



# *Hemophilia Saskatchewan*

May 2015

Spring Newsletter



2366 Avenue C North, Saskatoon, SK S7L 5X5

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

Email: [hemosask@hemophilia.ca](mailto:hemosask@hemophilia.ca)

## Hemophilia Saskatchewan celebrates it's 50th anniversary this year!



## President's Message

I think this is my favourite newsletter to write for...saying good bye to the winter cold, and looking forward to warmth and exciting summer events. Without jumping ahead just yet though, I have to tell you about our AGM/Family Weekend this past March. It took place at the Elk Ridge Resort in Prince Albert National Park, and it was beautiful. In all honesty though, it wasn't the beauty of the resort that made this AGM/Family Weekend special, it was our families. We were thrilled by the attendance - we had a blend of our faithful regular folks, and we met new ones. Of our new people, there were many that wanted to contribute to HSK. That means so much to us.

As we go forward now, we just had our World Hemophilia Day (April 17) with activities planned throughout the province. Our next big event is our Guy's Getaway that would include all our guys with bleeding disorders and their guy family. Same venue as last year - Missinipe (outfitting camp), fun included!!!

A number of the board members will be taking part in the CHS National weekend conference in Halifax - *Rendezvous* May 28 - 31, 2015. This year Hemophilia Saskatchewan has been nominated for a chapter award.

We will let you know how we do!

Lastly...**WE ARE 50 YEARS OLD THIS YEAR!!** A milestone for HSK, look forward to a future celebration.

Enjoy all your warm days ahead, stay in touch.

Wendy Quinn  
HSK President



### Board of Directors

<b>President:</b>	Wendy Quinn	<b>Director:</b>	Vanessa Lockhart
<b>Vice President:</b>	Angie Bedard-Haughn	<b>Director:</b>	Sandra Dionne
		<b>Director:</b>	Ann Lukian
<b>Treasurer:</b>	Derek Bissonnette	<b>Director:</b>	Celena Moody
<b>Secretary:</b>	Lorrie Kagle	<b>Director:</b>	Jae Won Hur

### Thanks for the Help!

Thanks to Bayer Inc. for the grant supporting this newsletter.



Bayer HealthCare



# Calling All Guys!!!



To all "guys," once again it is time for the "Guys Get Away." This year's version will once again take place at Churchill River Canoe Outfitters, Missinipe, SK. Enjoy a weekend in beautiful northern Saskatchewan. Canoeing, kayaking, fishing, swimming and everything that goes with "roughing it" in northern Saskatchewan (Well not too rough!!). Come and join your fellow "Guys" July 24 to 26 at Missinipe Lake.

This is open to all guys affected with bleeding disorders and male family members directly affected or involved with family members with a bleeding disorder. Please contact us if you are interested in attending this fun filled weekend at [hemosask@hemophilia.ca](mailto:hemosask@hemophilia.ca).

Meals and lodging provided. Registration \$50/Family or \$25/Single.

For more information about the location, check out [www.churchillrivercanoe.com](http://www.churchillrivercanoe.com).







## AGM Family Weekend

An enjoyable weekend at Elk Ridge was well attended by members of HSK. It is always good to reconnect with old friends and to meet some new ones. Elk Ridge resort in northern SK was the location of this year's Hemophilia SK annual AGM and family weekend. Kids and adults enjoyed the amenities offered by this beautiful location.

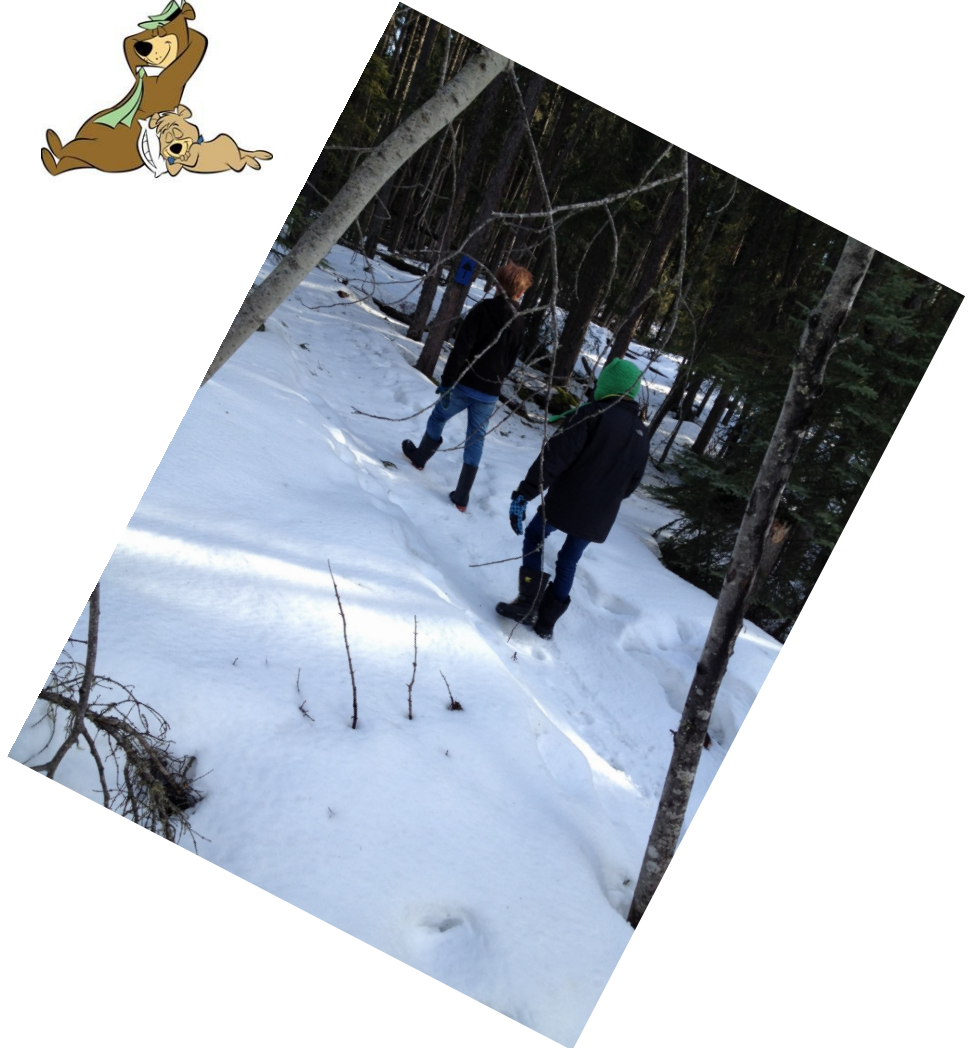
There were presentations including a new board game introduced by Bayer "Don't Press your Luck" as well as "Bleeding Disorder Awareness and Social Media" presented by Deborah Currie from CHS and of course the AGM. Saturday night included an excellent meal followed by great entertainment by Roger Boucher.

It is great to see the enthusiasm with members whom are new to the society and with our existing members who are not so new anymore. It should be noted that Hemophilia SK is considered one of the strongest chapters in Canada and this is evident by the participation of our members, and is noted by participating sponsors and representatives from CHS.

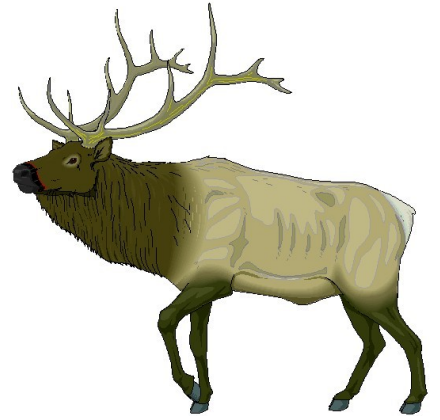


We all should be very proud and fortunate to be held in such regard. A special thanks to the members of the HSK board for making this such a special weekend!!

Daryn Moody







*Pictures submitted by  
Angie Bedard-Haughn*





2015



AGM







*Pictures submitted by  
Derek Bissonnette*





My name is Justin Lockhart and at three months old my son, Jayden, was diagnosed with Severe Type A Hemophilia. Since this didn't run in our family's genes, we had quite the learning curve ahead. At the time, the only knowledge our family had of Hemophilia was that it had to do with bleeding.

Being part of a family owned and operated furniture and appliance store in Humboldt, SK, has given me a unique opportunity to host a local fundraising and awareness event for Hemophilia in our community. My father, Kim Lockhart, and I decided to put this campaign together to hopefully raise some awareness and money for the Canadian Hemophilia Society and Hemophilia Saskatchewan.

For the entire month of May, we pledged to donate \$20 for every appliance sold, and then we decided to approach our manufacturers' representatives about matching each donation. They generously accepted and we are pleased to be donating \$40 to be split between the Canadian Hemophilia Society and Hemophilia Saskatchewan for every appliance sold! We are also excited to be hosting an on-site radio campaign which we hope will bring additional awareness to inherited bleeding disorders. This was important to us as many friends and family members were equally unaware of the details and severity of an inherited bleeding disorder like Hemophilia until our son was born.

We look forward to raising money and awareness for a cause that hits so close to home.

## Family Hosts Local Fundraiser and Awareness Event for Hemophilia





No one is more cherished in this world than someone who lightens the burden of another.



*Want to find out more information about*

*Hemophilia Saskatchewan?*

*Check us out online at*

[www.hemophiliask.ca](http://www.hemophiliask.ca)



## Saskatchewan Bleeding Disorders Program

### To Hemophilia Saskatchewan-



Just a short note to the Hemophilia Saskatchewan community to say a **HUGE THANK YOU**.

It is a rare thing to have a health consumer group like HSK that is so generous, thoughtful and dedicated to providing and improving care. It has been my privilege to work together with you for the past almost 8 years, during my time as a social worker on the team at Sask Bleeding Disorders Program.

It was a pleasure to get to know you and your families at clinics and at other events. My sincere best wishes to all.

My last day of work here is April 30, and then in June I am moving to Victoria, to live near family. I am excited to start this new chapter in life, but I will always remember my time here as a gift. Thanks again!

And, I know I will be leaving the social work role in good hands! I was delighted to have the SBDP hire Jennifer, (whom I had been hopefully preparing for some time)!

So, I want to introduce **Jennifer King**—

“Over the past several months, Michelle and I have had opportunity to discuss the SBDP. As I have anticipated a start date, I have been eager to learn about bleeding disorders and how social work supports families and patients. Most of my work until now has been with children and in rural areas (south east and central), first as a school social worker and then as a mental health counselor for children and youth. Kids are pretty awesome and I am excited to keep working with them (they keep me on my toes). The next few years was a bit of a mash up but was focused on acute care with adult patients in both RUH and Saskatoon City Hospital.



My hope in the next year or so is to learn your stories, as much or as little as you want me to know, and to better understand what I can do as a social worker to support you in this lifelong management of a bleeding disorder. Please feel free to contact me at 306-655-6503 or [Jennifer.king@saskatoonhealthregion.ca](mailto:Jennifer.king@saskatoonhealthregion.ca). My typical office days will be Tuesday, Thursday and Friday. I look forward to seeing you in the near future!”

Submitted by Michelle Sims, Social Worker (past!) of the Saskatchewan Bleeding Disorders Program.



## Saskatchewan Bleeding Disorders Program



### ***HIRT?* gets the Connected to the Community Awards from CWTA**



The Canadian Wireless Telecommunications Association (CWTA) celebrated 30 years of cell phone coverage in Canada this spring. They gave 5 “Connected to the Community Awards” in each province. ***HIRT?*** (Hemophilia Injury Recognition Tool), an injury self-management app for young men with mild hemophilia received this award in both Saskatchewan and Manitoba. The awards were given to the Manitoba and Saskatchewan Bleeding Disorders Programs. Celebrations were held March 17<sup>th</sup> in Regina and March 18<sup>th</sup> in Winnipeg. ***HIRT?*** has been developed through evidenced based research and has been supported through research grants from CHS Care-until-Cure Program, Bayer Hemophilia Awards Program (BHAP-Caregiver awards 2011, 2014) and the CHS-Baxter Inherited Bleeding Disorder Fellowship for Nurses and Allied Health Care professionals.

Photo 1: Douglas Rudolph (and dog Indi), JoAnn Nilson and Richard Lomotey accepted the award on behalf of the Saskatchewan Bleeding Disorders Program, from Bernard Lord and Laura Markle, Manager, Public Affairs, Huawei Canada.



Photo 2: Award accepted by Kathy Mulder and Kristy Wittmeier on behalf of the Manitoba Bleeding Disorders Program, accepted from Bernard Lord and Health Minister Sharon Blady





# Saskatchewan Bleeding Disorders Program



## Treatment Centres

Saskatchewan Bleeding Disorders Program

Royal University Hospital  
103 Hospital Drive, Box 113  
Saskatoon, Saskatchewan S7N 0W8  
Tel.: 306-655-6504 (main office)

### Clinic directors

Rick Stene - Program Manager  
Dr. Kelsey Brose - Medical Director, Hematologist  
Dr. Robert Card - Associate Medical Director, Hematologist  
Dr. Roona Sinha - pediatric hematologist

### Nurse coordinators

Nancy Hodgson  
O'Lynda Lovas  
Tara Schlosser  
Tel.: 306-381-4185 (nurse's office)  
Fax: 306-655-6426

### Physiotherapists

JoAnn Nilson  
Janice Block (back-up)  
Tel.: 306-655-6628 or 306-655-2431  
Fax: 306-655-6426 or 306-655-2994

### Social worker

Jennifer King  
Tel.: 306-655-6503  
Fax: 306-655-6857

### Administrative Officer

Shannon Buckingham  
Tel.: 306-655-6623

### Administrative Assistant

Laurie Guenther  
Tel.: 306-655-6504 (main office)

**Clinical Nurse Coordinator on duty**

**@ 306-655-6504**

**For any concerns or questions**

**Available Monday—Friday 8:00 am—4:30 pm**

**After-hours on call for urgent matters**

**Daily 4:30 pm—10:30 pm**

**&**

**Weekends 8:00 am—10:30 pm**



## 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](mailto:sldaizy@yahoo.com) or [hemosask@hemophilia.ca](mailto:hemosask@hemophilia.ca)



## World Hemophilia Day April 17, 2015



Photo Courtesy of  
Vanessa Lockhart  
Humboldt District  
Health Complex

## Insurance and Medical Conditions—

Hi everyone- I just want to draw your attention to the useful new link on the Canadian Hemophilia Society website- under Support and Education, the last item in the dropdown menu is **INSURANCE**.

There are guides to **Individual Insurance, Travel Insurance and Provincial Health Plans**.

The Individual Insurance section has some excellent advice for considering a policy and some useful links to the **OmbudServices for Life and Health Insurance ( [www.olhi.ca](http://www.olhi.ca) ),**

There is also information about the Medical Insurance Bureau, a non profit data sharing service where, if you have applied for insurance in the past 7 years, your data may be stored there and shared. You can request to check your information for accuracy. Do so by visiting **[www.mib.com](http://www.mib.com)** and completing the request for information or contact the MIB at 416-597-0590.

The Travel Insurance section reviews insurance by province and by the two most common travel insurance policies- Blue Cross and RBC Travel Insurance. There is a link to a helpful Guide to Travel Insurance , which lists questions that you should ask. Please note that information on travel health insurance can be obtained on the Web site of the OmbudService for Life & Health Insurance:

**[www.olhi.ca/downloads/pdf/Brochure\\_Guide\\_To\\_Travel\\_ENG.pdf](http://www.olhi.ca/downloads/pdf/Brochure_Guide_To_Travel_ENG.pdf)**

The **Provincial Health Plan** shows a comparison across Canada of provincial coverage for prescription medications. There are also comparisons for coverage for medications for Bleeding disorders ( DDAVP for example), Antiretroviral Therapies, and Hepatitis C therapies.

The web addresses are hyperlinked on the **CHS website**.

It's a great resource! Check it out!



Submitted by Michelle Sims Social Worker, SBDP

## 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





## Children's Wish

Children between the ages of 3 and 17, who have moderate to severe Hemophilia (or other severe bleeding disorders) are eligible to apply for consideration of a wish from the Children's Wish Foundation!

Wishes tend to fall under 3 categories- travel, an item, or a celebrity contact (which often involves travel). Examples have been trips to Disneyworld, home entertainment centers or computers, specific home renovation/decoration projects, contact with a sports or entertainment figure. The idea is that it be something meaningful and special for the child.

They have a One Child, One Wish policy, and will not grant a wish to a child who has previously received a wish from another wish granting agency. A child who has received a wish grant in the past, can apply for a subsequent wish in the event of a new high-risk life threatening illness.

The process to apply is as follows:

### **Contact**

**Shelley Chalmers**

**The Children's Wish Foundation**

**Phone: 306-955-0511**

**Fax: 306-653-9474**

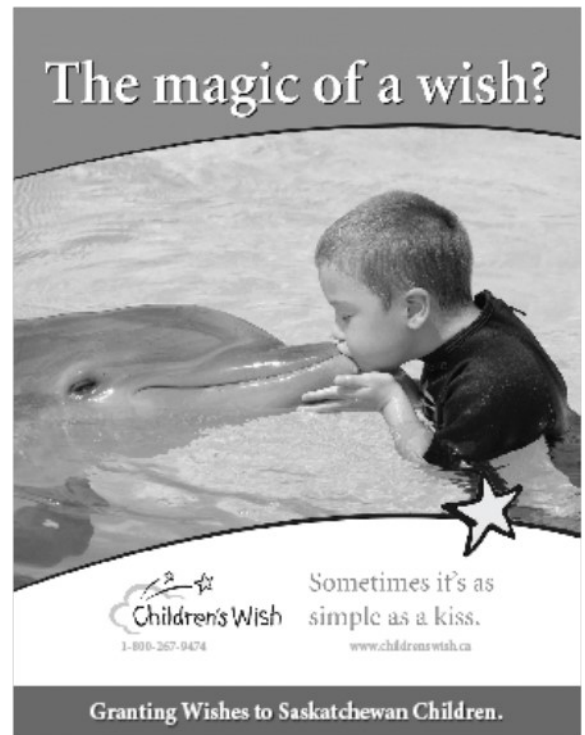
**Email: [shelley.chalmers@childrenswish.ca](mailto:shelley.chalmers@childrenswish.ca)**

You will need to sign consents for release of information. Your child's doctor or haematologist will be contacted to verify the medical condition. Shelley would then assist you in submitting the wish request, which is then referred to their national office for a decision. If the wish is granted, Shelley would assist you in planning how to fulfill the wish.

Don't hesitate to contact me if you have questions, or if I can be of any help!

Jennifer King

Social Worker, Sask. Bleeding Disorders Program



## 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, 2015**. 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 Donation Form

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

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

Reg. # 119139954 RR0001

The next newsletter deadline is July 20, 2015. Your contributions are always welcome.

Email: [hemosask@hemophilia.ca](mailto:hemosask@hemophilia.ca).

Or send to the office,

Hemophilia Saskatchewan acknowledges Action Printing, Baxter, Bayer, Biogen Idec, Pfizer, SaskTel, Telcare, and SaskTel, for the support given to our programs and printing of the newsletter.

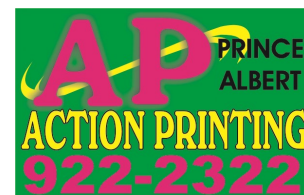
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SaskTel



This newsletter has been generously sponsored by a grant from Bayer Pharmaceuticals.

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 2015

Deadline for Summer HSK Newsletter	July 20
Guys' Getaway	July 24 to 26
Queen City Marathon, Water Aid Station, Regina	Sept 13
HSK Steaknight	Nov

### Just a friendly reminder!



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) can be reached 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 nurses Nancy and Tara at 306-655-6504.

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 306-966-6378

### 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](mailto:hemosask@hemophilia.ca) with your name and email information.