



Hemophilia Saskatchewan

November 2016


Fall Newsletter



2366 Avenue C North, Saskatoon, SK S7L 5X5

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

Email: hemosask@hemophilia.ca



*Hemophilia Saskatchewan
Invites Our Membership to Attend:*

Annual Family Christmas Party
2016

When; November 26, 2016
Where: Radisson Hotel
Saskatoon, SK.

Time: 1:00 – 4:30 PM – Swimming
***6:00-10:00 PM – Christmas Banquet
and Celebration***

***Come join us for fun,
festivity and the chance to share the
warmth of the Season***

RSVP October 26, 2016
(See Reverse for Details)

President's Message

Our fall edition of the newsletter is here and it means that the warm weather is changing, but my favorite time of year is just around the corner. The fall brings that cool crisp sometimes unexpected early storms, and in Saskatchewan we have to be prepared for it all and we are subsequently resilient in whatever we face. This rings true for those of us who are challenged by or care for bleeding disorders. These disorders pose challenges that change lifestyles, but it isn't a life ending or disabling condition as it may have been in the past and that speaks loudly to the work that has been done in the last 25 years with emergence of safe prophylaxis. Now the trend is moving toward genetic therapy that may be available in 5 years, and may mean a single genetic intervention could be all that is needed to keep factor levels adequate. These aren't just dreams for a cure, this is reality.

While we wait for the next phase of treatment approaches, we are still involved with home infusion prophylactic program. Our boys participated in a Youth Activity day that focused on self infusion in September, the SBDP was actively involved. This is the type of activity that is the most meaningful to us. The boys gained knowledge and support from each other.

Ok all....how are you doing with MyCBDR? Please remember how important it is to log your product use, the Canadian Blood system supplies blood products for no charge to the consumer, it is our responsibility to ensure there is an account of it.

Please don't forget to log your product. Australia uses MyCBDR and they are challenging Canada to see who can get the most people actively using MyCBDR. Look for a contest in the future.

So I am going to say the word....CHRISTMAS...we would love to see you at our Christmas party this year, please see the details in this edition.

Happy Fall...All!!
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
Secretary:	Vanessa Lockhart	Director:	Jae Won Hur
		Director:	Angie Lucyshyn

**Want to know more about
Hemophilia Saskatchewan?
Check us out online at**

Internet: www.hemophiliask.ca

Twitter: [@HemophiliaSask](https://twitter.com/HemophiliaSask)

Facebook: [Hemophilia Saskatchewan](https://www.facebook.com/HemophiliaSaskatchewan)

Kids Day 2016

Youth around Saskatchewan gathered for the 2nd straight year in Saskatoon for a fun day full of education and social activities. During the morning, we were fortunate to receive great, group education sessions within realms of physiotherapy, social life, and self-infusion from the great staff at Saskatchewan Bleeding Disorders Program. After a pizza lunch, we took a party bus over to a glow bowling alley where we had a great time.

It is exciting to see a new generation of hemophiliacs forming a community within Saskatchewan. Through communal synergy, we can develop support networks and lifelong friendships. Hemophilia Saskatchewan is looking forward to continuing this sense of community through ventures like these and many more for years to come.

We would like to extend the most sincere gratitude to the Saskatchewan Bleeding Disorders staff. They are tremendous in going above and beyond their job descriptions for sustainable health within this province. Words cannot describe how fortunate we are to have such great professionals.

Looking forward to next year,

Jae Won Hur
Board of Director



Guys Day, September 10, 2016

This exciting event planned by Jae Hur in collaboration with the SBDP team was held at the Travel Lodge in Saskatoon. Seven guys and seven of the SBDP team attended.



Educational sessions were offered by:

The Nurses:
Nancy, Tara and
O'Lynda

The Physiotherapist: JoAnn





Social Worker: Jen and student,
David and Dr. R Sinha

Groups allowed
for interesting
discussion.



“Musical hoops” kept us all active!!

Pizza lunch was followed by a ride in a
limo to a fun afternoon of glow bowling.

If you missed this event, come join us
next year!!

Submitted by JoAnn and the whole
SBDP team.

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

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"

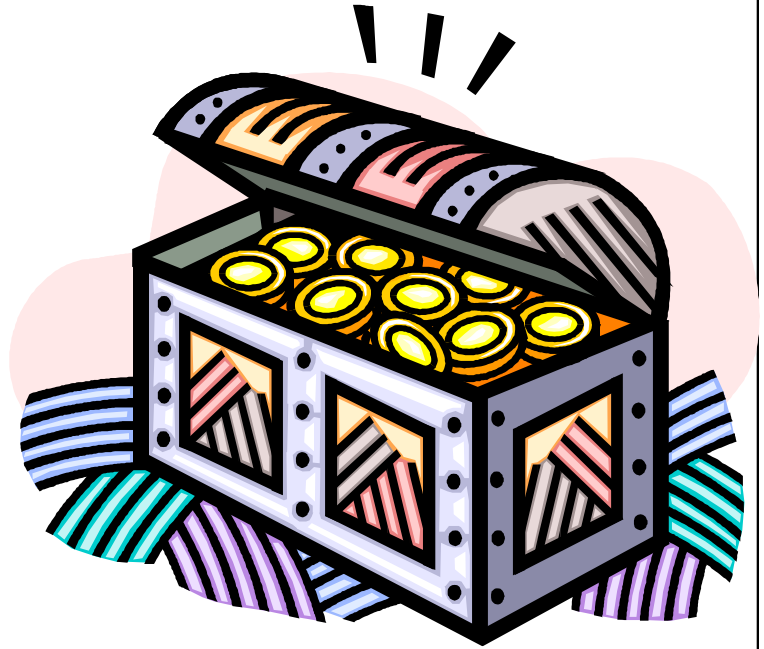
Purpose: To provide a stable, reliable, predictable, ongoing and adequate source for funding. If we can find at least 100 families, groups or individuals who will pledge a minimum of \$200 per year on an ongoing basis for the foreseeable future, Hemophilia Saskatchewan would be assured of a minimum income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



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.





HEMOPHILIA SASKATCHEWAN

Canadian Hemophilia Society
 213 - 2388 Avenue C North
 Saskatoon, Saskatchewan
 S7L 5X5
 Tel.: 308-853-4368
 Toll-free: 1-866-953-HEMO (4368)
 E-mail: hemosask@hemophilia.ca

For HEMOPHILIA SASK use only

Date: _____

Approved By: _____

Declined By: _____

Comments: _____

REQUEST FOR SERVICE FORM:

Date of Application: _____ Date Service Received: _____

Name: _____

Address: _____ Postal Code: _____

Phone Number(s): _____

BACKGROUND OF APPLICANT NEEDS, AND PURPOSE OF REQUEST: *(A brief letter may be attached to provide more details)*

REQUEST CHECKLIST:

Amount of funding requested: \$ _____ (Attach original receipts for reimbursement)

Have all other avenues been explored (private health insurance and/or employer benefits, such as Saskatchewan Blue Cross, etc.)? Yes No

If "YES", please provide details:

Are you a member of Hemophilia Saskatchewan* Yes No

*Applicant and/or family must be members of Hemophilia Saskatchewan to access services. If NO, fill out HSK membership form along with this application and submit both together.

Applicant (print): _____ Signature of Applicant _____

Authorized by (print)**: _____ Authorizing Signature _____

**Must be authorized by most responsible practitioner (i.e., attending physician/nurse or member of SBDP team). Signature confirms that treatment is directly related to bleeding disorder, or a surgical procedure that requires extended care due to the presence of a bleeding disorder.

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.

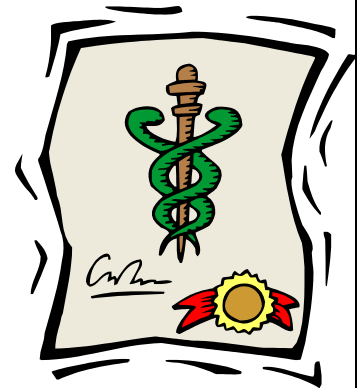
Start at the CHS website <http://www.hemophilia.ca/en/>. On the left menu bar click on Support and Education. From the new menu pick Insurance Coverage.

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

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



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



Physical Activity



Bursary Program

*Sponsored by
Hemophilia Saskatchewan
Canadian Hemophilia Society
213 - 2366 Avenue C North
Saskatoon, Saskatchewan
S7L 5X5
(306) 653-4366
1-866-953-HEMO (4366)*

Physical Activities can be chosen on an individual basis, there is Risk Levels and these must be discussed with the PT

Think Once: Excellent Activities to participate in
Swimming, Golfing, Tennis, Badminton, Bicycling, Tai Chi, & Yoga

Think Twice: Activities which require preparation and equipment
Volleyball, Basketball, Nordic Skiing, Running & Dance
Windsurfing, Squash/Racquetball, Baseball, Soccer, Ice Skating,
Rollerblading & Weight Lifting

Think Again: Activities with increased risk of injury
Karate/Judo, Waterskiing, Football (tackle), Rugby, Skateboarding, Ice
Hockey, Downhill Skiing, Road Hockey, Horseback Riding & Wrestling

What is the Physical Activity Bursary Program?

- A Chapter funded program to promote a healthy lifestyle for children, youth and adults with bleeding disorders through safe and beneficial physical activities.

Who Qualifies for the Program?

- Chapter members with a bleeding disorder. *(Some restrictions may apply.)*

Guidelines *(subject to revision)*

- Hemophilia Saskatchewan will fund one bursary (maximum of \$250), per person, per year.
- Funding may be used for registration fees and/or safety equipment required for the sport; however, the amount of bursary remains a maximum of \$250.
- Activity must include instruction from a qualified individual.
- Funding does not include club drop-in fees, or health club memberships, but if a specific program at one of these facilities meets an individual's physical activity goals then it may be permitted with physiotherapy approval.
- **ALL** activities require consultation and co-signature from a Care Team physiotherapist **PRIOR** to commencing program.
- Funding will be awarded after an application form is submitted to the Chapter together with original **receipt of cost** and **evidence of completion** of the activity. *(Must be submitted within six months of the end of the activity).*
- Activities in "high risk" category are excluded from the bursary program, unless a letter from the physical therapist approving the program is included.

A full listing of activities and risk categories can be found in the WFH publication "GO FOR IT" which can be obtained online at Hemophilia.org.



****Physical Activity BURSARIES ARE SUBJECT TO CHANGE AND AVAILABILITY OF FUNDS.****

Physical Activity Program Application

Please Print:

Applicant's/Parent's Name _____

Address _____

Phone Number _____

Child's name _____

Birth Date (for Child only) _____

Activity description _____

Start date _____

End date _____

I have consulted the physiotherapist regarding the activity that I / my child will be participating in.

Physiotherapist's Signature

Date

Parent's Signature

Date

Revised September 2003

Parents Release & Waiver

On behalf of myself, my child, or other persons for whom I am responsible, I hereby release and indemnify Hemophilia Saskatchewan and the Canadian Hemophilia Society and all of their members, directors, officers and employees, of and from all liability, suits, actions, claims, costs, expenses, demands and causes of action of whatever kind or nature without restriction in respect of, or in any way arising out of receipt of this bursary or participation in the activities contemplated by this application, howsoever caused, including without limitation, any injury to a person or damage to property that may have been caused, contributed to, or occasioned by the negligence of the above-noted organizations and people and any one or more of them. I understand that by providing information during the application process, and by providing this bursary, the above-noted organizations and people are not providing any opinion in relation to the safety of the contemplated activities and that the determination of the safety of such activities is solely my/our responsibility.

I have carefully read this Release and Waiver, I fully understand it, and I am freely and voluntarily executing it.

Applicant/ Parent's

Signature _____

Dated _____

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)

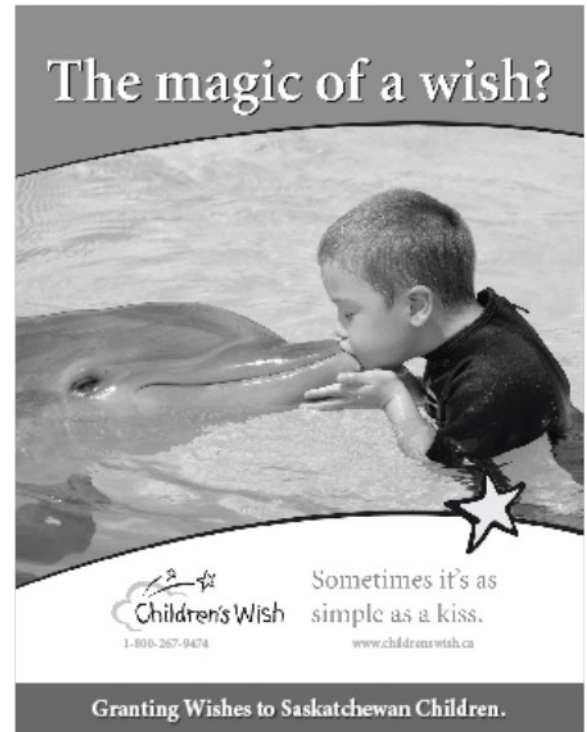
Children with moderate and severe hemophilia and other severe bleeding disorders between the ages of 3-17 can qualify for a wish. Wishes are to be special and meaningful to the child and the possibilities seem endless (take a look at the Children's Wish webpage and read all the stories). Typically the 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

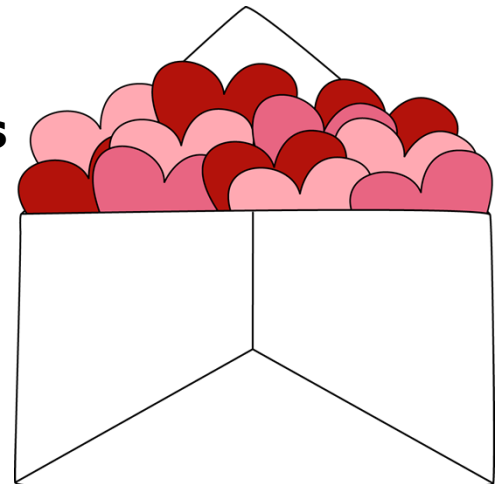
They do require a doctor to confirm the medical condition which will require the parent/legal guardian to sign a consent form for the health region to provide that information. We can help complete this and assist with any forms in order to start the wish granting process.

Jennifer King RSW
SBDP - Social Work



I Believe...
I believe in the power that
comes
from a world brought together as
one
I believe together we'll fly
I believe in the power of you
and I

“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



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 January 15, 2016. Your contributions are always welcome.

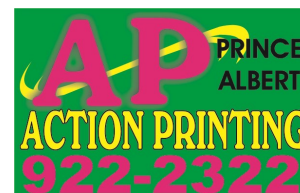
Email:
hemosask@hemophilia.ca.

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.



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 2016/2017

Family Christmas Party	November 26
Grey Cup Pool	November 27
Deadline for Louise Paisley Memorial Bursary	November 30
Deadline for Winter HSK Newsletter	Jan 15



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.