Hemophilia Saskatchewan become self-sufficient, not depending on any help from CHS.



Tavis Duncan Foundation

Through the Tavis Duncan Foundation, Hemophilia Saskatchewan is able to offer help for parents seeking to defray a percentage of the costs associated with the maintenance and treatment of children with hemophilia. Application for coverage is to be made in advance, if possible. Applicants must be registered members of Hemophilia Saskatchewan.

The Foundation will reimburse for items and/or expenses such as:

- * the purchase of safety apparel (ie. head gear, elbow pads)
- * \$50.00 per year per affected child, under the age of 18 years, towards the purchase of adequate footwear
- * assistance with in-hospital costs during an extended visit
- * assistance with out of province medical costs
- * summer camps
- * an educational opportunity for a family member to increase their knowledge of hemophilia

For application forms, please contact the Hemophilia Saskatchewan office by mail, phone or email.

Hemophilia Saskatchewan
2366 Avenue C North,
Saskatoon, SK S7L 5X5 Phone: 1-866-953-4366 or 653-4366
Email: The Duncans at sldaizy@yahoo.com or hemosask@hemophilia.ca



Did you know that Children's Wish Foundation has granted over 20, 000 wishes in the last 30 years? And they do it because wishes make a difference.

"Joy is a wonder drug"

"Wishes work wonders"

(Children's Wish Foundation Website)

Children with moderate and severe hemophilia and other severe bleeding disorders between the ages of 3-17 can qualify for a wish. Wishes are to be special and meaningful to the child and the possibilities seem endless (take a look at the Children's Wish webpage and read all the stories). Typically the wishes fall into one of three categories: travel, item or celebrity contact (often involves travel). One wish is granted in a child's lifetime although a child can reapply if there are any subsequent, new, high risk life threatening diagnosis.

Anyone can make a referral but the parents or guardians must also express interest to the Foundation. Our contact in Saskatoon is:

Kristen Allen

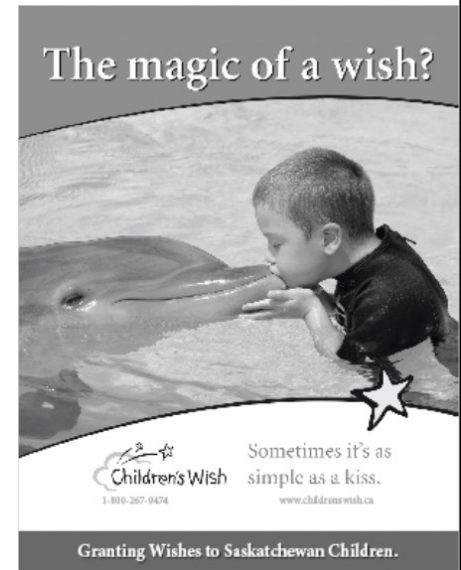
kristen.allen@childrenswish.ca

Phone: 306-955-0511

They do require a doctor to confirm the medical condition which will require the parent/legal guardian to sign a consent form for the health region to provide that information. We can help complete this and assist with any forms in order to start the wish granting process.

Jennifer King RSW

SBDP - Social Work



Insurance and Medical Conditions—

Considering Insurance? There can be a lot of information and a lot to consider when looking at medical insurance for you or your family. The Canadian Hemophilia Society has provided a breakdown of what you should consider when looking at insurance.

Start at the CHS website <http://www.hemophilia.ca/en/>. On the left menu bar click on Support and Education. From the new menu pick Insurance Coverage.

Here you will find three categories:

Individual Insurance Coverage – Working with a licensed insurance broker, anticipating needs, knowing your policy, disclosing your health status guaranteed insurability policies, and much more.

Travel Insurance Coverage – Examples of travel insurance and issuers, travel outside your province, studying abroad and away from your province, visitors and new arrivals to Canada and other helpful tips.

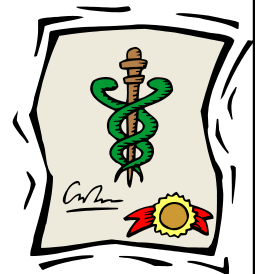
Provincial Drug Insurance – Provincial coverage, coverage levels for prescriptions drugs frequently used, anti-retroviral drug plans and provincial drug coverage and chronic Hepatitis C medication.

You can also find information on the OmbudServices for Life and Health Insurance (www.olhi.ca).

I carry copies of this information to all clinics so please ask if you want to review with me.

Jennifer King RSW

SBDP – Social Work



Hemophilia Saskatchewan Donation Form

2366 Avenue C North, Saskatoon, SK S7L 5X5

Tel: 1-866-953-4366 or 653-4366

Email: hemosask@hemophilia.ca

\$200 Club

The objective is to provide HSK with stable, reliable, and ongoing funding that would help us to plan our activities and reduce reliance on outside sources of funds.

Our goal is to find 100 families, groups or individuals who will pledge a minimum of \$200 per year on an ongoing basis.

A commitment to the \$200 Club is made on the understanding that if the contributor's financial situation changes, the yearly commitment could be discontinued at anytime.

Please note, this donation can be paid in installments through monthly giving.

_____ *Yes! I would like to join Hemophilia Saskatchewan's \$200 Club*

_____ I prefer to make a one time donation of \$200

_____ I prefer to make a monthly donation in the amount of \$_____ and authorize Hemophilia Saskatchewan to charge the indicated amount on my credit card

Monthly Giving Program

Your monthly gift helps Hemophilia Saskatchewan meet its commitments to people affected by bleeding disorders by providing a steady stream of income.

_____ I want to make a monthly donation of \$_____

_____ I have enclosed 12 post dated cheques for the amount indicated

_____ I prefer to make my monthly donation by credit card and I authorize Hemophilia Saskatchewan to charge the indicated amount on my credit card

Please Note: You may cancel or change your monthly donation at any time by notifying us.

One Time Donation

_____ *Yes! I would like to support Hemophilia Saskatchewan with a donation in the amount of:*

_____ \$250 _____ \$100 _____ \$50 _____ \$25 Other\$ _____

Please charge my: _____ Visa _____ MasterCard

Card #: _____ Exp. Date: _____

Name on Card: _____ Signature: _____

Address: _____

Telephone: _____ E-mail: _____

Thank you for your generosity. Charitable Reg.# 119139954RR0001



HEMOPHILIA SASKATCHEWAN

Canadian Hemophilia Society

Help Stop the Bleeding

Membership Form

Benefits of membership in Hemophilia Saskatchewan include:

- Opportunity to learn more about bleeding disorders;
- Networking by meeting others facing the challenges you face;
- Opportunity for children and youth, with bleeding disorders, to meet others with the same challenges they have;
- Notification and right to attend all chapter meetings of members;
- Entitlement to vote on any matter voted on by members;
- A free subscription to the *Hemophilia Saskatchewan's Newsletter*;
- Notification of and opportunity to attend HSK events;

Benefits of membership in the Canadian Hemophilia Society include:

- Notification and right to attend all national meetings of members;
- Entitlement to vote on any vote taken of members;
- A free subscription to *Hemophilia Today*, the CHS national newsmagazine serving the bleeding disorders community.

Name: _____

Address: _____

Town/City: _____ Province: _____ Postal code: _____

Telephone number: _____ E-mail: _____

Signature: _____

Family Members (*please list immediate family members including yourself*)

Name	Spouse/ partner/or child	DOB dd/mm/yy	M/F	Type of Bleeding Disorder



HEMOPHILIA SASKATCHEWAN

Canadian Hemophilia Society

Help Stop the Bleeding

Membership Form

- _____ Please check here if you would prefer to receive an electronic copy of our newsletter.
- _____ Please check here if you do not want HSK to send you its chapter newsletter.
- _____ Please check here if we can contact you regarding volunteer opportunities with our chapter.

Hemophilia Saskatchewan (HSK) works closely with the national organization, Canadian Hemophilia Society (CHS). Members of HSK are members of CHS.

Canadian Hemophilia Society will use the information above to:

- build a membership list, as required by the Canada Corporations Act
- send you *Hemophilia Today*

With the exception of CHS, HSK does not sell or give our membership list to others.

2366 Avenue C North, Saskatoon, SK S7L 5X5

Tel: 1-866-953-HEMO (4366) or 306-653-4366

Email: hemosask@hemophilia.ca

improving the quality of life for all people in Saskatchewan living with inherited bleeding disorders Charitable

Reg. # 119139954 RR0001

The next newsletter deadline is October 15, 2016. Your contributions are always welcome.

Email:
hemosask@hemophilia.ca.

Or send to the office,
2366 Avenue C
North, Saskatoon,
SK S7L 5X5.

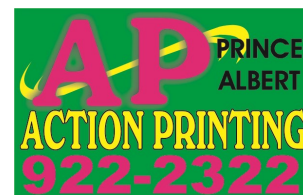
Hemophilia Saskatchewan acknowledges Action Printing, Baxalta, Bayer, Biogen, Pfizer, SaskTel Telcare, and SaskTel, for the support given to our programs and printing of the newsletter. Thanks to Bayer Inc. for the generous grant supporting this newsletter.



Biogen Baxalta



SaskTel



Please Note: Opinions expressed herein are those of the authors, and do not necessarily represent the views of Hemophilia Saskatchewan. We do not guarantee the accuracy of information contained herein, and accept no legal responsibility for information quoted from other sources.

Upcoming Events for 2016

A Guy's Day

September 10

Deadline for November HSK Newsletter

Oct 15

Deadline for Louise Paisley Memorial Bursary

November 30

Family Christmas Party

December



Just a friendly reminder to contact the Saskatchewan Bleeding Disorders Program (SBDP) at least 2- 4 weeks PRIOR to any scheduled surgeries, medical or dental procedures that may cause bleeding.

This would ensure we had adequate time to make the required arrangements to control possible bleeding that may occur, as well as to educate the health care personnel that may be involved with your care/treatment.

If enough notice isn't received your scheduled surgery, medical or dental procedure could be postponed or even canceled.

The Nurse Coordinators with the Saskatchewan Bleeding Disorders Program (SBDP) at 306-381-4185.

Saskatchewan's Help Lines

For bleeding problems we all know we can contact the **Saskatchewan Bleeding Disorders Program** by phoning our nurse coordinators at (306) 381-4185.

The **Saskatchewan Health Line**, 811, gives you access to a nurse to help you decide, based on your symptoms, if there is a need to see your doctor or if a visit to the Emergency Room is warranted.

Saskatchewan Consumer Drug Information Service can give you advice on over the counter and prescription drugs as well as herbal remedies.

Phone 1-800-665-3784, or in Saskatoon 966-6378

Updated July 13, 2015

What's new?

If you would like to receive an electronic copy of our newsletter instead of a print copy please email hemosask@hemophilia.ca with your name and email information.