Hemophilia Saskatchewan

May 2016 Spring Newsletter

2366 Avenue C North, Saskatoon, SK S7L 5X5

Tel: 1-866-953-4366 or 653-4366 Email: hemosask@hemophilia.ca

How Did You Recognize World Hemophilia Day?

Jayden Lockhart from Humboldt, SK helped raise money and awareness for Hemophilia Saskatchewan on Monday, April 18th in support of World Hemophilia Day. Jayden helped his mother, Vanessa Lockhart, for over 2 1/2 hours handing out cupcakes, information, and taking donations! Submitted by Vanessa

President's Message

Hello All!

This winter has been kind but the thoughts of longer brighter days is the best, I am sure you all agree! Here is our Spring edition of the newsletter to kick it all off!! We brought in 2016 with a couple of events that really brought our membership together. Our annual AGM was a great meeting as it always is. There was opportunity to see what Hemophilia Saskatchewan has done over the past year and what plans we have in place. We sadly said farewell to 4 board members, and brought on 3 new members which is so exciting to us. Our second big event was the Women and Bleeding Disorder conference. We had a wonderful attendance with Manitoba and Alberta joining in. It was an opportunity to educate women on bleeding disorders, but also an important chance to get to know new people and feel like you are not alone in the bleeding disorder challenges.

Hemophilia Saskatchewan continues its important work. We were involved in National Hemophilia Day and set up awareness booths in select areas across the province on or around April 17, 2016. We are also acting in an advocacy role as we are aware that a second pediatric hematologist is needed to adequately provide service to the pediatric bleeding disorder community. The posting for a second pediatric hematologist did go up, but was taken down pending the election. This is not acceptable from our perspective. Patient advocacy groups have powerful ways of getting results if we speak unified and for an important reason. Nothing is more important than the care of our children. We will let you know the status of this situation as it presents.

Enjoy the beautiful inklings of warm days ahead as you read through the pages of our newsletter, and as always....keep in touch!!

Wendy Quinn

Board of Directors

President:	Wendy Quinn	**Director:**	Shawna McDougall
Vice President:	Celena Moody	**Director:**	Micaella Fiacco
Treasurer:	Angie Bedard-Haughn	**Director:**	Brittany Lee-Acton
		Director:	Jae Won Hur
Secretary:	Vanessa Lockhart	**Director:**	Open

Want to know more about Hemophilia Saskatchewan?

Check us out online at

www.hemophiliask.ca

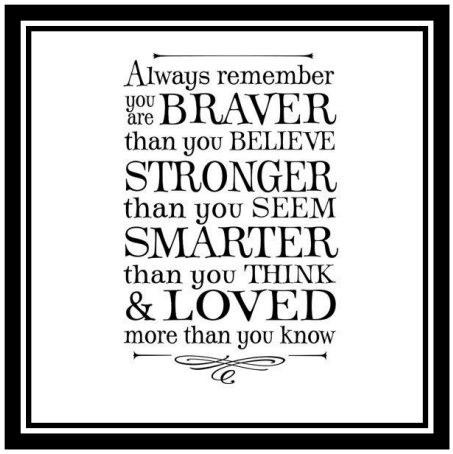
A special congratulations to Dr. Robert Card for his years of service to the bleeding disorders community and his leadership in our Saskatchewan Bleeding Disorders Program. Here he is pictured receiving the Lisle and Elaine Spence award from Tom Spence who was the first patient that he ever saw in clinic....Tom got to send him off with this award.

First and Last: Dr. Robert Card (left) and Tom Spence (Right)

Tom was Dr. Card's very first patient, here he is presenting the Lisle and Elaine Spence Award to Dr. Card on the actual last day of work at the SBDP.

Saskatchewan Bleeding Disorders Program

Reaching In… Reaching Out
Free Online Resource!



In chronic disease management there are many times life moves with only a slight and hardly noticeable disturbance. Then the tides change and waters rush in crashing at the rocks. While it seems unpredictable and out of control there are some key things that can help you and or your child to navigate the difficulty of having a chronic illness.

Reaching In...Reaching Out is a free online resource for people to learn about resilience and developing skills that help move us through the difficult times. The most effective ways to help build resiliency is to develop caring relationships, role model resilience to children, develop self-control and create new thinking skills that help solve problems that occur. A positive outlook and confidence also help to develop resilience.

Resilience is about navigating the serious challenges in our lives and coming through with the help of community and self-determination. You can find out more on the website— www.reachinginreaching out.com.

As always you can phone our office to find out more.

Jennifer King, Registered Social Worker
306-655-6503

A Reminder…

The CHS Scholarship Program deadline is April 30, 2016. For award categories, criteria and application go to: http://www.hemophilia.ca/en/support-and-education/scholarship-program/#c545

Please let us know as soon as possible if you need the Proof of Eligibility Form.

Jennifer King BSW, RSW
SBDP Social Work
306-655-6503

Saskatchewan Bleeding Disorders Program

HIRT? (Hemophilia Injury Recognition Tool)

Perceptions from young men with mild hemophilia on the use of the mobile app

Smart phone apps have the potential to more actively engage young individuals in self-directing their care. Smart phones provide an avenue to be easily accessible, contain specific information and provide connections to the health care provider. Young men with mild hemophilia exhibit characteristics such as infrequency of bleeds and limited ability to recognize an injury needing medical attention. There is potential that young men with mild hemophilia could be assisted with this type of technology.

HIRT? the mobile app was developed to assist in injury self-management for young men with mild hemophilia. The development team included clinicians, computer experts and the young men with mild hemophilia. The mobile app was released in December 2014, so has been in use for about 1 ½ years. There has been significant interest in ***HIRT?*** with 244 downloads in Canada and 700 throughout the world from December 2014 to September 2015. An evaluation was completed in 2015. This evaluation consisted of a mixed methods research approach which included both qualitative (telephone interviews) and quantitative (self -report questionnaires) to identify the perceived use of the mobile app for injury self-management from young men with mild hemophilia. 12 young men from ages 17-34 participated in the study from 6 different provinces. Five themes emerged from the interviews. The self-report surveys provided perceived injury self- management strategies and confidence levels. Statistical tests were used to determine the association between perceived self -management strategies and confidence levels with using the app and not using the app.

HIRT? the mobile app, has been perceived by young men with mild hemophilia in Canada to be accessible, credible and useful. The young men interviewed in this study unanimously agreed that the format of ***HIRT?*** was preferential to paper-based educational information on injury self-management. The emphasis of "*handy*" and "*at your fingertips*" was observed. The unique alarm system of the mobile app was generally supported by the respondents. With their bleeds being so infrequent they tended to forget they had mild hemophilia, "*because you can sometimes forget, any time you get complacent about it".* The alarms re-enforcing the rechecking of an injury was perceived by the young men participants as a great feature of the app.

This study supports that ***HIRT?*** shows promise among participants to positively influence perceived self -management skills particularly when they are younger and first diagnosed with this bleeding disorder. ***HIRT?*** can assist the young men by significantly increased perceived confidence to identify and manage bleeds. Therefore the mobile app could impact the number of unrecognized bleeds in this population.

This research study has also provided enhanced knowledge regarding mobile app technology for injury self-management, identified potential barriers and facilitators to the use of ***HIRT?*** and provided considerations for future app development.

This research project was led by JoAnn Nilson. The research team included Kathy Mulder, Kristy Wittmeier, Candice Schachter, Richard Lomotey, Cathy Arnold and Sarah Oosman. Funding from CHS-Baxalta fellowship fund and the BHAP Caregiver's Awards program assisted in completing this project.

Submitted by JoAnn Nilson, Physical Therapist

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!

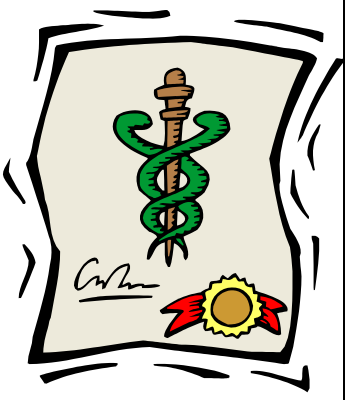
Submitted by: Nancy Hodgson
Clinical Nurse Coordinator
Saskatchewan Bleeding Disorders Program

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 "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

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"

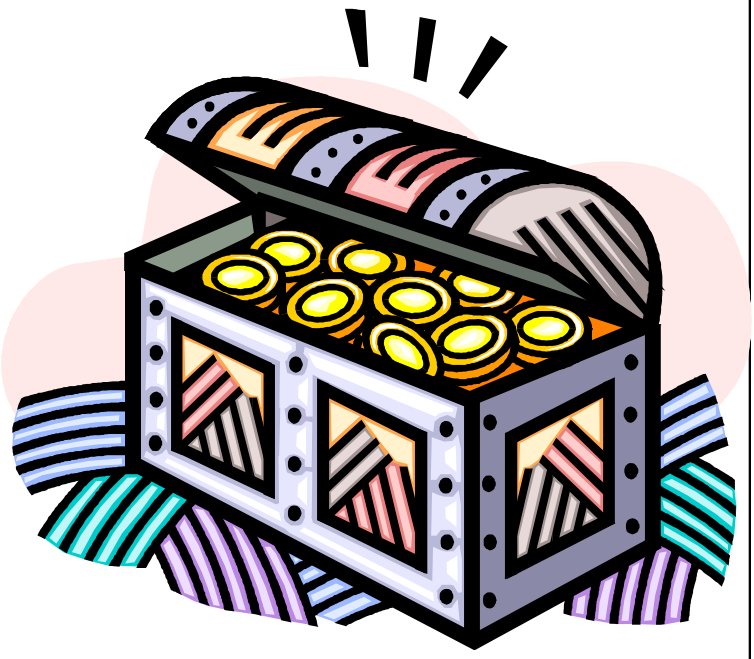
Purpose: To provide a stable, reliable, predictable, ongoing and adequate source for funding. If we can find at least l00 families, groups or individuals who will pledge a minimum of $200 per year on an ongoing basis for the foreseeable future, Hemophilia Saskatchewan would be assured of a minimum income 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.



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.

AGM and Linger Longer Day

Our AGM was held on March 19, 2016. We like to thank all those that attended. We had a significant change to our board which saw the departure of four of our members - Anne Lukian, Sandra Dionne, Lorrie Kaglea, and Derek Bissonnette. We are sad to see them go, but they assured us that they are willing to stay involved in various capacities.

We also want to welcome our new board members : Shawna McDougall (Regina area), Micaella Fiacco (Regina Area), and Brittany Lee-Acton (Saskatoon area). We are grateful that these enthusiastic ladies have stepped forward.

Photos provided from the AGM and Women's Conference are courtesy of Vanessa Lockhart.

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

Women and Bleeding Disorders...Those Who Have, Those Who Carry, Those Who Care For

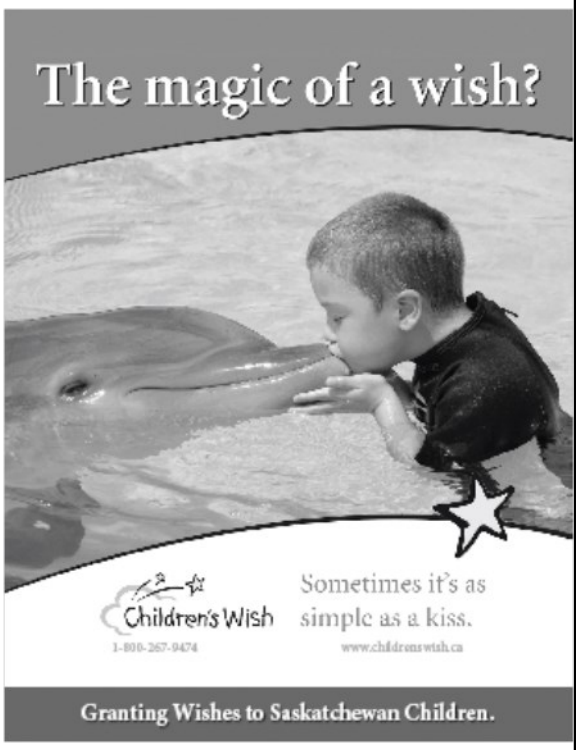
This is the second conference for women and bleeding disorders for Hemophilia Saskatchewan and what a grand success it was!! We had familiar faces and new ones too....each extremely special to us. We had guests from Manitoba, Alberta , BC and Quebec along with our SBDP staff and industry. The weekend was filled with education from our speakers, wonderful food and lodging at the Delta Bessborough Hotel, great activities such as a NIA session, and wonderful entertainment featuring Jeff Richards the Mentalist. The room was full, the discussions were rich and the knowledge we walked away with was abundant. We can't wait to do it again!!

Submitted by Wendy Quinn

...And we finally met Carrie LaVallie. The person who organizes the newsletter. Thanks Carrie.

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.



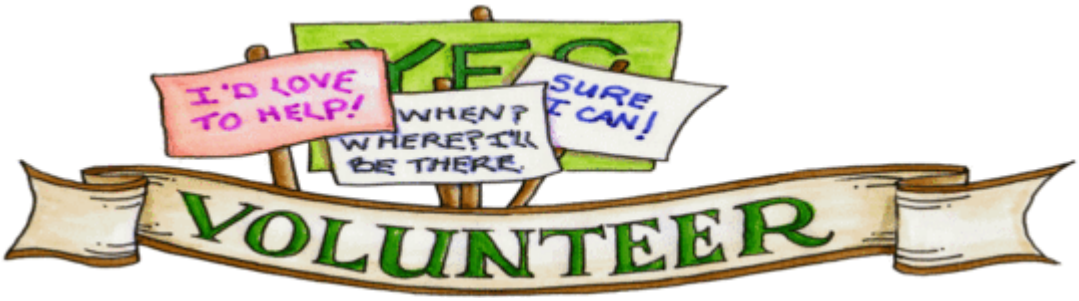
Anyone can make a referral but the parents or guardians must also express interest to the Foundation. Our contact in Saskatoon is:

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

We make a living by what we get, but we make a life by what we give.



"Hemophilia Saskatchewan thanks all our volunteers for their ongoing support"

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

The next newsletter deadline is August 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.

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

CHS Scholarship Program Deadline	April 30
Deadline for Summer HSK Newsletter	August 15
Queen City Marathon, Water Aid Station, Regina	Sept 11

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 a 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.

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

2366 Avenue C North, Saskatoon, SK S7L 5X5
Tel: 1-866-953-4366 or 653-4366 Email: hemosask@hemophilia.ca

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