

Hemophilia Saskatchewan



February 2016

Winter Newsletter

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Special Edition Hemophilia Saskatchewan 50th Anniversary Enjoy the celebration!



President's Message

Hello All!

Well it's another new year and there is already so much on the horizon for Hemophilia Saskatchewan even as early as this. But first we must acknowledge a great event that happened at the end of 2015 that was very special to us - the celebration of our 50th anniversary. The event was filled with many of our past and present members, presidents and families, and we inaugurated our award for long service and dedication - the Lisle and Elaine Spence award. The evening was beautiful, but for me personally, it was the planning of the event that had the most meaning. We celebrated our past presidents and while doing their biographies we discovered just how much work it took from those before us to make us what we are today. We have a new found respect and it has deepened our knowledge of how and why we do what we do. Hemophilia Saskatchewan has a foundation of excellence, and it was gratifying to celebrate with the people behind that excellence. Please take time to read our special 50th anniversary edition and see if you can find the familiar faces.

We are also pleased to announce our Women and Bleeding Disorder conference in

April. This conference will address women who have a bleeding disorder, those who are carriers and those who care for bleeding disorders- look for the details within. We would also love to see you at our AGM which will take place on March 19, 2016 - see the details within.

As always, thank you for being a part in all we do, we welcome your involvement in any way!

Wendy Quinn



Board of Directors

President: Wendy Quinn Director: Vanessa Lockhart
Vice President: Angie Bedard- Director: Sandra Dionne

Bedard- **Director:** Sandra Dionne Haughn **Director:** Ann Lukian

Haughn Director: Ann Lukian
Treasurer: Derek Bissonnette Director: Celena Moody
Secretary: Lorrie Kaglea Director: Jae Won Hur

www.hemophiliask.ca

Want to know more about Hemophilia Saskatchewan?

Check us out online at



HEMOPHILIA SASKATCHEWAN'S 50TH ANNIVERSARY

Help Stop the Bleeding

Saturday, November 7th, 2015 Travelodge Regina

> COCKTAILS 5:00 - 6:30 PM

SUPPER 6:30-7:30 PM

CEREMONY & PROGRAM 7:30-9:00 PM





CEREMONY & PROGRAM

OPENING REMARKS

Jae Won Hur

COMMEMORATION OF TAINTED BLOOD TRAGEDY - Moment of Silence

Jae Won Hur

MESSAGE FROM CHS

Helene Bourgaize

50 YEARS OF HEMOPHILIA SASKATCHEWAN

Angie Bedard-Haughn Presented by: Wendy Quinn

PRESENTATION TO PAST PRESIDENTS

LISLE & ELAINE SPENCE AWARD FOR EXEMPLARY SERVICE

Daryn Moody Presented by: Tom Spence

PAST LEADING TO OUR PRESENT

CLOSING REMARKS

-Video Presentation

Wendy Quinn

CAKE CUTTING

SILENT AUCTION FINALE

HEMOPHILIA SASKATCHEWAN

Hemophilia Saskatchewan is a chapter of the Canadian Hemophilia Society and is a voluntary health charity. Its mission is to improve the health and quality of life of all people with inherited bleeding disorders and ultimately to find a cure. Its vision is a world free from the pain and suffering of inherited bleeding disorders. We strive to provide services for all those with inherited bleeding disorders in Saskatchewan in the areas of care and treatment, building awareness, research to find a cure, education/support and we help to keep our blood supply safe and secure.

Join Us!



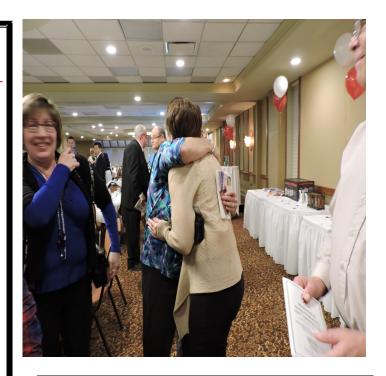
Hemophilia Saskatchewan



@hemophiliasask

Check out our new website! www.hemophiliask.ca





A MESSAGE FROM CHS

HÉLÈNE BOURGAIZE



Hélène Bourgaize began working for the CHS in 1985 where she shared her time between the Quebec Chapter and the National Office before

making the change to full-time at the national level of the organization in 1988. Since 2005 she holds the position of National Director of Volunteer Development and Human Resources. For the past six years, she has been volunteering on the Board of Directors of the Volunteer Management Professionals of Canada where she actually holds the position of Past-President.

PRESIDENT'S MESSAGE

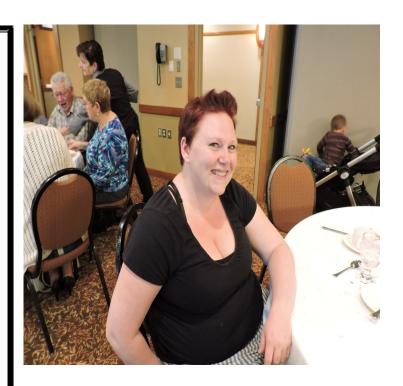
WENDY QUINN



It is my honor and privilege to be celebrating 50 years of Hemophilia Saskatchewan with you. This organization is the truest form of a "grass roots beginning" as it began at a

kitchen table in a farm house in Rosetown - how far we have come! The tiny steps that each chapter president has taken since then has helped shape who we are today. Join me today to honor the past that has built our present, and will guide where we go tomorrow. Thank you all for being a part of our 50th anniversary celebration.





OUR FOUNDERS

LISLE & ELAINE SPENCE



Lisle Spence was the first
President of the
Saskatchewan Chapter of
the Canadian Hemophilia
Society – known today as
Hemophilia
Saskatchewan, His wife

Elaine was an integral part of the development and management of the chapter. They did their work at a small kitchen table in farm house in Rosetown, Saskatchewan and worked provincially and nationally to help form the society we know today.

LISLE & ELAINE SPENCE AWARD RECIEPENTS:

DR. ROBERT CARD



Dr. Robert Card is a graduate of Queen's University Faculty of Medicine and received a FRCPC in Internal Medicine and Hematology in 1972. He moved to Saskatchewan in 1973 and became a full-time faculty

member until 2007. He has remained active clinically with part-time practice in the area of bleeding disorders until 2011. He has been the Hemophilia Clinic Director for the Saskatchewan Bleeding Disorders Program since 1978. He has a special interest in the history of hemophilia care and is currently working on a project with the Medical Council of Canada on that subject. He has been married to his wife Helen for 52 years and has three children and three grandchildren.





DR. BRIAN MCSHEFFREY



Dr. Brian McSheffrey is a pediatrician and hematologist and has been involved in hemophilia treatment

for 51 years, most of those years as the pediatric hematologist with Saskatchewan Bleeding disorders Clinic. He began his long career of dedication to pediatric hematology in Winnipeg Children's Hospital in 1961, and never looked back. He has three daughters from his first wife Grace who passed away and currently lives in Saskatoon with his second wife Wendy and has three stepchildren. He has become an active volunteer for the Saskatoon Council on Aging in his retirement.

DR. RAMACHAND DEVERAJ

Dr. Deveraj has served the bleeding disorders' community in Regina since 1982. Dr. Deveraj was born in Madras, India and trained to be a hematologist in Edinburg, Scotland. One of his classmates came to Canada to start a practice, and he decided to follow and became a hematologist for the Regina district and this is where he has stayed for 33 years to serve our bleeding disorders' community. Dr. Deveraj is married and has two children.





PAST PRESIDENTS OF HEMOPHILIA SASKATCHEWAN

Lisle Spence

Nadien Tom

Linda Laxdal

Harvey Lavallie

Dennis Zech

Peter Verbeek

Craig Wright

Eric Stolte

Faye Katzman

Clara Penner

Ann Wood

Anne Lukian

Maia Meier

Wendy Quinn

LISLE AND ELAINE SPENCE





NADENE TOM



LINDA LAXDAL



HARVEY LAVALLIE





DENNIS ZECH

























ANNE LUKIAN













MESSAGE FROM THE SBDP



COMMEMORATION...





2015 HSK BOARD MEMBERS



CLOSING REMARKS AND THANK YOU'S...

- x 1. Pharmaceuticals: Bayer, Baxalta, Pfizer and Biogen Idec
- * 2. All membership Donations
- * 3. Special Contributors Norm Little who's ongoing funding supports the "Louise Paisley Memorial Scholarship. The Duncan Family for the Tavis Duncan foundation bursary.
- × 4. Carrie Lavallie Newsletter Creator

THANK YOU'S....



THANK YOU'S....

* A-Line Furniture Humboldt...



THANK YOU FOR HELPING
HEMOPHILIA SASKATCHEWAN
CELEBRATE ITS 50TH
ANNIVERSARY!







2016 Notice of

Hemophilia Saskatchewan's Annual General Meeting

March 19

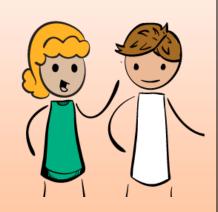
11:00 am —2:00 pm

902 33rd Street West Mayfair United Church Saskatoon, SK Lunch provided



Act as if what you do makes a difference. It does.

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



Women and Bleeding Disorders Conference

Hemophilia Saskatchewan

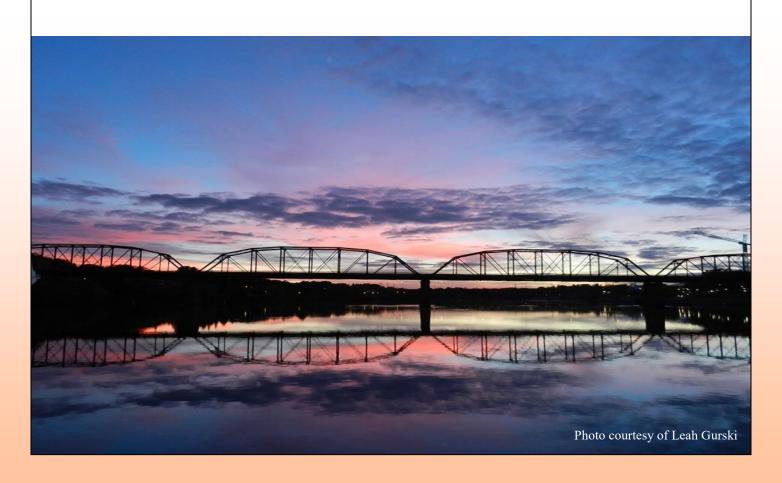
presents a Weekend Conference on:

Women and Bleeding Disorders..

Those who have, those who carry, and those who care for.

April 8-10, 2016 Delta Bessborough Saskatoon, SK.

Details to follow, please email hemosask@gmail.com if you are interested in attending or register online at www.hemophiliask.ca.





Saskatchewan Bleeding Disorders Program

Emergency Department and Hospital Visits



At Planning Day 2015 we discussed how important it is to know what to do in an emergency. The emergency department has many people directly involved in care for one person. You have the most knowledge and expertise about your bleeding disorder and so it will be important for you to share this information. You may also find you have to tell them more than once.

First, we urge you to **phone the nurse on call as soon as possible (306)381-4185** when you are going to the emergency department or when you have arrived. They can advocate with you for needed treatment. Treat before coming to the hospital if it is safe to do so. In Saskatoon we encourage you to go to Royal University Hospital and in Regina to the General Hospital. In smaller centers go to the nearest emergency center.

Be clear that you (or your child), has a bleeding disorder, you have a hematologist that meets with you at regular appointments and you have a treatment protocol that needs to be followed. **Know your diagnosis and have your FactorFirst or TreatFirst Card with you.**

The Saskatoon Health Region also discusses Patient Safety on the Region website, saskatoonhealthregion.ca. Here is a list of what you can do for your own safety in the health region:

- 1. Give information and tell the medical team everything you can about you and your history
- 2. Get information by asking questions until you understand
- 3. Bring a friend, family member or support person who can speak for you, listen and understand
- 4. Keep clean with good hand washing
- 5. Know what to do after each visit for follow up and which physician will complete follow up.

There may come a time when you have done all of these things and believe that you are not being heard or that a safety issue has occurred. The Saskatoon Health Region now has a safety reporting line for staff and patients that can be accessed at 306-655-1600 (24 hours a day, 7 days a week).

Client Representative Services is also available if you have concerns about the care you or your family received. They outline that if you have discussed your concern with staff directly involved and the manager of the department and feel that your concerns have not been addressed, you can ask the Client Representative to help. They can be reached at 306-655-0250, or client.rep@saskatoonhealthregion.ca. If you require this same type of support in another health region, we can help you to find the information you need.

As always our staff at the Saskatchewan Bleeding Disorders Program is available to help. Please feel free to call if you have a question or concern.

Submitted By:

Jennifer King, Social Worker O'Lynda Lovas, Registered Nurse

306-655-6503 306-655-2433

jennifer.king@saskatoonhealthregion.ca olynda.lovas@saskatatoonhealthregion.ca



Saskatchewan Bleeding Disorders Program

HSK Article – Social Work Week March 14-18 Social Work: The profession of choice



It was 1997 when I was introduced to the second medical social worker I would have working in my personal life. My grandmother was in palliative care at Saskatoon City Hospital. Watching how they respected and navigated the medical system and worked with my family introduced me to the idea that this was my profession of choice. Six years later I was a social worker and starting my new profession in the school system. Now in the medical system again social work is my profession of choice.

The role of social work in hemophilia care and with the Saskatchewan Bleeding Disorders Program (SBDP) is a unique one. We fill many of the same roles as social workers in other areas but we also have the experience of ongoing relationships with our clients as bleeding disorders are a lifelong condition. As such we speak to the need of supporting individuals and families with the resources you need. Finding information and assisting with applications. Giving ideas and allowing you as an individual make a decision that fits your life at this time. Social work is also available for counseling and support around pain management, school, family and social concerns and can always make a referral to further support if needed.

The Canadian Social Workers in Hemophilia Care developed a Standards of Practice document in May 2009. This document seeks to provide a common standard of care to all patients who have a bleeding disorder diagnosis across the country as we work in a multi-disciplinary team (hematologist, nurses, and physiotherapist). Social workers in health care have a degree from an accredited university and must be in good standing and registered with their local association. The Saskatchewan Association of Social Workers (SASW) provides that governance and also sets out Code of Ethics, and Standards of Practice. We seek to maintain confidentiality, ethics, documentation, education, and team work in our multi-disciplinary team. We also seek to advocate, and help make sense of the medical system while seeking to protect your right to make decisions. But at the end of all this we want to listen and support you and that is why this is my profession of choice.

Jennifer King, Registered Social Worker Saskatchewan Bleeding Disorders Program Saskatoon Health Region

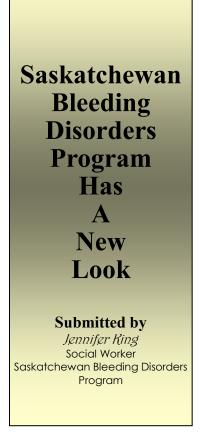
Top 4 things to Know about Medical Expenses and Income Tax

- 1. Claims can be made over a 12 month period.
- 2. Based on \$2,208 or 3% of your net income (whichever is less), you receive a 15% tax credit on anything over this amount.
- 3. Prescriptions, medical supplies, dentist/orthodontics, glasses prescription are a few of the things you can claim when this has been paid out of pocket. You can also claim mileage for trips over 40km one way and for other travel expenses for trips over 80km one way.
- 4. It is always good to talk to a professional. Here is a CRA links for any extra information http://www.cra-arc.gc.ca/tx/ndvdls/tpcs/ncm-tx/rtrn/cmpltng/ddctns/lns300-350/330/llwbl-eng.html

Submitted by: Jennifer King, Registered Social Worker Saskatchewan Bleeding Disorders Program 306-655-6503 Saskatoon Health Region We have a new banner...since this last summer we have been working on a way to show who we are. Here is a new banner that we will have placed at our clinics and other events we are at. Thank you to everyone who had input into the design. The blood drop was specially made for us by Nancy Carlson in the LiveWell Program.







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.



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

Email:

hemosask@hemophilia.

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

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

Hemophilia Saskatchewan Annual General Meeting March 19

Women with Bleeding Disorders Conference April 8-10

Deadline for Spring HSK Newsletter April 15

World Hemophilia Day April 17

Deadline for CHS Scholarship/Bursary April 30



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

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.