CHS ALBERTA CHAPTER MEMBER AWARDED THE ORDER OF CANADA

On December 28, 2007, Her Excellency the Right Honourable Michaëlle Jean, Governor General of Canada, announced that Ken Poyser, a long standing member of the Canadian Hemophilia Society, was appointed to the Order of Canada in recognition of “his life long dedication to improving the lives of those living with hemophilia in Canada and abroad.”

For over 35 years, Ken Poyser has contributed to the improvement of care for people impacted by hemophilia and related bleeding disorders. Ken has been responsible for significant advancements at the local, national and international levels.

Ken served the Canadian Hemophilia Society (CHS) Alberta Chapter as President and as Treasurer, each for two terms. While serving the CHS Alberta Chapter, Ken was responsible for organizing a lobby group which submitted a funding proposal toward the development of the Comprehensive Care Programs in Edmonton and Calgary. While the initial proposal was turned down, Ken and his colleagues were not deterred. Following the organization of a symposium with specialists from the US and Eastern Canada that also included the attendance of Provincial Health Administrators, the team was successful in obtaining the government funding needed to establish our Hemophilia clinics in Alberta in 1977. Both clinics remain in operation today and have saved the province significant dollars by dramatically reducing In-patient treatment through education and support of home treatment options for the provincial bleeding disorders community.

Ken was a Director on the CHS National Board for 12 years. During this time, Ken held the CHS National Executive positions of Treasurer, Vice President and President. During Ken’s tenure as President of the CHS, the organization was instrumental in creating twelve Comprehensive Care Clinics across Canada – a great legacy for everyone involved.

The first step in Ken’s contribution to the international community was achieved through his vision and implementation of the “Hemophilia Research Million Dollar Club”. During 12 years under Ken’s direction, the fund grew to and exceeded its one million dollar goal. This fund has and continues to support multiple research initiatives toward a cure. The development of the Million Dollar Club is a very important contribution to the national and international bleeding disorders community because Ken had the foresight to recognize the road to a cure would have a positive impact on the lives of all individuals suffering from a bleeding disorder.

For almost a decade Ken participated in the World Federation of Hemophilia (WFH) prior to his election as Vice President-Finance in 1992. He was subsequently re-elected for two additional terms. During Ken’s 12 years of service on the WFH Executive, he chaired or sat on the Executive, Investment, Compensation, Fundraising, Accreditation and Assessment and Internet/Web-Site committees.

Continued on pg. 2
Contact Us

Perhaps you or a family member has been recently diagnosed with a bleeding disorder, or perhaps you have relocated to Alberta from elsewhere. Please let us know if you would like to receive a Welcome Package with information about the CHS Alberta Chapter - who we are and what we do.

Canadian Hemophilia Society Alberta Chapter
P.O. Box 58060, Edmonton, Alberta T5L 4Z4

Telephone: 1-780-421-9851
Toll free: 1-866-425-9851
Voicemail box 1: Alberta Chapter
Voicemail box 2: Northern Alberta Region
Voicemail box 3: Southern Alberta Region
Fax: 1-780-459-2548
Email: albertachapter@hemophilia.ca

Northern Alberta Bleeding Disorders Clinic
Dr. John Akabutu Comprehensive Centre for Bleeding Disorders
University of Alberta Hospitals
Edmonton, Alberta T6G 2B7

Telephone: (780) 407-6588

Canadian Hemophilia Society National Office
625 Avenue Président Kennedy, Suite 505
Montréal, Québec H3A 1K2
Telephone: 1-514-848-0503
Toll free: 1-800-668-2686
Fax: 1-514-848-9661
Email: chs@hemophilia.ca
Website: www.hemophilia.ca

Southern Alberta Bleeding Disorders Clinics
Children’s Hemophilia Clinic, Alberta Children’s Hospital
2888 Shaganappi Trail NW
Calgary, Alberta T3B 6A8

Telephone: (403) 955-7311
Email: alice.laut@calgaryhealthregion.ca

Adult Comprehensive Clinic
Unit 57B Special Services Building
Foothills Hospital
1403 - 29 St. N.W.
Calgary, Alberta T2N 2T9

Telephone: (403) 944-4057
Email: morna.brown@calgaryhealthregion.ca

Order of Canada
Continued from pg. 1

Ken was responsible for establishing the computerized accounting system that would be required to manage millions of dollars of congress revenues and expenditures.

Ken brought financial rigor to the WFH and they now are in a healthy financial position. The financial stability of this global organization continues to provide assistance to people with bleeding disorders around the world where they may not be organized or have available resources to provide effective care. Ken has participated in the World Congress organizing and selection committees for the past four congresses. Each new congress has seen significant growth in attendance and has brought profits of over 3.5 million – funds that help provide education and care for developing nations.

Ken envisioned the creation of a national member organization twinning program that would foster the growth of hemophilia support in developing countries. The program is designed to pair organizations in developed nations with those in the developing world to aid them in becoming organized to assist their local hemophilia community. Today there are more than 20 such twinning arrangements established through the WFH. A proud legacy to Ken’s inspiration is that CHS National considers twinning a primary objective and Canada now participates in a significant number of twinning partnerships around the world.

In 1994, Ken recommended and oversaw the creation of the WFH website (www.wfh.org) which was implemented in the spring of 1995. This remains a valuable tool for the dissemination of bleeding disorders information to the global community.

It is with great pleasure that the Executive of the CHS Alberta Chapter supports the appointment of Kenneth Poyser to the Order of Canada. We believe that Ken is most deserving of this national recognition for his unwavering dedication to the Bleeding Disorders community and cause on a local, national and global scale.

In 2005, Ken Poyser was the first recipient of the newly created International Contribution Award as part of the Canadian Hemophilia Society National Awards Program.
CHS Alberta News

CHS Recognizes Alberta Clinic Staff with National Awards

At the CHS Awards Banquet, held November 24, 2007 in Ottawa, in conjunction with the CHS Semi-Annual Board meeting, the CHS recognized a group of dedicated volunteers, health care providers, and staff members who had made a significant contribution to the bleeding disorders community in 2006 or during preceding year(s).

2006 Recipient
Dr. Man-Chiu Poon

International Contribution Award

This award is presented in recognition of a volunteer who, through his/her continuing efforts over a number of years, has contributed to the development of care and services for people with bleeding disorders at the international level.

Dr. Man-Chiu Poon’s contribution to the improvement of care and treatment for people with hemophilia in China is outstanding. In 1993, sponsored by the CHS, Dr. Man Chiu Poon traveled to Tianjin, China, to lead a workshop organized by the WFH for the first time. From this point on, Dr. Poon began to devote his time and skills to improving care and treatment for hemophiliacs in China. He was the contact person between China and the WFH whenever someone in China needed information on hemophilia care. In 1997, an official WFH centre twinning was established between the Hematology institute in Tianjin and the HTC in Calgary. Based on the success of this project, and thanks in large part to the dedication of Dr. Poon, the WFH launched a priority project for China in 2000, hoping to increase not only the rate of diagnosis, but the training of medical personnel. Two twinning partnerships were added: Guangzhou (Nanfang Hospital) with Ottawa (Dr. Brian Luke) in 2000, and Shanghai (Ruijin Hospital) with Calgary and Ottawa in 2002. Dr. Poon and Dr. Luke continue to work together to advance the care of hemophiliacs in China. In 2005 Dr. Poon took a year-long sabbatical. True to his devotion to the cause, he chose to continue to offer a great deal of his time to the twinning project in China, spending significant time working with the centres. Thanks to his courage and dedication, China now has a National Hemophilia Treatment Centre Collaborative Network to coordinate future development. Dr. Poon’s contribution on the international level is staggering. Along with his colleague, Dr. Luke, Man-Chiu has impacted the lives of millions of people with hemophilia in China.

Dr. Cecil Harris Award

This award honours distinguished contributions in the areas of hemophilia-related research or the advancement of the care of patients with hemophilia or related bleeding disorders.

Dr. Bruce Ritchie’s accomplishments as Assistant Director and most recently Clinic Director of the Edmonton Comprehensive Centre for Bleeding Disorders have been both local and national in scope. Dr. Ritchie is extremely dedicated to the care of his patients and goes far beyond the requirements of a physician and medical director in this regard. He advocates for services that his patients require and is willing to try new treatments. He is dedicated to patient care but is also driven by his participation in research and education. While President of the Association of Hemophilia Clinical Directors of Canada (AHCDC), Dr. Ritchie worked to improve the funding of the organization and roll out improved technology for the CHARMS database. A significant contribution to the potential future care of hemophilia was the organization and delivery of the Blood Borne Pathogens program that is being maintained at the University of Alberta under his direction. Dr. Ritchie has been a strong supporter of standards of comprehensive care and has lent his support to other regions of the country who were advocating for improved comprehensive care in their region. In addition to serving as Chair of the CHS Medical and Scientific Advisory Committee (MSAC), Bruce is an active member of the CHS Blood Safety and Supply Committee and the National Rare Blood Disorders Organization. Dr. Ritchie is a most deserving recipient of the Dr. Cecil Harris Award for his unwavering dedication to the care of of people with bleeding disorders over the years.

Award of Appreciation

This award honours individuals who have demonstrated outstanding service to the care of persons with hemophilia or related bleeding disorders over and above their responsibilities as a member of the hemophilia health care team.

Ruanna has been the social worker at the Calgary Children’s Hospital Hemophilia Treatment Centre for over ten years. She has been an active member of the Canadian Social Workers in Hemophilia Care (CSWHC) and has served as co-chair for the past 7 years. She is an excellent advocate for the role of social workers in the care of patients and families living with bleeding disorders and has served as a mentor with her national colleagues. Ruanna’s commitment to the larger bleeding disorders community has been reflected in her willingness to become involved in CHS projects. She has worked on the planning committee and as a facilitator at several national inhibitor workshops. On the international stage, she has been the Canadian representative on the National Hemophilia Foundation social workers committee and participated on the newly formed WFH Psycho-social Committee. Ruanna has recently moved to another program and her contribution to the Southern Alberta Bleeding Disorder Community, the CHS and CSWHC will be greatly missed.

2006 Recipient
Ruanna Jones, RSW

2006 Recipient
Dr. Bruce Ritchie

2006 Recipient
Dr. Man-Chiu Poon
Hemophiliacs Unite at Leadership Conference Submitted by Alex Little

Blood brothers from around the world came together at the First Annual ‘Step Up Reach Out’ program that took place in San Francisco, California from September 14-17, 2007. The program brought Hemophiliacs together from Britain, Germany, New Zealand, Spain, Canada, and the United States in order to encourage them to become more active in their respective communities. Participants shared stories about their separate experiences having Hemophilia, learned a great deal about their condition in the valuable ‘Hemophilia 101’ session, and toured the abundant San Francisco attractions. Great accommodation was provided, delicious meals enjoyed, and friendships created. The participants were treated to a baseball game, a tour of the plant where Kogenate is created and distributed, and meals overlooking the gorgeous San Francisco wharf. It was a very unique and rewarding opportunity to spend time with other young people born with the same life-altering condition.

Conversations and information sessions focused around the concept of living with a bleeding disorder, depending on different cultures, ages, and backgrounds. The men gathered at the conference were brought together with only one unifying thread, but other undeniable similarities came through and it proved to be a fascinating look into how such a condition can shape one’s beliefs and identity. Care for bleeding disorders in different countries was compared and the participants got a first-hand look into how this care differed around the world.

This trip to San Francisco was the first part of the two-part program that sees the participants heading to Houston for the second part in February of 2008. In the interim, participants are encouraged to become more active in their respective countries and take the first steps to becoming a leader in the bleeding disorders community. These participants are ideally stepping up to fill the shoes of the valued leaders that the community currently has. If the excitement and anticipation that was exhibited at the end of the first session was any indication, these men are more than willing to do what it takes to fill these shoes.

A very special thanks to Ed Kuebler, Manisha Patel, and everyone else involved in these sessions for their excellent organization, donation of their valuable time, and welcoming presence.

Hemophiliacs on Face Book

The Face Book craze is now bringing Hemophiliacs together. Check out the following groups on the World Wide Web at www.facebook.com:

Step Up and Reach Out
Canadian Hemophilia Society
Haemophilia Society

July 6 - 11, 2008

Registration Deadline: June 1, 2008

camp info: Mary Mueller (403)883-2469

This year’s CHS Alberta Chapter camp will be held July 6 – 11th so watch for your camp packages on your clinic day or in the mail. Camp inquiries may be directed to Mary Mueller at 403-883-2469.

VOLUNTEER NEEDED

CHS Northern Alberta Region is looking for a transportation Coordinator for Hemophilia Camp Chief Hector for July 6th and 11th, 2008. Please contact Mary Mueller at 403-883-2469 if you can help!
Southern Alberta Region AGM and Christmas Party

At the CHS Southern Alberta Region Annual General Meeting, highlights of the past year were reviewed and those who attended had a chance to talk informally about the significant change in clinic arrangements and staffing.

The following were elected to the Executive: Susan Anderson, President; Stacey Johnson, Vice President; Crystal Verbeek, Treasurer and Lisa Little, Secretary.

The Christmas Party is an ongoing tradition that brings people together and welcomes new members of the bleeding disorders community. Children enjoyed the crafts, activities, visit from Santa and the chance to have their faces painted (some adults even participated in this opportunity!)

Thanks to Kathy and Stacey Johnson for planning such a great event, complete with fantastic door prizes!

Northern Alberta Region Events

On Saturday November 3rd, members of the CHS Northern Alberta Region gathered at the Woodvale Community League in Edmonton for the Region’s Annual Volunteer Appreciation Dinner. Besides great food and fellowship, highlights of the evening included honoring several volunteers including Craig Upshaw as the Volunteer of the Year in the Northern Alberta Region. In addition, a very informative presentation was provided by Naturopath, Dr. Angela Kirk. Dr. Kirk operates her own practice in Calgary and is also affected by a bleeding disorder. Dr. Kirk provided very relevant information to our community on additional treatments available to complement conventional therapies. Sincere thanks to Dr. Kirk for an excellent presentation. Thanks also to Joanna Halliday for organizing this event.

Southern Alberta Pediatric Bleeding Disorder Clinic Meet and Greet

Date: Saturday March 1, 2008
Time: 2:00-4:00 p.m.
Location: Alberta Children’s Hospital Hematology and Oncology Clinic Foyer
RSVP: February 27, 2008

Come and meet the staff of the comprehensive care team.
This event is co-sponsored by Baxter and the CHS Southern Alberta Region

On Saturday, January 26th, the Northern Alberta Region held the Region’s Annual New Year’s Celebration. The afternoon included the Annual General Meeting of the CHS Northern Alberta Region. The 2008 Executive was elected. Executive members are as follows:

President: Craig Upshaw
Vice Presidents: Juanita Pickerl, Brent Buchanan, Jessica Neurauter
Treasurer: Dan Wilson
Secretary: Bonnie Buchanan

The AGM was followed by a visit from the CHS National Executive Director, David Page. David provided excellent information on the current projects and issues the CHS is involved in and also solicited input from our members. It was good to learn more about our organization from a National perspective. Many thanks to David for his willingness to be part of our event and provide us with this input. During the AGM and David’s presentation, the kids were entertained with crafts. To close our time together, we all enjoyed a wonderful meal and time of visiting. Thanks go to Natasha Wilson for organizing this enjoyable event.
Kudos to our 2007 Volunteers

The Executive of the CHS Alberta Chapter want to acknowledge everyone who gave of their valuable time to the CHS Alberta Chapter in 2007. You Lighten Our Load by Volunteering! THANK YOU! We would not have been able to provide the number of Regional events, undertaken fund raisers, offered Kids’ Camp, etc. without you. We extend our sincere thanks to you for your dedication to our Society.

We hope to be in a position to expand our programs in 2008. This can happen provided we have the support of our membership. If you have never volunteered for the CHS before, or if you have volunteered in the past and would like to take on a more active role, we invite you to contact us either via our 800 number or email (see Contact Information on Page 2 of this newsletter). We will do our best to match you with a volunteer opportunity.

Current volunteer opportunities include:

• Northern Alberta Region – Family Picnic Coordinator
• Southern Alberta Region - Clinic Days Coffee Server - Adult clinic.

Save the Date for
GoldEye 2008
September 19, 20, 21 2008
GoldEye Retreat Centre
Nordegg, Alberta

CHS ALBERTA EVENTS

CHS ALBERTA CHAPTER
BEACH PARTY
MARCH 8, 2008
1:30PM TO 5:00PM

COME AND SPEND AN AFTERNOON WITH YOUR CHS PALS ON THE BEACH AT WEM
FOLLOWED BY AN EARLY SUPPER AT BOSTON PIZZA (EVERYONE WELCOME)

RSVP REQUIRED BY MARCH 1, 2008
PHONE 1-866-425-9851, VOICEMAIL BOX 1

Please leave your name and phone number along with the number of adults and kids (with their ages) attending.
Irene McPherson Northern Alberta Region
Youth Memorial Bursary

Irene McPherson was a dedicated member of the CHS Northern Alberta Region. Sadly, Irene passed away in 2006. Irene left a generous legacy to the Region which has been used to establish a Memorial Bursary in her honour. In order to promote the development of future leaders in the CHS Northern Alberta Region, the bursary is being directed to sponsor a Youth in the Northern Alberta Region to attend the 2008 World Federation of Hemophilia Congress taking place in Istanbul, Turkey, June 1-5, 2008.

This bursary is open to a youth from the Northern Alberta Region with an inherited bleeding disorder between the ages of 18 and 30 years of age. A Selection Committee will choose the youth from the received applications based on merit and quality of the application.

To qualify, the following criteria must be met:

- Applicant must be a Canadian citizen or permanent resident of Canada and a resident of the Northern Alberta Region (Red Deer and North) between the ages of 18-30 with Hemophilia, von Willebrand Disease or another rare factor deficiency (including carriers).
- Applicant must be able to communicate in English, the official language of the Congress.
- Applicant must have been an active volunteer of the CHS Northern Alberta Region within the last two years.
- Applicant must be committed to working with CHS for at least the next two years.

Bursary Criteria

Youth Delegate will receive:

- Hotel accommodation in Istanbul from May 31 to June 5, 2008 inclusive
- Return economy class airfare from the airport nearest to where they live to Istanbul along with airport tax and transportation to and from airports;
- Free registration to 2008 World Congress.

Not included: Meals

Please note that there will be medical personnel and a bleeding disorder treatment centre on site.

Interested youth should complete the following application form and forward it, along with the relevant documentation, to the CHS Northern Alberta Region, P.O. Box 58060, Edmonton, AB T5L 4Z4 by April 14, 2008.

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<td>Tel. (home)</td>
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Also attach a document with answers to the following questions:

Why would you like to participate?

Why should the Northern Alberta Chapter choose you as a youth delegate?

What will be your future involvement with the Chapter?

Other comments to support your application?

Please include the following with your application:

- a recent curriculum vitae
- a letter of recommendation from an employer or an institution where you studied or volunteered (other than the chapter)

Note: Incomplete applications will not be considered.

Signature ______________________ Date ________

CHS Alberta News
The CHS Alberta Chapter will sponsor up to five individuals to attend the 2008 World Federation of Hemophilia Congress taking place in Istanbul, Turkey, June 1-5, 2008.

The sponsorship program is open to members of the CHS Alberta Chapter with an inherited bleeding disorder. A Selection Committee will choose the delegates from the received applications based on merit and quality of the application.

The delegates will be required to pay expenses and then submit receipts for reimbursement.

**Sponsorship Criteria**

To qualify, the following criteria must be met:

- Applicant must be a Canadian citizen or permanent resident of Canada and the province of Alberta with Hemophilia, von Willebrand Disease or another rare factor deficiency (including carriers).
- Applicant must be able to communicate in English, the official language of the Congress.
- Applicant must have been an active volunteer of CHS Alberta Chapter within the past two years.
- Applicant must be committed to working with CHS Alberta Chapter for at least the next two years.

**Delegate will receive:**

- 75% of air travel, accommodation, and registration costs up to a maximum of $1000.00 (One Thousand Dollars CDN). Please note that there will be medical personnel and a bleeding disorder treatment centre on site.

Interested individuals should complete the following application form and forward it, along with the relevant documentation, to the CHS Alberta Chapter by **April 14, 2008**.

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**What is your current involvement with the chapter?**

**Why do you wish to participate in the congress?**

**How will you share the knowledge gained at the congress with the chapter?**

Signature ________________ Date ________________