In action at home and abroad
We would like to thank the following companies who have generously accepted to participate in our new National Corporate Sponsorship Program:

BAXTER
BAYER
NOVO NORDISK
WYETH
ZLB BEHRING

This program is intended for companies that sell pharmaceutical products for the treatment of bleeding disorders. The participating corporations accept to donate an amount proportional to their share of the Canadian market without specific restrictions or conditions. This creates a transparent, equitable and arms-length relationship.

The National Corporate Sponsorship Program supports the Canadian Hemophilia Society to better serve families confronted with a bleeding disorder.

In this way the pharmaceutical companies generously contribute to the well being of those who use their products.

We would also like to thank our numerous donors – individuals, corporations and foundations – who each year express their confidence in us by making substantial donations.

Thanks to all of these generous contributions, the Canadian Hemophilia Society...

• Offers national programs of training, education and awareness
• Supports research into hemophilia and other bleeding disorders
• Produces educational publications, periodicals (such as Hemophilia Today) and keeps up to date an Internet site www.hemophilia.ca
• Interacts with stakeholders in the health care field to promote the well being of all our families.
Eight months after the unanimous vote by all federal Members of Parliament to extend the hepatitis C class action settlement for those who contracted HCV from tainted blood between January 1, 1986 and July 1, 1990 to all, and more than a year after his announcement in the House of Commons to begin discussions and study the various options open to him, the Federal Health Minister, Mr. Ujjal Dosanjh announced on November 18 the signing of a Memorandum of Understanding with the lawyers of the “forgotten victims”. By virtue of this agreement, the federal government is formally committed to providing compensation to those people who were infected with HCV before January 1, 1986 or after July 1, 1990. While this is an important step forward, the amount of compensation and the schedule for its payment remain to be determined. The different parties are continuing their negotiations, a process which will likely require several months.

The CHS has always maintained that there should be no distinction between victims of contaminated blood based on the date on which they were infected. Nor should there be a difference as to the amount of compensation to which they should be entitled. The benefits of this new compensation programme should be identical to those offered to the people in the 1986-90 settlement.

It is critical that the Minister commits to releasing additional funds to respond to the needs of all those in the pre-1986, post-1990 group and, ideally, that he names a separate administrator. In addition, the government should foresee an initial emergency payment to those excluded from the original settlement, while waiting for the conclusion of the different analyses needed to evaluate the size of the new fund.

Years have passed and the inequity continues. It is time to end the procrastination and speedily pay compensation to the forgotten victims who have already been made to wait far too long.

On a different topic, the news on the Multi-Provincial/Territorial Assistance Program (MPTAP) is encouraging. Following Ontario in May 2001, within the past few months, two other provinces, Manitoba and Newfoundland & Labrador, have decided to act by indexing to the cost of living the annual payment for those contaminated with HIV through blood or blood products. It can only be hoped that this movement will create a domino effect with the other provinces which, to date, have refused to budge on this matter. Remember that, for all practical purposes, this annual income constitutes the only program managed by the provinces and territories that isn’t indexed to the cost of living.

Season’s Greetings
PRESIDENT’S MESSAGE

Destiny in the Making

Destiny. That word conjures up a variety of notions and questions. Can a person determine his destiny? Is there such a thing as fate? What shapes one’s destiny?


This popularizes the notion that our destiny is shaped by our choices. Luke chooses in the end to deny his hatred which would have led him down a path to the Dark Side and, instead, to demonstrate love and forgiveness to Darth Vader, his father. As a result of this choice, Darth Vader acts on the good that Luke sensed was still in him and tosses the Emperor to his death. Luke, by choosing love, faith and forgiveness, seals his own destiny as the special saviour restoring balance between good and evil.

We recently held the first meeting of our newly formed National Fundraising Council (NFC). Stéphane Bordeleau and Joyce Gouin, CHS Direct Marketing Coordinator, put in yeoman’s service in preparation for this time and deserve our heartfelt thanks. The NFC is determined to create a destiny for the CHS of financial strength and vitality. The energy, creativity and determination in the room over the weekend was extraordinary. It was evidence of the new beginning we determined for ourselves through the Fundraising Summit in February and the action of our Board in passing the Resource Development Program in May. We’re now on our way!

But there are many and important choices left before us. These choices involve each and every member of the CHS and its chapters right across our country. Each of us can choose to participate in a destiny of strength and dynamism. This will require hard work – the kind of effort that we put into securing a safer blood system for Canada. We’ve done it before, we can do it again.

But our lack of participation in future fundraising initiatives is also a choice. With the constant menace of reduced care lurking around every bend of increased health costs, it would only be a matter of time before we’re compromised. All you need is to look at the lack of care around the world. In many countries children with severe hemophilia never see their eighteenth birthday. That destiny is frightening!

We need public sources of financial support to insure our volunteers and staff have the resources needed to keep up the fight for proper care. If we await a destiny brought on through apathy and complacency, lulled into a false security by our current good care, when the time for action comes, our strength will have atrophied into helplessness. Tragic!

I have a strong belief in the power of our society – not the institution, but the people. We are the Canadian Hemophilia SOCIETY. A “society” is a voluntary association of people dedicated to a common purpose. Our purpose is to improve the quality of life for all people with hemophilia or other inherited bleeding disorders and to find a cure. As we come together in one strong organization, we can take our destiny into our own hands and create the strength we need for all those with bleeding disorders and for those yet to be born.

It is this strength we hope to lend to the South African Hemophilia Foundation (SAHF) through a twinning partnership. Pam Wilton has written an account of our assessment visit. We hope to help the SAHF with a strategic planning initiative that will re-energize volunteer involvement. Their presence with us is a glaring reminder that our strength can mean better care not only for our own population, but also for those in the bleeding disorder community around the world. Although South Africa has a comparatively good level of care, they, too, must be vigilant in keeping up their own fight for continued and improved levels of care. Remember, 75% of people with hemophilia have no access to treatment with modern concentrates. By our helping South Africa, they can lend their strength to other African countries where care is deeply compromised.

So, our volunteer work is both deeply satisfying and calls forth full engagement. When the call comes to be involved in fundraising efforts, be sure to show up with enthusiasm and hopefulness. Then we’ll ensure a bright and promising destiny!

FROM THE EXECUTIVE DIRECTOR

A new vision for the CHS?

If I were to ask you “What do you think has been the greatest accomplishment of the CHS in its history?”, you would perhaps choose the compensation programs for people infected with HIV or HCV. Or maybe the creation of a new and safer blood system in Canada. Or universal access to the best treatment products. Or the establishment of the 25 clinics specializing in hemophilia across Canada. As the CHS achievements have been numerous, there would probably be many different answers.

Now what if I were to ask you to imagine what you think the most important accomplishment of the CHS will be in the decades to come? Maybe you’d talk about improved treatment. Or better access to care for people living in outlying areas. Or greater public awareness about our cause. You might answer, increased and fairer compensation programs. Or stronger international aid for the hemophilia community. Many would answer, a cure.

Over the next few months, we’ll be asking ourselves a lot of questions like these. Questions that are fundamental and that will define the future of our organization. Questions that will help us evaluate our successes and our strengths. Questions that will make us think about our future.

You may be asked to take part in this process that we’re presently establishing. In fact, we’d like to offer as many people as possible the opportunity to share their history, their successes and their dreams. We want to build the future of the CHS on the ideas you and all people affected by bleeding disorders will be sharing.

This consultation process is part of strategic planning. And the objective is to identify a vision that we can all share. This vision will be important because it will serve as a roadmap for all our efforts. It will guide our actions, our investments and allow us to work quickly and efficiently to reach our goals. The process will soon be implemented and will culminate with a national meeting on February 18th and 19th.

I’d like to thank you all in advance for the time that you’ll be spending participating in this process. Above all, don’t hesitate to contact the CHS—at the national, chapter or regional levels—to let us know your ideas, your expectations and your dreams. In this way you’ll be contributing to the future of your organization and to the future of all families living with a bleeding disorder.
they can see it as soon as it is posted to the CHS web site.

Most respondents feel that Hemophilia Today is easily readable with good layout, excellent balance of text and photos and attractive colour scheme. Suggestions included a little more white space, lighter backgrounds behind text, and larger type and photos. We will make every attempt to achieve this while not sacrificing too much content.

Several readers suggested separate English and French editions to save paper and postage. In fact, Hemophilia Today is published bilingually because one print run is more economical, even with added postage. We also use the two-colour, rather than four-colour, format to cut costs.

And, most importantly, the content. The vast majority of respondents rated the different sections of Hemophilia Today as good, very interesting or extremely interesting. Many took the time to make suggestions. They included:

– A section for youth
– A feature article on a different clinic each issue
– A regular update from the different care teams (See Global Nursing Symposium on page 24)

The second announcement is now available at www.hemophilia2006.org. We hope that many members of the bleeding disorders community will take advantage of this unique educational opportunity and attend the Congress in Vancouver next May.

Several pre-congress sessions / workshops will be offered to all delegates on Sunday, May 21. These sessions will allow delegates to gain valuable skills and knowledge that they can integrate into their own work and communities once they return home. Although the sessions are free, pre-registration is highly recommended. Check the Congress web site regularly for further updates.

Each Congress day will begin with two plenary sessions led by some of the world’s most distinguished researchers, physicians and community leaders.

The balance of each of the four

continued on page 6
UPCOMING EVENTS

■ JANUARY 20 AND 21, 2006 - Toronto Central Ontario Region will have a booth with information sessions as part of the Women’s Health Matters Forum at the Toronto Metro Convention Centre. For more details, contact (416) 972-0641 or tcor@hemophilia.on.ca.

■ FEBRUARY 3-5, 2006 - The Network of Rare Blood Disorder Organizations, coordinated by CHS, will hold a conference entitled Comprehensive Care for Rare Blood Disorders in Toronto. For details on the programme and registration, see the home page of the CHS web site at www.hemophilia.ca/en/index.html.

■ FEBRUARY 18-19, 2006 - The CHS Strategic Planning Session, Toronto.

■ FEBRUARY - Toronto Central Ontario Region will host a Volunteer Appreciation Tea. For more details, contact (416) 972-0641 or tcor@hemophilia.on.ca.

■ MARCH 6-7, 2006 - Atlantic Region Hepatitis C Conference, Halifax, Nova Scotia. For more information, contact Jeff Rice at 1-800-668-2686 or jrice@hemophilia.ca.

■ MARCH 17-19, 2006 - Quebec Chapter will hold its annual Family Weekend and Annual General Meeting at L’Auberge Matawinie. Watch L’Écho du facteur for details.

■ MARCH – Toronto Central Ontario Region will host a Bowl-a-Thon. For more details, contact (416) 972-0641 or tcor@hemophilia.on.ca.

■ MARCH - Hemophilia Ontario will be hosting a community information forum on solid organ transplants for those who are HIV-positive or co-infected individuals. For more information, please contact Hemophilia Ontario’s office toll-free at 1-888-838-8846 or email sspink@hemophilia.on.ca.

■ SPRING, 2006 - The Third National Family Workshop for Families with Inhibitors will be held in Quebec. Watch the CHS web site for details at www.hemophilia.ca/en/index.html.


■ MAY 27-28, 2006 – CHS Annual General Meeting, Vancouver, B.C.

VANCOUVER 2006

World Congress continued from page 5

Congress days will be divided into three 90-minute concurrent sessions with 7 tracks, which will include state-of-the-art symposia, peer-reviewed abstract sessions and Meet the Experts sessions. Here are some highlights of the programme.

MEDICAL SESSIONS

Health care professionals and others attending this track will learn about the latest scientific developments and progress in research, diagnosis, treatment and care of people living with hemophilia and other bleeding disorders. The following are examples of topics which will be offered:

• Prophylaxis
• Pharmacokinetics and Pharmacoeconomics in Hemophilia Care
• Gyn/Ob Management of Women with Inherited Bleeding Disorders
• Blood Product Safety, Supply and Affordability
• Ethical Issues in Hemophilia
• Rare Bleeding Disorders
• Congenital Platelet Disorders
• Von Willebrand Disease – Clinical Management
• Novel Therapies for Hemophilia
• Current Issues in Immune Tolerance
• Understanding Why and When Inhibitors Develop

MULTIDISCIPLINARY SESSIONS

The Multidisciplinary track will include topics of special interest to a wide range of people, including members of national hemophilia organizations, nurses, social workers, physicians, physiotherapists and psychologists. The sessions will explore psychosocial issues, socio-economic issues, and access to care and care delivery issues. By attending the sessions in this track, you will learn about:

• Implementing National Models of Care Through the WFH Global Alliance for Progress
• Musculoskeletal Issues Through the Generations
• Strategies to Introduce, Maintain or Improve Hemophilia Care

• Psychosocial Issues Related to HIV/HCV Infection
• Strategies for Easing the Socio-Economic Impact of Bleeding Disorders on Families
• Treatment of Inhibitors from a Multidisciplinary Perspective
• Pain Management for Children and Adults
• Patient/Healthcare Provider Relationships
• Women’s Concerns Around Their Own Bleeding Disorders

MUSCULOSKELETAL SESSIONS

This track is designed to encompass a broad spectrum of treatment and methods of managing musculoskeletal complications of hemophilia. Congress 2006 will offer topics such as:

• Tissue Engineering and Bone Substitutes
• Diagnostic Imaging
• Sports and Activity Selection
• Surgical Management
• Physiotherapy Assessment and Treatment

CAPACITY BUILDING SESSIONS

Targeted to the hemophilia community and people working in patient organizations worldwide, the Capacity Building Sessions will feature:

• Recruitment of Young People into National Member Organizations
• Building Alliances Outside the Bleeding Disorders Community/Integrating New Patient Populations
• Opportunities and Challenges in Building Strong National Member Organizations
• Fundraising Strategies in a Competitive Environment

DENTAL SESSIONS

You will learn about the latest advances and new approaches in dental care for hemophilia patients by attending the Oral Surgery Based Problems and Restorative Dentistry sessions.
LABORATORY SCIENCE SESSIONS
This track will feature presentations on quality assurance, laboratory diagnosis including genetic testing, as well as experiences of laboratory diagnosis in developing countries.

For more information on the program or to register for the Congress, please do not hesitate to visit the Congress website at: www.hemophilia2006.org.

HOW TO GET THERE!
The Congress air travel provider, Uniglobe Advance Travel, is a leading travel management company located in Vancouver. Uniglobe offers the experience and ability to successfully manage the airline needs for the congress. In conjunction with Uniglobe, the WFH plans to negotiate congress air programs with several airlines. Uniglobe will ensure that the delegates receive the lowest available airfares. For quotations on airfares to Vancouver or to benefit from negotiated discount rates, CONTACT Uniglobe Advance Travel directly at Airdesk@uniglobe-advance.com or by phone at 1-888-221-5221 and make sure to mention that you are attending the Hemophilia 2006 World Congress.

EXPERIENCE THE INSIDE PASSAGE AND SPECTACULAR GLACIER WILDERNESS WHERE EAGLES AND WHALES ROAM FREE
Expect the unexpected – a massive glacier calves, a bald eagle soars above, a humpback whale clears the water and the night sky awakens to waves of colour. The only thing predictable about a Holland America premier, week-long Alaska cruise is exquisite service, exciting excursions and a magnificent transport through the last great wilderness. And at the end of each day’s adventure, your cruise ship is waiting with fine dining, dazzling entertainment and luxurious accommodations. There is no better way to experience Alaska than with Holland America Line.

7-Day Glacier Bay Inside Passage Sailing Date: May 14, 2005
Ship: Holland America – ms Ryndam Roundtrip sailing from Vancouver. Arrive back with sufficient time to attend WFH Congress Opening

Prices from: $1043.00, plus $70.00 port charges

Sign your friends, family and colleagues up for a spectacular 7-day Alaska cruise and reap monetary rewards.

• Become a Group Cruise Leader and profit from spreading the word about our fabulous 7-day cruise. You’ll not only benefit personally but also raise money to support the CHS and the WFH.

• The secrets of success: Book two people on the cruise and you’ve reached the entry requirement to become a cruise group leader. For every additional person you book on the cruise after becoming a group leader, you’ll receive $50 (CAN).

We’ll provide you with promotional materials to support your efforts.

For more information or to register as a group leader, contact Johanne Lambert at the WFH (514) 394-2835 or jlambert@wfh.org.

Vancouver is nestled between the rugged Coastal Range Mountains and the brilliant blue Pacific Ocean. It has been described as one of the most spectacularly situated cities on earth. Don’t miss it!
turn to John Plater because of our confidence that he will effectively represent the CHS and the interests of persons with bleeding disorders. As further confirmation of the well-deserved regard in which he is held, John Plater was made an Honorary Life Member of Hemophilia Ontario, and was recognized by CHS with the Frank Schnabel Award as well as being presented with the Queen Elizabeth II Jubilee medal. Through his exceptional leadership and devotion to CHS over many years, John has already shown that he is a life member of the organization and it is very fitting that we should now make it official.

**Frank Schnabel Award**

This award was initiated to honour the outstanding service of Frank Schnabel, the founder of the Canadian Hemophilia Society, for his valued role in the growth and development of the CHS, the education of and care of hemophiliacs, and the education of the public regarding hemophilia needs. The award is presented in his name to honour a volunteer who, over a number of years, has rendered distinguished services and noteworthy contributions to the mission and objectives of the Canadian Hemophilia Society.

When her son was diagnosed with severe hemophilia twenty years ago, Pam immediately got involved in projects that embody all the objectives for which this award was created, working to develop educational and support services for people in the bleeding disorders community, as well as better treatment for all. Pam has sat on various boards and committees over the years at the regional (South Western Ontario Region, or SWOR), provincial (Hemophilia Ontario) and national (CHS) levels, and continues to do so. She served as Regional Chair of the SWOR region for at least 6 years and has been a member of the Hemophilia Ontario Board for over 10 years. She has been a delegate for Ontario on the National Board for over 10 years and has been Vice-President of Programs and a member of the Executive Committee and chaired the Program Committee for 8 years. She served as Co-Chair of the Standards of Care Committee at the National level and is currently a CHS representative on the AH CDC.

**Honorary Life Membership Award**

This award is given for exceptional leadership and devotion to the CHS over many years, particularly at the CHS Board level, to further the growth and development of the mission and objectives of the CHS, the development of public recognition of the CHS and its goals at the National and Chapter levels.

John Plater has contributed almost twenty years of dedicated leadership in support of the CHS mission and objectives at all levels of the organization. After years of service on local and provincial boards, he became the youngest President of Hemophilia Ontario in 1991 and accepted to take on this position again in 2001-2003 and 2004-2006. John has served on the National Board for the past 14 years and has held many positions on the CHS Executive Committee. He has also served as chair of the CHS HIV/HCV Task Force for many years. When CHS needed an effective public advocate at any level of the organization, on a range of issues, it has more often than not turned to John Plater because of our confidence that he will effectively represent the CHS and the interests of persons with bleeding disorders. As further confirmation of the well-deserved regard in which he is held, John Plater was made an Honorary Life Member of Hemophilia Ontario, and was recognized by CHS with the Frank Schnabel Award as well as being presented with the Queen Elizabeth II Jubilee medal. Through his exceptional leadership and devotion to CHS over many years, John has already shown that he is a life member of the organization and it is very fitting that we should now make it official.

**Chapter Leadership Award**

This award is given to an individual who has merited special national recognition for having provided exceptional leadership and devotion to a specific CHS chapter over many years and for outstanding efforts to further the growth and development of the chapter.

François joined the CHSQ in 1993 and immediately put his journalism skills to work by reviving the chapter newsletter. He is still editor-in-chief, writing articles and doing the layout and editing. He is also the Editor of Hemophilia Today, the CHS national newsmagazine.

François joined the Board of Directors of the Quebec Chapter in 1996 and has served twice as president and recently returned to serve as First Vice-President. He was a Quebec delegate to the National Board for two years. François served as CHSQ Interim Executive Director for one year as a volunteer and he played a key role in the eventual hiring of the E.D. and other chapter staff. He is a member of numerous committees including Governance, Programs and is responsible for the Communications and the Comprehensive Care Committees.

He has participated in the chapter’s International Twinning projects and travelled to Senegal and Tunisia during assessment visits. He has played an active role in advocacy efforts for HCV compensation and indexation of MPTAP benefits. As Chair of the Comprehensive Care Committee he is currently working for changes to the redistribution of blood product budgets in Quebec that threaten the expert care of hemophiliacs in Quebec. He is the official spokesperson for CHSQ whenever there is contact with the media. François has been actively involved in the Quebec Chapter for ten years and has worked tirelessly for the cause of people with bleeding disorders. His dedication, integrity and talents have brought the Quebec Chapter through many difficult moments.
**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 other inherited bleeding disorders. It is named after the late Dr. Cecil Harris, in recognition of his contribution as one of the pioneers in the care and treatment of hemophiliacs in Canada.

As Director of the Pediatric Hemophilia Clinic at the Health Sciences Centre in Winnipeg, Dr. Sara Israels has been providing care for patients with bleeding disorders since 1993. Over the years she has been involved with the CHS both provincially and nationally and has been a member of the CHS VWD Advisory Committee and the National Standards of Care Committee. She sat on the AHIDC executive committee from 1993 to 1997, and continues to contribute to the following sub-committees: prophylaxis, women and bleeding disorders, standards of care, and von Willebrand disease. She has also participated in and presented at almost every CHS medical symposium over the past 11 years. Provincially, Dr. Israels has always been a champion for the Manitoba Chapter and has been tireless over the past years in her efforts to obtain the gold standard of care for patients with bleeding disorders in the province of Manitoba. Dr. Israels approached the provincial government with her proposal for a recognized provincial comprehensive care program for individuals with bleeding disorders in Manitoba and thanks to her efforts, a provincially funded program has been approved. Dr. Israels is kind, caring and considerate with her patients, supportive of her fellow care team members and has demonstrated outstanding leadership among her colleagues. She is most deserving of the Dr. Cecil Harris Award.

**Award of Appreciation**

This award honours an individual who has demonstrated outstanding service to the care of persons with inherited bleeding disorders.

**Jenny Aikenhead**

Physiotherapist, Alberta Children’s Hospital, Calgary, Alberta

Jenny has been employed at Alberta Children’s Hospital as a physiotherapist for 17 years and for the past 10 years assigned to the Bleeding Disorders Clinic. Recently she was assigned to a different caseload. Over the years, Jenny has been an active participant in the Canadian physiotherapy group, now known as Canadian Physiotherapists in Hemophilia Care, generating many good ideas and helping to mentor the new therapists. She was a member of the working group that produced the resource binder for Canadian physiotherapists which is now used in all HTCs. Jenny was also one of the first physical therapists to tackle a clinical research question. In 2003, Jenny served as a mentor to a visiting physical medicine specialist from Tianjin, China and shared her clinical skills and knowledge and made suggestions for the program development in China. Recently she helped develop a patient education brochure on radioactive synovectomy. Jenny participated in the CHS Pain Management Working Group and contributed a chapter to the new publication, Pain: the Fifth Vital Sign. She will be sorely missed in Calgary and by her peers in CPHC.

**Rose Jacobson, R.N.**

Nurse Coordinator, Health Sciences Centre, Winnipeg, Manitoba

Rose was originally trained as an ER Nurse and was cross-trained to provide care for children and adults with a bleeding disorder at HSC in Winnipeg in 1996. Within the program Rose is responsible for educating nursing staff in the management of patients with bleeding disorders. She is also responsible for assisting patients make the transition from hospital-managed care to home care by providing support, education and supervision in the home setting. Over the years, Rose has made a large professional contribution to the education of health care professionals in relation to bleeding disorders. In 2002-2003 she participated on the National ER Advisory Committee and has presented at an educational session via Tele-Health for health care professionals and providers in rural and urban areas of Manitoba. Rose is a reliable volunteer for the Manitoba Chapter and for the past seven years has volunteered as camp nurse at the week-long summer Family Camp. She is very deserving of the Award of Appreciation in recognition of her exceptional contributions to the bleeding disorders community.

**Jennifer Crump, R.N.**

Former Nurse Coordinator, London, Ontario

Jennifer Crump is one of those ’70s “hemophilia moms” who began her service to the Hemophilia Society at her kitchen table, where she and her husband worked with other parents to better understand their sons’ condition and to improve their care. She went on to become Chair of the Central Western Ontario Region and eventually served as a Vice-President at Hemophilia Ontario. Jennifer returned to school and graduated as a nurse in 1983. Dr. Martin Inwood hired her to work as the nurse coordinator in the South Western Ontario Regional Hemophilia Program. Jennifer was hired to work “part-time”, but she made herself available on a full-time basis to provide care to patients and support to the Program and she went beyond the “call of duty” all of the time. Jennifer became an essential part of a world-class hemophilia treatment centre, which provided leadership and mentoring to clinics throughout Northern Ontario and Manitoba and around the globe. Patients, families and health care providers in SWOR remember Jennifer’s professionalism, leadership, strength and courage that helped many of them through the darkest days of hemophilia care. Although Jennifer transferred to the Neonatal Intensive Care Unit at St. Joe’s in 1988, she has continued to serve as a volunteer, sharing her expertise and supporting others in the bleeding disorders community.

**Michelle Hendry**

Lab Technologist, St. John’s, Newfoundland

Michelle Hendry has made a career for over 20 years helping people in Newfoundland and Labrador who suffer from genetic bleeding disorders. Michelle has assisted in research and traveled to all parts of Newfoundland and Labrador to determine the true extent of the problem in the province. She also travels with the clinic outreach program and provides the expertise that is required to carefully collect, prepare and analyze blood samples. Much of the time spent outside the lab is on her own time, unpaid and volunteered. Recently, she was credited with saving a child’s life. A child presented at the continued on page 10
children’s hospital with bleeding issues but all blood work came back negative and no diagnosis was made. Because the child lived in what Michelle knew was a high prevalence area, she took it upon herself to perform some additional tests. Her work led to a diagnosis and the child remained in hospital to receive the proper treatment. If the child had been allowed to be discharged and sent home, the outcome would surely have been tragic. The work performed, provided and volunteered by Michelle is more than worthy of appreciation.

**Pierre Latreille Award**

This award for excellence is given to a staff member of the CHS working at either the national, chapter or regional level. The award winner is expected to show skills, patience, passion and accomplishments beyond normal duties, such as supporting volunteers and colleagues in their work, maintaining morale and showing a sense of humour under difficult circumstances, and showing others new ways to accomplish the mission of the CHS.

**Karen Olson**

Executive Director, Manitoba Chapter

Karen came to the Manitoba Chapter in 1990 as Secretary to the Executive Director. In 1995 she was awarded the title of Program and Services Director and has been working in the capacity of an Executive Director since that time. Karen is committed to the success of all chapter activities. She is responsible for directing programming and some fundraising. She participates as a volunteer on all member-initiated fundraising ventures and activities. She comes to meetings that are held in off-hours and will work on weekends and evenings to see that activities run smoothly. Karen is always working towards improving the chapter. She spurred the chapter on to strategic planning sessions in 2002 and 2005 and has created the awards programs, committee guidelines, and many other tools that the Manitoba Board uses. Most recently she created the outline for doing an in-house needs assessment. Karen’s most recent professional and personal achievement is to have successfully lobbied the Manitoba Government to index the MPTAP to the cost of living for Manitobans. Karen’s level of commitment to her job and to the members is overwhelming. She is very knowledgeable about all aspects of living with a bleeding disorder because she listens to the members, asks questions and offers to help. She is very deserving of the Pierre Latreille Award.

**Chapter Recognition Awards**

This award is designed to recognize chapters who have demonstrated an achievement over the preceding year in a specific area such as fundraising, patient services, education, or chapter/regional development.

**Alberta Chapter**

Chapter Development

The Alberta Chapter made significant efforts in 2004 in terms of chapter development. In September 2004, the chapter changed its governance structure to enable the two regions, Northern Alberta Region (Edmonton) and Southern Alberta Region (Calgary), to work together more cohesively. With the new structure the chapter now has designated directors to the National Board from each region. The chapter is now governed by the treasurers from each region as well as the presidents or designated individuals. This executive committee is responsible for organizing the Annual General Meeting and allocating the grass roots funding for programs that are being delivered in each region.

**Manitoba Chapter**

Advocacy and Diversification of Funding

The Manitoba Chapter has worked very hard over a 10-year period to lobby the Manitoba government to fund an accredited bleeding disorders clinic in Manitoba. Thanks to the dedicated work of staff, board and members, the chapter learned in 2004 that funding will be in place in the 2005/2006 budget. In addition, advocacy efforts carried out by the chapter in 2004 regarding the indexation of MPTAP benefits to the cost of living have resulted in success.

Diversifying the funding base was a major focus for the Manitoba Chapter in 2004. Their largest source of funding over many years has been their bingo hall. The citywide smoking ban that was enforced in September 2003 has had a negative effect on revenue. In anticipation of this, the chapter organized two very large fundraising projects that proved to be hugely successful – an annual Golf Tournament and a Gala Dinner. Other fundraising initiatives, including a youth car wash, wiener roast fundraisers and the Puma Road Race, helped to raise public awareness and bring in additional revenue.

Editor’s note: The complete awards package, including past winners, is available on the CHS website at www.hemophilia.ca/en/11.5.php.

**Newfoundland & Labrador**

Government to index MPTAP income support

Norman Locke

Past President, Newfoundland & Labrador Chapter

ST. JOHN’S, NF, October 21, 2005 - The Newfoundland and Labrador Chapter of the Canadian Hemophilia Society (CHS) announced on October 21 that after many years of advocacy efforts on behalf of the Multi Provincial/Territorial Assistance Program (MPTAP) recipients in Newfoundland and Labrador, John Ottenheimer, provincial Minister of Health and Community Services, has agreed to immediately index to the cost of living benefits received by recipients under the MPTAP.

This decision recognizes the economic erosion and the injustice of failing to index this important income support program over the last 12 years. People from Newfoundland and Labrador, who are still living, and who were originally infected with HIV from tainted blood in the 1980s and 1990s, will see an immediate increase of $7,900 in their annual payments, with further indexing anticipated in subsequent years.

The province of Newfoundland and Labrador now joins Ontario and Manitoba in seeing this important income support indexed to the cost of living.

Members of the CHS from across Canada applaud the actions of the Government of Newfoundland and Labrador, and are increasingly hopeful that those provinces that have not yet decided to index MPTAP (British Columbia, Alberta, Saskatchewan, Quebec, New Brunswick and Prince Edward Island) and Nova Scotia, which has a separate compensation program, will soon follow Newfoundland and Labrador’s example.
The fight for MPTAP indexation in Manitoba

Karen Olson  
Executive Director, Manitoba Chapter

In June 2005 the Manitoba government announced it would index Multi-Provincial/Territorial Assistance Program (MPTAP) payments. Since the package was introduced in 1993, inflation has decreased the value and spending power of the $30,000 yearly payment by approximately 23%. For the handful of assistance recipients left in Manitoba, the announcement of MPTAP indexation resulted in an additional cheque this year in the amount of $7,370.

We began asking our government for MPTAP indexing in 1996 but unfortunately, due to other issues facing the Chapter, this issue was put aside. In 2003 Tony Tavares and Jimmy Love began urging the board to take up the fight again. It was thought that not asking for retroactive or estate payments would make the cost of indexing more palatable to government. We asked that MPTAP payments be indexed on a “go forward” basis.

We experienced many setbacks along the way, from the tragic loss of Jimmy Love, to several changes in Health Ministers. Then our file was handed to a newly createdportfolio, Office for Healthy Living, which also experienced several changes of Minister. Each time this happened it was like starting over again.

Years were spent asking for meetings, meetings were held, follow-up letters were sent but nothing moved forward... until January 2005. On January 21, 2005 several Chapter members and I attended a meeting with the Minister for Healthy Living, Theresa Oswald. That was the meeting when the personal and heartfelt stories told by Tony Tavares and another member caught the ear and heart of government. Minister Oswald pledged to do what she could to help us and pledged to do it in a timely manner. It took six more months of letters (sometimes weekly), phone calls (sometimes daily) to the Minister’s office. The Minister’s assistant patiently explained to me all the complicated but necessary government channels that the request had to travel through before it could be approved, and what its current status was. On June 9, 2005 Minister Oswald personally phoned me to tell me the good news. She then proceeded to call Tony and several others who had been involved. By mid-August, cheques had been issued.

It is a relief to know that after all these years the remaining individuals and their families will now realize some financial comfort from MPTAP indexation. The Manitoba Chapter’s board has pledged its support to help other Chapters move this issue forward in their provinces. Many thanks to the Manitoba Chapter, CHS-National HIV/HCV Task Force, Tony Tavares, the late Jimmy Love, and all those who worked behind the scenes to make this happen.

Memorandum of Understanding marks progress in Hepatitis C compensation discussions

OTTAWA, Nov. 18 - Health Minister Ujjal Dosanjh and legal representatives for individuals infected by the Hepatitis C virus through the blood system before 1986 and after July 1, 1990, today announced that they have signed a Memorandum of Understanding (MOU) committing the federal government to provide compensation to those individuals. Discussions will continue as both sides negotiate the amounts and categories of compensation.

On November 22, 2004, Minister Dosanjh announced the launch of discussions to explore options for financial compensation to the pre-1986/post-1990 class. The discussions began immediately and both the federal government and legal representatives for the class have been working diligently to resolve the complex issues surrounding compensation.

Over the past year, the Government of Canada and legal representatives of the pre-1986/post-1990 class have made progress in their discussions on options for compensation. This commitment to compensate is an important step in advancing compensation discussions further.

“The Government of Canada recognizes the tremendous burden Hepatitis C places on the lives of people infected and on the lives of their families,” said Minister Dosanjh. “By entering into this MOU, both sides have made a clear commitment to the ongoing negotiation process. The federal government will compensate the pre-1986/post-1990 class because it is the right and responsible thing to do.”

Discussions are now at the point where finalizing the settlement is dependent upon both sides obtaining additional information as to the current size of the class, their current health status and the likely progression of the disease in the class. It is expected that the process of obtaining the necessary information and concluding the negotiations will require a minimum of several months.

The federal government and class counsel recognize there are people awaiting an outcome. The MOU is evidence of their commitment to concluding the discussions as soon as possible once the appropriate information is available.

Both sides will continue their discussions over the coming months to negotiate amounts and categories of compensation recognizing the actual and legal circumstances of the claimants.

Claimants do not have to take any steps at the moment. A further announcement will be made once a settlement agreement has been concluded to advise claimants what they need to do to apply.

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Media Enquiries: Adèle Blanchard, Office of Minister Dosanjh, Minister of Health,  
(613) 957-0200; Public Enquiries:  
(613) 957-2991, 1-866-225-0709; Health Canada news releases are available on the Internet at www.media.health-canada.net.
What’s new on the CHS web site?

- A whole new section called “Support us” showing how people can support the work of the Canadian Hemophilia Society: [www.hemophilia.ca/en/1.4.0.php](http://www.hemophilia.ca/en/1.4.0.php)
- A new section to describe the National Corporate Sponsorship Program: [www.hemophilia.ca/en/1.7.php](http://www.hemophilia.ca/en/1.7.php)
- Summaries of the research projects funded in 2005 through the... [www.hemophilia.ca/en/3.1.php](http://www.hemophilia.ca/en/3.1.php)

New publications

Guidelines Published by the Society of Obstetricians and Gynaecologists of Canada (SOGC)

SOGC Clinical Practice Guidelines on the Gynaecological and Obstetric Management of Women with Inherited Bleeding Disorders were published in the July, 2005 issue of the Journal of Obstetrics and Gynaecology Canada. Publication of these guidelines was one of the key recommendations arising from the 2003 1st Canadian State of the Art Conference on von Willebrand Disease organized by the Canadian Hemophilia Society. The CHS would like to acknowledge the authors: Drs. Christine Demers, Michele David, Christine Derzko and Joanne Douglas whose expertise and efforts made this achievement possible. The guidelines are available in PDF format on the CHS website at [www.hemophilia.ca/en/13.1.php](http://www.hemophilia.ca/en/13.1.php).

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Book review

David Page

Dying in Vein: Blood, Deception… Justice

Photographs by Kathy Seward MacKay, text by Stacy Milbouer and Foreword by Donald P. Francis, M.D., formerly at the U.S. Centers for Disease Control, this is the first book I’ve seen that focuses on the people and the faces of the tragedy, rather than on the story of how this happened. This is not surprising, given that Ms. MacKay, a documentary photographer by trade, lost her husband, to whom the book is dedicated, to tainted blood in 1997. And the faces, present on almost every page, are compelling. As are the stories of approximately 75 people and their families.

While the stories of the people and their search for justice are essentially American, the book is not without its links to Canada. The chapter entitled The Warriors depicts some well-known Canadians from the hemophilia community demonstrating in Washington.


books@hollispublishing.com
NEWFOUNDLAND AND LABRADOR CHAPTER FAMILY CAMP

“One of the best,” exclaimed all at this summer’s Family Weekend. This year the weather did cooperate and everyone had a wonderful time. We would like to thank everyone who came and helped to make this weekend such a success. As well, we would like to thank everyone who donated prizes. A special thank-you goes out to Dr. Scully and Marilyn Harvey for making the trip out and presenting. Also we acknowledge Bayer and Baxter who not only sent representatives to present but also helped financially.

NOVA SCOTIA CHAPTER ADVENTURE CAMP AND FAMILY WEEKEND

The summer of 2005 marked a milestone in the Nova Scotia Chapter for children with bleeding disorders. After years of hard work, chapter members and pharmaceutical partners organized the first Summer Camp exclusively for children and families living with a bleeding disorder. From August 21 to 28, members took part in a memorable camp experience that paved the way for years to come.

On Sunday August 21, the kids left the IWK for what was to be a fun-filled week at Adventure Camp 2005. The week was filled with various well-planned activities that gave the kids a chance to let loose and enjoy the great outdoors.

The Family Weekend also turned out to be a positive experience for family members. On Friday, several families arrived to meet the children and take part in the two last days of camp. Those who decided to participate in the weekend truly enjoyed their stay! Many made new acquaintances and shared experiences, information and knowledge about living with someone who has hemophilia.

For all the participants Adventure Camp 2005 was a great experience and the provincial chapter is looking forward to repeating the event next year. Our thanks to staff members, the organizing committee and all the kids who participated in this memorable week. Also, a very special thank you to our pharmaceutical partners for making this weekend possible.

QUEBEC CHAPTER’S SECOND WEEKEND FOR FAMILIES LIVING WITH INHIBITORS

Seven families dealing with inhibitors gathered at the Manoir des Sables in Orford, in the Eastern Townships of Quebec on October 15 and 16 to share two days of workshops, meetings and family fun.

The plan for this weekend, based on recommendations from participants the year before, was to alternate workshops with leisure time. On the first day, parents got to learn more about the effects of joint immobilization from Nichan Zourikian, physiotherapist at Sainte Justine’s Hospital, and to ask him questions. Then they joined their kids and the employees and volunteers from the CHSQ for a visit to the Capelton Mines, fully equipped with safety helmets. After a family swim in the pool, the whole group danced the evening away to the rhythm of music that charmed both young and old.

The next day, parents gathered once again for a group discussion on overprotection led by psychologist Hélène Paré. During this time, the children made Halloween crafts or went swimming under the watchful eyes of volunteers, facilitators and Sylvie Lacroix, nurse coordinator from the Quebec Inhibitor Reference Centre, which is actively involved in the organization of this activity.

Following this weekend that was filled with all kinds of sharing, but lacking in sunshine (!), evaluations were very positive, encouraging us to make plans for another inhibitor family weekend in the autumn of 2006. The families really enjoy getting together and parents are able to leave their children in total confidence, allowing them to fully participate in the workshops that are offered. It also permits us, as an organization, to better understand the problems that these families encounter and think about ways to help improve their quality of life.

CENTRAL WESTERN ONTARIO REGION (CWOR)

CWOR hosted its first annual golf tournament in October. The tournament had 32 participants and raised $1200 for the region. The region has already begun to plan for next year’s tournament which will be even larger and held in July.

In December, the region will also be holding a Red Day in local schools within their community. Children and teachers will be asked to contribute two dollars and will receive a bookmark as thanks. Local volunteers and the Regional Service Coordinator will also speak in the schools to help educate staff and students on bleeding disorders.
SOUTHERN ONTARIO REGION (SWOR)

SWOR hosted its 13th annual summer camp, Pinecrest Adventures, from August 24-28. Pinecrest is a five-day live-in camp for children with bleeding disorders and their siblings. This year’s theme was Prehistoric Pinecrest, dedicating the entire week to dinosaurs!

In fundraising news, SWOR’s Chuck Catton, father of 2-year-old Aidan Catton, hosted a seminar for homeowners on how to build their own water garden. In addition to the seminar, the Cattons also hosted a fundraising BBQ, raising $1200 for SWOR! ▶️

Aidan enjoys playing in his new waterfall, a fundraiser organized by SWOR.

TORONTO CENTRAL ONTARIO REGION (TCOR)

On October 17, TCOR hosted its successful, first-ever Transition Program Orientation Evening. The goal of the evening was to alleviate stress for both parents and youth who were making the transition from The Hospital for Sick Children to St. Michael’s Hospital.

The Toronto Marathon/Hemophilia Ontario Families in Motion took place on October 16. The event was extremely fun and successful. TCOR would like to send big thanks to all of those who raised pledges, ran, walked or volunteered at the finish line and the water table! ▶️

Meghan Cox, TCOR Regional Service Coordinator; Susan Janakovic, Bayer Sponsor; and Bill Wade, TCOR board member.

CWOR AND SWOR

The two regions hosted a joint Just the Guys weekend on October 14 for boys 5 to 15 years of age with bleeding disorders and their male role models. The event was held at Camp Ki-Wa-Y Outdoor Centre just outside St. Clements, Ontario. Despite the chilly air, fifteen adults and twenty-one children participated. ▶️

Paolo Ciccaglione, CWOR ▶️

High Ropes ▼️

Low Ropes Course and Rock Wall▼️

Emrik and Gary Burrows, SWOR

Kay Decker and Kelsey Erwin, CWOR
**MANITOBA “CHARTS ITS COURSE”**

October 11, 2005 marked the beginning of the Passport to Well-Being program for the Manitoba Chapter. Eleven chapter families came out for an information evening that included the “Charting Your Course” component of the program. Nurse co-coordinator Nora Schwetz guided the members through the PowerPoint presentation and the booklet. Members were particularly interested in how recalls and quarantines work, and about CHARMS. Thanks to Cory Prestayko who built the Passport booth for us. The members really enjoyed having the booth here and Cory had the honour of stamping the Passports following the presentation.

**SASKATCHEWAN CHAPTER “SELF CARE WORKSHOP”**

On Saturday, August 20-21, Hemophilia Saskatchewan held its first “Self Care Workshop,” a day of education and fun designed to help kids with bleeding disorders become more independent and more involved in taking responsibility for their own health care. On the Sunday, Hemophilia Saskatchewan parents, Daryn and Celena Moody, launched the Step By Step program by presenting an overview of the program, including live Internet demonstrations of the Parent to Parent and Forum sections of the website and the signup of some new parents from our region!

**ALBERTA CHAPTER**

On September 9–11, 2005, the Alberta Chapter hosted its Family Weekend and Annual General Meeting in Goldeye, Alberta.

**StepbyStep**

Canada. Overall the event was a huge success! It brought patients in our area together, most for the first time. It allowed families who felt isolated because of hemophilia to realize they are not alone. It created a safe atmosphere for the exchange of information, stories, and the ability to celebrate successes. And it granted the opportunity to formally recognize the incredible team of medical staff that exists in our community. “Thank you to the Alberta Chapter of the CHS and Bayer Canada for sponsoring this event and giving us a great foundation to build on.”

**Medicine Hat and Area Parents Launch Hemophilia Support Group!**

On September 17, 2005, Patients, parents, and medical staff from Medicine Hat and the surrounding area stepped out for lunch on Saturday to celebrate the inaugural event for the Medicine Hat and Area Families with Bleeding Disorders. In all, 30 people, some from as far away as Lethbridge, attended the catered luncheon, which was served in the Fireside Room at the Medicine Hat Exhibition and Stampede. The itinerary included joint presentations by Bayer Pharmaceuticals and the Calgary Hemophilia Clinic. The day wrapped up with a presentation from former Saskatchewan Chapter President Clara Penner and Lori Watt on the CHS Step-by-Step program. Patients received their just-released Step-by-Step kits and learned how they can link with other families across Canada.
The Canadian Hemophilia Society currently runs three research programs:

The CHS Research Program, funded in equal parts by the Hemophilia Research Million Dollar Club and the CHS
www.hemophilia.ca/en/3.1.php

The Care Until Cure Research Program, funded by Wyeth Pharmaceuticals
www.hemophilia.ca/en/3.2.php

The Novo Nordisk Canada Inc., Canadian Hemophilia Society and Association of Hemophilia Clinic Directors of Canada Fellowship in Congenital and Acquired Bleeding Disorders, funded by Novo Nordisk Canada, Inc.

The following pages provide short summaries of the research projects funded in 2005. They are selected through a competitive grant application and review process, chaired by Dr. Patricia McCusker, pediatric hematologist and member of the hemophilia treatment team in Winnipeg, Manitoba.

Readers can also read the latest news from the Hemophilia Research Million Dollar Club and review the names of those people who have made valuable contributions to this endowment over the years (see facing page).
HEMOPHILIA TODAY FALL 2005

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Ken, Darlene and Tony Poyser
Terry Douglas
Lynne Kahn & Family
C. Kang Tan
Mr. and Mrs. Joe Laxdal
Audrey Irene Sagner
Poyer, Schultz & Glass
Hemophilia Ontario
Hemophilia Manitoba
In Memoriam
Northern Alberta Region
Toronto & Central Ontario Region
Ray & Helen Poyer
Nova Scotia Chapter
Central Western Ontario Region
British Columbia Chapter
Dr. and Mrs. Ron George
Desharnais-Pepin Family
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Estate of Mary Jan Olson
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Poyer, O'Shaughnessy & CHS
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Ian & Gail Austin (Jay & Bin Austin)
Canadian Hemophilia Society
Ontario & Eastern Ontario Region
South Western Ontario Region
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Frank Bott & Family
(In Memory of Gregory Bott)*
Jamie Hill*
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Dr. David Llacrap*
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and Guy Jenvey*
Northern Alberta Region
British Columbia Chapter
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Catherine Hordons
(In Memory of Andrea J. Hordons)*
Volunteers from the 1st Annual Road Hockey Tournament (In Honor of Trevor Sauve and Jamie Villeneuve)*
Friends and Family of Marjorie Calderwood
(In Memory of Marjorie Calderwood)*

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Lorraine Berner and her Team
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In Memory of Martin Bott
In Memory of Ann Louis Brown
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DONORS*

The following represent general donations, and those made in honor of Mary MacLeod, and Marjorie Calderwoods, and in memory of R. Andrew, Norman Boswell, Martin Bott, George Forben-Bentley, John Fulton, Joaquim Hime, René spokesperson, Dr. Ron Burke, Hélène Bourgade and Norman Lincoln.

Valerie Alexander and Greg Rumpel
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Carole & Dan Young

* These donors represent contributions made during our current campaign (2000-2005).
Supporting research towards improving the quality of life for persons with hemophilia and finding a cure have been goals of the Canadian Hemophilia Society (CHS) since it was founded in 1953. Since 1989, through funds provided by the Hemophilia Research Million Dollar Club and the CHS, the Society provides basic scientific research grants and studentships aimed at developing treatments for hemophilia and finding a cure. The following reports describe the projects funded in 2005.

**Genetic Differences between Obligate Carriers of Type 3 VWD and Individuals with Type 1 VWD**

**1st YEAR FUNDING**

Dr. Paula James  
Queen's University, Kingston, Ontario  
CHS Research Program

Von Willebrand disease (VWD) is the most common known inherited bleeding disorder in humans, affecting as many as 1% of the population. People with VWD have difficulty with bleeding from mucous membranes such as the nose, mouth or lining of the uterus, or can have problems with bleeding after injuries, dental work or surgical procedures. There are 3 subtypes: Type 1 VWD is the most common and least severe and is caused by a mild to moderate deficiency of a blood clotting factor called von Willebrand factor (VWF). Type 3 VWD is the least common and most severe and is caused by a severe deficiency of VWF. Type 2 VWD is caused by VWF that doesn’t function properly. Type 1 VWD is inherited from one parent while Type 3 VWD is inherited from both parents. In this study, entitled *Genetic Differences Between Obligate Carriers of Type 3 VWD and Individuals with Type 1 VWD*, we are interested in examining the genetic changes in VWD. A person affected with Type 1 VWD would have inherited it from one parent, while a person affected with Type 3 VWD must have inherited it from both parents. A parent of an individual with Type 3 VWD is usually not affected by any bleeding problem and is referred to as a “carrier”. By using special techniques that allow us to examine an individual’s genetic make-up, we hope to improve our understanding of the types of genetic changes that might lead to Type 1 VWD and those that would lead to being a carrier for Type 3 VWD.

**Fibrinolytic Variables in Severe Hemophilic A Patients**

**2nd YEAR FUNDING**

Dr. Jerome Teitel  
St. Michael’s Hospital, Toronto  
CHS Research Program

The bleeding tendency of people with severe hemophilia varies considerably. This can be explained by differences in levels of their deficient proteins (clotting factor VIII or IX) which are too small to be easily measurable. We think that an additional source of variability could lie in fibrinolysis, the process by which blood clots dissolve. Severe hemophilia patients who have rapid fibrinolysis (clots that dissolve quickly) might tend to bleed more severely than others. In this project, we propose to conduct a thorough and systematic study to test the hypothesis that the bleeding tendency in severe hemophilia is correlated with increased fibrinolytic activity. We will measure the levels of four key blood proteins which contribute to fibrinolysis in 100 severe hemophilia patients. We will also monitor the number of bleeding episodes as well as the amount of factor VIII or IX concentrate that these patients have needed over the preceding 2 years. We will statistically determine whether increased values of the fibrinolytic proteins correlate with increased bleeding tendency, and vice versa. At the end of this project, we hope to better our understanding of why bleeding tendencies in severe hemophilia patients are variable. If our hypothesis is confirmed, we will be able to provide a novel rationale for individualized management approaches. These may include selecting target amounts of factor VIII or IX for treatment or prevention of bleeding in hemophilia patients. They may also include selecting patients for prophylaxis with clotting factor concurrently with factor VIII or IX replacement therapy, after surgery and other interventions. We may also be able to predict the risk of clotting of central venous catheters, a serious complication of prophylactic factor VIII or IX treatment in young children.
In this study we are planning to recruit 2 groups of women: 20 normal and 25 with an inherited bleeding disorder. The first objective of this study is to evaluate how the levels of coagulation factors vary over the course of pregnancy in both groups, and also to determine the rate with which these coagulation factors return to the baseline after delivery. Coagulation factors will be measured 3 times during pregnancy, at delivery and 4 times in the 4 weeks postpartum. We will try to coordinate this blood testing, whenever possible, with the regular testing of pregnancy.

Post-partum bleeding is very difficult to assess and at the present time there is no way of objectively measuring it. However, there is a graphical chart that has been extensively evaluated in women with heavy periods. The second objective of the study is to evaluate if a modified version of the chart is a useful tool to measure post partum bleeding. All women will complete the pictorial chart during the 4 weeks postpartum.

With this study, we hope that a better understanding of coagulation during and after pregnancy will result in a better management of pregnancy for women affected with inherited bleeding disorders.

Persons with severe hemophilia (clotting factor activity below 1%) tend to bleed frequently and spontaneously into joints, leading to disabling arthritis.

The current standard of treatment is regular, preventative factor concentrate infusion. This primary prophylaxis started at an early age improves quality of life but the treatment is intensive, representing a burden to those with hemophilia and their families. It is also expensive. Often, a device is implanted to facilitate infusion and this may be complicated by infection and thrombosis.

Among severely affected individuals, approximately 10-15% have milder than expected bleeding symptoms. It is important to identify these persons so that their treatment can be customized, avoiding unnecessary infusion. We believe that some severely affected persons have factor VIII in their blood, but below the 1% detectable by routine laboratory methods. Furthermore, in the ongoing Canadian Prophylaxis trial (Dr. Victor Blanchette), some severely affected need only once or twice weekly FVIII infusion – the FVIII levels would be below 1% for a period before the next infusion and yet appear protective.

The focus of this research is to develop a sensitive assay to accurately measure circulating factor VIII levels between 0 and 1%, based on measurement of the activity of the enzyme, thrombin, that develops in proportion to the level of FVIII activity present. Three aspects of hemophilia treatment will then be investigated with participation from clinics across Canada. First, we will measure FVIII activity in 200 severe hemophilia A persons at a time when they have not been treated for 5 days or more (or at diagnosis) to determine if their “baseline” FVIII levels have a bearing on when they had their first spontaneous joint bleeding. We will take into account whether the affected individuals have inherited other mutations thought to promote clotting despite very low FVIII
Vitamin C (ascorbic acid) plays a critical role in preventing bleeding by keeping blood vessel walls sturdy. There are currently no normal values for children. Establishing normal ranges is important to serve as a basis for future research trying to understand why some children bleed more than others, especially if they have other bleeding tendencies. Perhaps low vitamin C levels play a role. Prior attempts to measure vitamin C levels have been unreliable due to testing methods which were affected by diet, time of day and other factors. We will measure vitamin C levels from a type of blood cell called lymphocytes. Lymphocyte levels of vitamin C are more accurate and less subject to daily fluctuation. We have developed a High Performance Liquid Chromatography (HPLC) method for measuring lymphocyte vitamin C levels. Pilot testing using 50 samples showed that the test works very well. We will get specimens of blood from patients who are already getting a blood count test for other reasons. No extra blood or needle sticks need to be taken. Patients will be identified from Departments and Divisions at The Hospital for Sick Children who have patients who are likely not to suffer from conditions that influence vitamin C levels and who do not have a bleeding disorder. Parents will answer a brief questionnaire designed to identify dietary habits which might be affecting vitamin C levels.

After establishing normal age and gender related values for vitamin C in healthy children, we will apply to begin researching the possible role of unrecognized vitamin C deficiency in bleeding disorders and eye (retina) hemorrhage. We will measure vitamin C levels in children with bleeding disorders such as hemophilia, von Willebrand disease, and idiopathic thrombocytopenic purpura, comparing those children who have prominent bleeding problems to those who do not. Likewise, we will examine vitamin C levels in victims of Shaken Baby Syndrome and accidental head injury with and without retinal hemorrhages. Lastly, we will examine the effects of routine childhood immunization on vitamin C lymphocyte levels.

The role of vitamin C in preventing bleeding is critical, but understanding its levels in children with bleeding disorders is equally important. This fellowship will provide opportunities to prevent this effect.

The Novo Nordisk Canada Inc. – Canadian Hemophilia Society – Association of Hemophilia Clinic Directors of Canada Fellowship in Congenital and Acquired Bleeding Disorders

The Novo Nordisk Canada Inc. – Canadian Hemophilia Society – Association of Hemophilia Clinic Directors of Canada Fellowship in Congenital and Acquired Bleeding Disorders is a fellowship program established in the fall of 2001. Novo Nordisk has a leading position within areas such as coagulation disorders, and manufactures and markets pharmaceutical products and services that make a significant difference to patients, the medical profession and society.

The goal of this fellowship program is to provide fellows in hematology or other relevant fields the opportunity to acquire clinical or research skills necessary to improve the care and quality of lives of patients with hemophilia and other congenital or acquired bleeding disorders. The following report describes the project funded in 2005.

NOVO NORDISK FELLOWSHIP

Approaches to investigate the cause and management of acute toxicities associated with adenovirus-mediated gene therapy in Hemophilia A

Dr. Maha Othman
Queen’s University, Kingston, Ontario

Gene therapy is an attractive potential treatment for hemophilia A. The condition is due to mutations in a single, identified gene, the clinical picture is dramatically improved with a small increment of plasma FVIII levels and excellent animal models are available for preclinical testing. Replication deficient adenovirus is an efficient vehicle for liver-directed gene delivery. However, a major obstacle to the successful application of these vectors in humans has been the activation of the host immune and inflammatory response. These responses limit the efficiency of transduction, prevent re-administration of the vector and cause adverse effects to the host such as acute liver injury and thrombocytopenia (reduction of the platelet count).

We have evaluated three approaches to reduce the early host immune responses to adenovirus-mediated gene delivery. These three strategies, the infusion of chilled (and thus structurally altered) platelets, intravenous immunoglobulin (IVIG) and the macrophage depleting drug Clodronate, have been evaluated in a mouse model of hemophilia A. We have shown that while the transfusion of chilled platelets did not benefit the outcome of the adenoviral gene therapy protocol, there is a potential for using Clodronate since it not only enhances the subsequent expression of FVIII but also significantly reduces the development of an antibody response to FVIII. Two other major advantages that we observed were that the acute thrombocytopenia that normally follows adenovirus administration was not encountered in each of the Clodronate and IVIG treatment groups and acute liver injury was minimal.

In continuing with this project, we are beginning to investigate the mechanisms responsible for the acute fall in the platelet count following adenovirus-mediated gene therapy. Preliminary studies have shown that adenovirus is capable of “activating” platelets and that this event may subsequently trigger other responses in the hemostatic system. The experimental plan will be focused on studying adenovirus platelet interactions, which will involve in vitro as well as studies in laboratory mice. These studies have the potential to significantly improve our understanding of the mechanism responsible for adenovirus-induced thrombocytopenia and may provide opportunities to prevent this effect.
Inhibitors: update on incidence and treatments for this complication

François Laroche, Editor

The development of an inhibitor, an antibody against replacement factor VIII, is a major complication in the treatment of subjects with hemophilia A, affecting between 20 to 30% of them. Basic research and clinical research have taken a keen interest in this phenomenon in recent years. Considerable effort is being made to better understand the immune disorder behind this complication. Here is a survey of the latest discoveries and news in the field, as outlined by Dr. Georges-Étienne Rivard, Co-Director of the Quebec Reference Centre for the Study of Patients with Inhibitors, during an interview Hemophilia Today conducted with him. Obviously, since these are new developments, it is better not to jump to conclusions; some of these hypotheses are taken from work in progress and will have to be confirmed by further findings.

Hemophilia Today: What is the latest news on the incidence of and risk factors for inhibitors?

Dr. Rivard: First, as regards basic observation, we know more and more about the genetics of factor VIII (FVIII). FVIII deficiencies are caused by genetic mutations; in about 40% of cases, a common mutation is found, inversion of intron 22 (also known as a flip), but it should be borne in mind that there are no fewer than 1000 other rare mutations that are responsible for hemophilia. These mutations manifest clinically as hemophilia of various degrees of severity; we now know that some subgroups of mutations entail a higher risk of developing an inhibitor.

Clinical observation, meanwhile, suggests that the risk of developing an inhibitor is higher in an inflammatory context, for example in major bleeding (e.g. intracranial bleeding) or in a hematoma following a vaccination. Other genetic factors predispose us to inflammatory reactions.

Now when these two predispositions (mutation - inflammation) are found in a single individual, he is at high risk of developing an inhibitor.

Research is in progress to find out more about racial differences and understand why Blacks are at a higher risk of developing an inhibitor.

It has also been found that administering FVIII at a very young age, especially in a context of inflammation, encourages the development of an inhibitor.

H.T: Are there ways to counter it?

Dr. Rivard: You have to try to eliminate or at least limit inflammatory events. You can also administer anti-inflammatory drugs. Genetically modified FVIII concentrates, which are less immunogenic (i.e. less likely to encourage the development of an inhibitor), are also being studied, including a recombinant hybrid human/pig FVIII concentrate.

H.T: What are the latest findings in treatment of people with inhibitors?

Dr. Rivard: Just to give you an idea, a French study will appear shortly in the journal Blood which will confirm that young hemophiliacs who were previously untreated and are treated with recombinant FVIII are three times more likely to develop an inhibitor than those treated with FVIII concentrates derived from plasma. This suggests that plasma derivatives are less immunogenic. Does this mean we will recommend reverting to treatment with these products? It’s not impossible.

Moreover, the basic research is promising, as researchers are developing an alternative treatment which would use small molecules called peptides (fragments of proteins) corresponding to the epitope (a portion of the sequence of amino acids) of the FVIII molecule occupied by the inhibitor to counter the inhibitor’s effects.

H.T: And what is new in the area of immune tolerance treatments?

Dr. Rivard: FVIII concentrates derived from plasma are good prospects as a treatment, since they actually contain immunosuppressor molecules that improve immune tolerance and result in a reduction of the inhibitor.

In addition, for individuals for whom conventional immune tolerance treatment fails, it appears to be promising to treat them with FVIII concentrates containing von Willebrand factor (such as Humate P’).

Lastly, it appears that treatments with Rituximab®, a monoclonal antibody used in the treatment of various auto-immune diseases, do not work well in subjects with hereditary hemophilia, though they work very well in persons with acquired hemophilia. We would like to know why, and we will have more on this soon…


We would like to thank Dr. Rivard for the medical review of this article.

Poon continued from page 19

activity. Secondly, for patients in the Canadian Dose Escalation Prophylaxis study (Dr. Blanchette), we will measure the plasma FVIII level prior to their next FVIII injection. This may help discover the minimal FVIII level that will protect against bleeding and hence determine the frequency of FVIII infusions. Lastly, we will investigate (with Dr. Carcao) if the baseline FVIII level of severe hemophilia A persons can be related to how much FVIII is recovered after an injection, and how quickly the recovered FVIII disappears.

In conclusion, this study will assess the minimum level of FVIII below 1% that is still protective to help customize treatment for individuals with severe hemophilia.
Hepatitis C
Press Review

Jeff Rice, Hepatitis C Coordinator

Large European study finds HIV/HCV co-infected patients do not have an increased risk of HIV disease progression

A study published in the September 15 issue of the Journal of Infectious Diseases reports that co-infection with hepatitis C virus does not increase the risk of HIV disease progression or death due to AIDS. Co-infected patients had a response to potent anti-HIV therapy comparable to that seen in those who were only infected with HIV. As would be expected, however, the data indicated that liver-related death was much higher amongst co-infected patients.

This is the third study to be published recently examining illness and death in HIV/HCV co-infected individuals since effective antiretroviral therapy became available. The conclusion that co-infected patients are no more likely than patients who only have HIV to progress to AIDS or die is in contrast to data from the Chelsea and Westminster Hospital in London, and a study conducted by the US Department of Veterans’ Affairs, which both found that, even after controlling for demographic factors and response to antiretroviral therapy, co-infected patients were more likely to progress to AIDS.

“Hepatitis C virus co-infection has become one of the most challenging clinical situations to manage in HIV-infected individuals,” note the investigators. It is estimated that since effective antiretroviral therapy became available, between 17% - 45% of deaths in HIV-positive individuals in richer countries are due to liver disease.


Hepatitis C: hope on the distant horizon

A June 2005 report from an independent market analyst, called Datamonitor, reports that the combination of high patient numbers and significant unmet medical needs in the area of hepatitis C have attracted big pharma and small biotech alike, creating a pipeline consisting of 28 drugs in clinical development and a range of potential drug candidates at the preclinical stage.

Chronic hepatitis C treatment is currently dominated by two pharmaceutical companies, each producing slight variations of the same drugs. Treatment outcomes following Pegylated interferon and Ribavirin (Peg-IFN plus RBV) combination therapy are highly heterogeneous and depend on the viral genotype with which a patient is infected. Sustained viral response (SVR) rates in genotypes 2 and 3 can be up to 88% of cases. Less than half of those who harbour HCV genotype 1 successfully respond to therapy.

Among the three drugs that are closest to market, only one drug, viramidine, is perceived as a key addition to HCV therapy. The most promising class may be protease inhibitors, if you’re able to get over the problem of toxicity. With the most developed protease inhibitor - VX-950 - still at least seven years from reaching the market, hopes are now centered on the polymerase inhibitors, most notably NS5B polymerase inhibitor valopicitabine (NM283). Clinical development, however, has also led to disappointment when early-stage trials showed only moderate reductions in viral load with NM283 monotherapy. This led to subsequent clinical trials being designed for combination therapy with Peg-IFN, with the end goal of potentially replacing RBV with NM283.

Future HCV therapy is more likely to consist of combination therapy, based on Peg-IFN plus one or more specific antivirals, or antivirals that could be capable of curing HCV infection on their own.

Double liver transplant survivor calls for negative-option donation in Canada

In August, a two-time liver transplant recipient called on provincial governments to follow the lead of European countries by allowing negative-option organ donor registration in Canada. George Marcello is recovering from his second liver transplant, received on his 50th birthday, 10 years to the day after receiving his first transplant due to hepatitis C.

Such a system would automatically put everyone on a donor list, unless people choose to opt out by signing a form indicating they don’t want to donate their organs upon death.

“What could be more important than trying to do everything we can do to save lives?” asked Marcello, who took his crusade to the Ontario legislature with a plea to enact presumed consent.

12th International Symposium on Hepatitis C Virus and Related Viruses

James Kreppner
Secretary, Canadian Hemophilia Society

On October 2 to 6, 2005, the 12th International Symposium on Hepatitis C Virus and Related Viruses took place in Montreal. I had agreed to speak at a Satellite program called Hepatitis C Prevention and Care in Canada: Research Issues and Challenges, and I had sent out an email asking for input as to what the community would like to see with respect to research issues. I would like to take this opportunity to thank everyone who responded for their input, and to let them know that their various ideas and concerns were presented at the Satellite meeting.

Besides talking about the many research issues which interest the infected/affected community, I also outlined a model of community input that is used by the HIV Clinical Trials Network (HIV CTN). The HIV CTN has a Community Advisory Committee, and a very good culture with regard to community consultation. There is also community representation on the Scientific Review Committee, the National Ethics Committee, and there are two community representatives on the CTN Steering Committee. The point was made that any future structure set up to promote and fund hepatitis C research should ensure that it creates similar mechanisms.

The main conference was essentially a basic science conference. This means that it
Cyclosporin’s structure has been altered to the most part. In this case, a part of an immunosuppressive drug in transplants, Cyclosporin is presently used as an analogue. Of real interest was the statement in association with other existing therapies (NIM811) which seemed to be very effective in the viral cycle.

There is research on protease inhibitors rather than research in clinical trials. The best and most positive research was presented consisted of test tube findings in the viral cycle. Of current treatments. With time, some of these new drugs will be forthcoming, and the last day of the conference was the most interesting in that respect as it was then that researchers reported on some of the drugs in development. Unfortunately, the drugs presented were in rather early stages, and are only now in the process of being tested for efficacy and safety. If I am aware of other drugs that are entering clinical trials at the present time that were not discussed at the conference, and this was likely because this conference was more focused on basic research than on clinical trials.

In summary, the necessary basic work is being done, and it has given ideas to researchers about how to find new drugs that will interfere with the virus and improve the efficacy of treatment. One researcher predicted that some of this research may see progress to new classes of drugs for clinical trials in four or five years.

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**Bone health in hemophiliacs**

Catherine van Neste  
Physiotherapist, Hôpital Enfant-Jésus, Quebec City

Osteoporosis a disease of the elderly, isn’t it? Yes, quite right! Osteoporosis is a loss of bone density, and the symptoms appear mainly in older persons. But in order to lose bone, you first have to have built up bones over the course of your life! And that’s what we’re concerned with here.

We are born with a certain bone density, and our bodies add more as we grow. The most critical period for bone growth is the pre-puberty period, i.e., between 11.5 and 13.5 in girls, and between 13.05 and 15.05 in boys. The most active children have more bone density compared to other children, and this reduction is more pronounced if the activity is done later in life, i.e., in adolescence or during adulthood. The most active children have more bone density than children at the same level of maturity who are less active.

But will doing these activities during childhood protect your bones? Everything depends on the level of activity you maintain during your adult life. One thing is certain, however: the higher your bone density, the stronger your bones will be, even after normal loss associated with age.

What about bone density in hemophiliacs? The facts is that children with severe hemophilia may show a moderate reduction of bone density compared to other children, and this reduction is more pronounced in children who present joint changes. The most likely cause appears to be a lack of weight bearing physical activity. In fact, children with hemophilia have had a very limited choice of sports activities for decades, and hemophilia associated arthropathy reduces their options even further. Hepatitis C can be a risk factor for osteoporosis, but opinions on this are divided.

In light of the above, osteoporosis could be called a childhood disease that manifests itself in the elderly. It is important to remember that the pre-puberty period is a unique opportunity to arm yourself against this disease by doing more weight bearing activities.

Studies show that this kind of activity during the pre-puberty period promotes more bone production and thus increases bone density. The effect is clearly less pronounced if the activity is done later in life, that is, in adolescence or during adulthood.

Osteoporosis is a disease of the elderly, isn’t it? Yes, quite right! Osteoporosis is a loss of bone density, and the symptoms appear mainly in older persons. But in order to lose bone, you first have to have built up bones over the course of your life! And that’s what we’re concerned with here.

We are born with a certain bone density, and our bodies add more as we grow. The most critical period for bone growth is the pre-puberty period, i.e., between 11.5 and 13.5 in girls, and between 13.05 and 15.05 in boys. Children build as much bone (26%) during this time as they will lose during their adult lives. How do you build bone? Well, the easiest way is to let nature do its work. Growth hormones will do the job. But if you grow too fast you end up with fragile bones that could give you problems in your retirement years. Another way is to take calcium supplements; however, studies have shown that the positive effects of these supplements do not seem to last beyond the treatment period. The last solution—the best, though perhaps not the easiest—is weight bearing physical activity.

Weight bearing physical activity is any activity that is done on the feet and produces an impact with the ground corresponding to at least 3 times the body weight. For example, walking produces an impact of 1.1 times body weight, running 2.5 to 3 times, jumping 6 times, and gymnastics 12 to 14 times body weight. Weightroom training, swimming and cycling are not regarded as weight bearing activities.

In summary, the necessary basic work is being done, and it has given ideas to researchers about how to find new drugs that will interfere with the virus and improve the efficacy of treatment. One researcher predicted that some of this research may see progress to new classes of drugs for clinical trials in four or five years.

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The best and most positive information was presented on a Cyclosporin Analogue (NIM811) which seemed to be very effective against HCV, and which could be used in association with other existing therapies.
Global Nursing Symposium  
SEPTEMBER 20-22, 2005  
Lori Laudenbach, RN, MScN  
Bleeding Disorders Nurse Practitioner,  
Bleeding Disorders Program,  
London Health Science Centre  

Baxter Healthcare held its bi-annual Global Nursing Symposium (GNS) in Dublin, Ireland on September 20-22, 2005. One hundred and fifty nurses from more than 20 countries were invited to attend. The objective of GNS is to enable nurses caring for patients with inherited bleeding disorders to:  
- engage in a peer-to-peer exchange to address the clinical needs in hemophilia care  
- network with other nurses, leverage their clinical experience and promote Best Practices  
- gain knowledge of current therapeutic practices  
- develop greater understanding of the needs of patients with hemophilia.  

Canada was well represented at GNS with fifteen nurses in attendance. Sylvie Lacroix, the nurse coordinator from the Quebec Centre for the Treatment of Patients with Inhibitors, was one of seven members of the GNS Steering Committee. In addition to this essential responsibility, Sylvie was a plenary speaker and facilitator for the concurrent breakout session entitled Paediatric Topics – The Evolution of Care. In her plenary address she discussed the theories and evidence regarding the effect of different prophylaxis regimens on the incidence of inhibitors. Nora Schwetz, from Winnipeg, and I were invited to present in the paediatric breakout session. Nora’s presentation was entitled Helping Children with Hemophilia and Their Families Adapt and Thrive. My presentation was entitled Prophylactic Protocols: Different Views, Concerns and Questions – Is There an Answer? Ann Harrington from St. Michael’s Hospital in Toronto presented in the Breakout Session entitled Managing Chronic Illness. Ann addressed the nursing responsibilities of pain management. In addition to this, Ann contributed to the EXPO introducing the recent Canadian Hemophilia Society publication entitled Pain: The Fifth Vital Sign. Ann Marie Stain from Sick Kids in Toronto was invited to participate in the third breakout session entitled Challenges in Nursing Practice. Ann Marie presented on the Management of Nursing Care in a Multicultural Clinic: We Are All in This Together. The fourth and final breakout session dealt with the practical diagnostic issue of inheritance patterns in both x-linked and autosomal conditions. The nurses from the Atlantic Provinces, Dorine Belliveau, Sue Ann Hannes and Carol Mayes, participated in the EXPO that opened the symposium on Tuesday evening. They highlighted the information booklets for school personnel and the Step by Step Program for Parents of Children with Bleeding Disorders. Kay Decker from Hamilton Health Sciences Centre presented a poster on the Life Beads Program for kids and adolescents with hemophilia.  

The GNS Steering Committee, with supporting facilitators from Baxter, did well to achieve the above-mentioned objectives of the symposium. The plenary sessions were informative and interesting. Topics ranged from an overview of hemostasis, rare bleeding disorders, management of inhibitor patients, pathogen risk, different therapeutic agents and the future of hemophilia care. Participating as a speaker in the breakout session prevented my attending some of the other presentations that were delivered in the other three sessions. The advantage of being part of a breakout session, however, was the depth of the peer-to-peer exchange. Sharing openly with one another the unique attributes of each Hemophilia Treatment Centre provided the opportunity to reflect on our own current practices. The environment was safe to challenge ways of doing things, providing opportunities to develop and implement changes.  

Bone health continued from page 23  

activities. But what can you do when you have to cope with hemophilia? The purpose of this article is certainly not to set off alarms; the idea is to get people thinking about it. Weight bearing activities are problematic when you have to deal with a painful target joint. The main recommendation is that each person should take part in an activity carefully selected for his or her restrictions, under supervision and with optimal prophylaxis. With regard to post-bleeding immobilization, which is generally fairly short, it is absolutely necessary and probably not a major factor in the onset or prevention of osteoporosis. No study has demonstrated that non weight bearing activities, such as swimming, slow down bone growth. You can continue to engage in this kind of activity, but watch for alarms; the idea is to get people thinking about the theories and evidence regarding the effect of different prophylaxis regimens on the incidence of inhibitors. Nora Schwetz, from Winnipeg, and I were invited to

References  
U.S. approval for room temperature storage of Kogenate

BERKELEY, California, October 6, 2005 - The United States Food and Drug Administration has given approval to the Biological Products Division of Bayer HealthCare, to allow Kogenate® FS to be stored at room temperature (77°F; 25°C) for up to three months. The new storage guidelines for the treatment will provide users with greater flexibility and simplify storage options. Approval was previously granted in Europe.

Rena Battistella, Marketing Director, Haemostasis & Plasma Proteins, with Bayer Canada, told Hemophilia Today that Health Canada is currently reviewing a similar proposal for this country. A response is anticipated in early 2006, and the first lots of room temperature-labeled Kogenate FS should be distributed several months later.

$10 million for factor IX transgenic pigs

LINCOLN, Nebraska, September 13, 2005 - A research project at the University of Nebraska-Lincoln (UNL) has received a $10 million boost from the National Heart, Lung and Blood Institute.

UNL Chancellor Harvey Perlman said the work of William Velander and others will hopefully lead to an abundant, inexpensive and safe supply of factor IX — a protein used to treat hemophilia B. The researchers developed the factor from the milk of transgenic pigs, which carry a human gene deliberately inserted into their genome.

Scientists and the Red Cross got together in 1987 to figure out how to make medicines derived from blood more safe and abundant. As the work has progressed, Velander said, the researchers have discovered that a few hundred pigs can make enough factor to treat all patients who need it around the world.

Hope of an alternative treatment option for hemophilia

SYDNEY, Australia, August 11, 2005 - Professor Denisa Wagner and her Harvard colleagues announced discoveries that provide hope of an alternative treatment option for hemophilia.

Presenting this research at the XXth Congress of the International Society on Thrombosis & Haemostasis in Sydney, Wagner said, "We have demonstrated that a protein called P-selectin is important for blood clotting and altering its levels in the bloodstream by infusion appears to have great therapeutic potential."

Infusion of P-selectin could provide an affordable and more effective means of achieving clotting to stop bleeding incidents in hemophiliacs. Because they carry it naturally in their bodies, patients are highly unlikely to make antibodies against P-selectin. P-selectin also has a longer half-life than clotting factors so treatment is likely to be less frequent.

“This promises to be a much easier and more effective approach for sufferers, particularly children,” said Wagner.

Redesigned protein accelerates blood clotting - study holds hope for next generation of hemophilia treatment

ROCHESTER, New York, July 21, 2005 - Researchers have doubled the potency of a protein that drives blood to clot, according to research published in the July 26 edition of Biochemistry. The study results may have profound implications for the treatment of hemophilia.

Researchers at the University of Rochester Medical Center have been studying the structure of factor VIII for 20 years, and are making subtle changes in the protein with the goal of offering more effective, less burdensome treatment.

“We set out to design a version of factor VIII that would improve on the naturally-occurring form of the protein,” said Philip Fay, Ph.D., professor in the Department of Biochemistry and Biophysics at the University of Rochester Medical Center, and the study’s senior author. “A more potent form of factor VIII, one that could treat effectively with a lower dose, would reduce the cost and, potentially, avert immune reactions.”

In past research, Fay’s team had identified a single amino acid (out of the more than 2,300 building blocks making up factor VIII) with the potential, if replaced, to change the performance of the entire protein. Researchers proved the theory in the current study by swapping out a glutamic acid naturally occurring at a specific point in a calcium binding site on factor VIII with 19 different amino acids. One of the replacements, alanine, doubled the ability of factor VIII to bind with factor IX.
The Blood Safety and Supply Committee

As long as anyone can remember, a group of people in the Canadian Hemophilia Society have devoted themselves to blood issues. Reflecting the changing times, they have gone by many names: Blood Committee, Coagulation Products Committee, Blood Safety Committee and, since last year, Blood Safety and Supply Committee (BSSC). In the 1970s, their major goal was access to a sufficient supply of factor concentrates for people with hemophilia. Then, in the 1980s as reports of blood-borne AIDS and hepatitis surfaced, the focus shifted to blood safety. The development of recombinant products in the late 1980s and early 1990s created a new set of challenges. And, in the wake of the tainted blood tragedy and the Krever Commission, an expanded interest in the entire Canadian blood supply system led the group to take on the challenge of being its “consumer watchdog”.

While the work of these people is well-known to members of the CHS Board of Directors and to other stakeholders in the blood system, including those at Health Canada, Canadian Blood Services (CBS) and Héma-Québec (HQ), they have largely worked in the background, their contribution generally unrecognized. All volunteers, their commitment has been enormous. While they meet face-to-face only once per year, they spend one evening per month via teleconference to discuss blood issues and frame policy recommendations for the CHS. In this age of Internet and e-mail, rarely a day passes without some kind of electronic communication: the latest news or research abstracts on blood safety, gene therapy or novel coagulation products; or a flurry of messages to debate a breaking issue. The members of the BSSC sit on a myriad of provincial, national and international groups (see insert), both to gain insight into the complex issues of blood safety and supply and to represent the interests of users of the blood system.

Hemophilia Today met many of the members of the BSSC to gain their perspective and share it with our readership.

Accomplishments

In recent years the BSSC has made a difference in many issues. For example...

• faced with the emergence of vCJD as a possible blood-borne pathogen, it played a key role in the 1999 decision to introduce donor deferral criteria for those who had spent time in the U.K. or France;
• it provided a valuable consumer perspective during the 2001 shortage of recombinant factor VIII;
• it influenced national recommendations during the 2002 donor selection criteria consensus conference;
• in 2002, it provided the CHS with a comprehensive blood policy;
• in 2003, it succeeded in having a public health expert named to the CBS Board of Directors;
• it critiqued the CBS plasma protein strategy and promoted the recovery of surplus proteins (FVIII and FIX) in Canadian plasma for use in developing countries;

“The BSSC,” says Bruce Ritchie, Clinic Director at the Dr. John Akabutu Comprehensive Centre for Bleeding Disorders in Edmonton, and valuable medical advisor on the committee, “has been able to improve and maintain the transparency of the new blood system. This has been critical in building confidence in the delivery of safe blood products in Canada. Without the work of the BSSC, it would be too easy to go back to the days of arbitrary decisions that hurt blood recipients.”

Bill Mindell, who represents the CHS on the CBS National Liaison Committee and whose contribution spans more than 20 years, adds, “It’s been a help to the blood system and the consumer. Both CBS and HQ want active consumer participation in their decision-making. The BSSC is uniquely and historically positioned to provide credible, diligent input on behalf of the CHS as the premier Canadian blood-related consumer organization. Our Report Card is widely acknowledged and respected.”

Michael King, recently appointed to chair the BSSC, also believes in the credibility of the BSSC. “As the committee’s title describes, our most important work is to review and audit the measures put in place to improve the safety and supply integrity of blood and blood products in Canada. The CHS provides a strong voice through the educated focus of the members of the BSSC who review changes to the technology of blood and blood product delivery and the potential emerging risks of blood therapies. Over time, the BSSC has become not only a consumer voice but one that, because its conclusions and recommendations are based primarily on medical science and the most recent safety data, has the potential to have significant impact on political decisions regarding blood safety.”

The other important achievement of the BSSC, according to Michael King, is its role as an educator. Because of the expertise of its members, he believes the BSSC is a recognized educational resource not only for members of the hemophilia society and other blood product recipients but also for blood system operators, governments and pharmaceutical companies.
A critical role
Stéphane Bordeleau, CHS Executive Director since 2004 and a fresh observer of the work of the BSSC, also believes it plays a critical role. “The members of the BSSC deserve the recognition of the entire Canadian population. Their volunteer contribution has been enormous, both in terms of time invested as well as expertise shared. The committee has played a crucial role in the blood supply system over the last many years. If Canadians today enjoy one of the safest blood supply systems in the world, the BSSC is at least partly responsible.”

Stéphane maintains that the work of the committee has contributed to the positive public image enjoyed by the CHS and that the influence of the CHS is closely linked to the respect accorded its expertise, professionalism and good judgment. According to Stéphane, these three qualities are particularly present in the members of the BSSC.

Bill Mindell agrees that the work is crucial. “The CHS and the Canadian public need an independent consumer-based advocate monitoring the blood system. The BSSC fulfills this role. Historically, when consumers have not been directly involved, or listened to, blood system decisions have not always been in their best interests and have sometimes been extremely harmful.”

Wilma McClure, Nurse Coordinator at the Dr. John Akabutu Comprehensive Centre for Bleeding Disorders and member of the BSSC for the last 5 years, is of the same mind. “The work of the BSSC is important because it provides a venue in which to discuss all issues involving the blood system in Canada. It serves as the ‘watchdog of the blood system’. There is no other committee able to do this in Canada at the present time.”

Reasons for volunteering
Spending long hours on teleconferences and in front of a computer screen does have its rewards. But Bruce Ritchie, it is a committee that allows him to make a difference.

Bill Mindell feels the same. “It is one of the most rewarding things I do. It is intellectually stimulating. I get to work with a great group of people and I know my participation makes a difference in people’s lives. When I speak on behalf of the BSSC to other groups, they listen carefully. It’s very gratifying to look at many of the positive changes that have happened in the blood system over the years and be able to say: ‘Hey, we helped make that happen!’”

Michael King feels that a particularly important aspect of the work is to provide a forum for input from consumers who are directly and regularly affected by the blood system. While anyone in Canada may need blood or blood components to treat a serious medical condition, committee members have especially close ties to the recipient community. Whether they themselves require blood

“...the work of the committee has contributed to the positive public image enjoyed by the CHS and the influence of the CHS is closely linked to the respect accorded its expertise, professionalism and good judgment.”

products, or they have family members who do, or they are part of the medical community which focuses specifically on blood, all have a unique and personal commitment to making a difference.

“I am frequently reminded, “Michael goes on, “of the profound debt I owe to the entire blood system. From the blood donor, to the safeguards in place to monitor against infection, to the medical professionals who help me look after my health, I am profoundly grateful. I can only hope that my contribution to the BSSC can begin to make sure the medical care I have benefited from continues to be available to all Canadians.”

Michael has some less philosophical reasons for volunteering. “The first of these is the people. Quite apart from the fact that the other committee members are fun to spend time with, the group is made up of people from diverse backgrounds, and gives me an opportunity to hear all the points of view that need to be considered. The final recommendations of the BSSC represent a deeply considered mix of consumer concerns, scientific understanding, medical knowledge, and a consideration of politics, law and epidemiology. My personal interests as a consumer and medical professional are further satisfied by opportunities to attend scientific forums and meetings outside of the hemophilia society that address topics related to blood and blood products.”

Wilma McClure volunteers in order to stay better informed. “The people involved are experts in the blood system and I am kept up-to-date on anything new—good or bad. If there are any issues that involve direct patient care, I am able to give my perspective as a nurse.”

Josie Sirna, member of the BSSC for the last 4 years, is from the thalassemia community, frequent users of fresh blood components. “I volunteer for the BSSC because it’s important for us in the blood community to stay connected and communicate with others who share a common goal: blood safety for users of the blood system, be they users of factor products or fresh components. The BSSC allows me to stay informed so I am better able to inform others in the thalassemia community as well as hospital blood bankers in Eastern Ontario. In turn, I can bring blood safety and supply issues from those communities back to the BSSC.”

The future work of the BSSC
Bill Mindell believes that the BSSC will continue to be the backbone of the CHS, that the safety and supply of blood and hemophilia treatment products are at the foundation of the CHS and can never be taken for granted. “Canada has a blood system that is one of the strongest in the world, in part, because we are there watching it and advocating for improvement. Newer and more expensive treatment products and therapies are always coming along, as are new threats. The BSSC will need to always be there to provide an informed consumer

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Progress on Canadian surplus protein recovery for use in developing countries

Bill Mindell
Member of the Blood Safety and Supply Committee and CHS representative to the National Liaison Committee of Canadian Blood Services

In the Spring 2005 issue of Hemophilia Today, I described recent efforts made by the CHS, the World Federation of Hemophilia (WFH), Canadian Blood Services (CBS), Héma-Québec (HQ) and other partners to address the issue of recovering Factor VIII (FVIII) and Factor IX (FIX) proteins which are currently being discarded during the process of fractionation of Canadian plasma collected by CBS and HQ. In particular, most of the world faces shortages of FVIII, a protein which is concentrated in a discarded plasma fraction product called cryo paste. This surplus cryo paste, which has no role in the Canadian blood system due to the virtually universal use of recombinant FVIII products, could be used to help meet the hemophilia treatment needs in countries without even minimally sufficient levels of FVIII. Although we had achieved consensus to address the problem, many unanswered questions existed at the time regarding the amount of FVIII in the discarded cryo paste, where it would be processed, who would receive it and a myriad of legal, regulatory and ethical issues that needed to be addressed.

This report is about the significant progress that has been made. Early in the summer, the WFH identified South Africa’s National Bioproducts Inc. (NBI) as a fractionator with excess capacity that was willing to consider processing Canadian cryo paste into FVIII products. These finished products could be distributed to the 12 nations of southern Africa (South Africa, Lesotho, Botswana, Mozambique, Angola, Zimbabwe, Zaire, Namibia, Swaziland, Zambia, Madagascar and Malawi) with which NBI has established agreements. If the project proceeds, the plan is that these products would be distributed at cost or as humanitarian donations to these countries.

Another important development was recognition that since 1993 CBS and HQ have already set a precedent by shipping a different surplus plasma portion (fraction IV paste) to Kumada, a fractionator in Israel, for further reprocessing into albumin which is then distributed to other countries. (Editor’s note: Fraction IV paste is the last portion of plasma left after the fractionation process is complete and most of the albumin has already been removed. Kumada has developed a unique commercially viable process that gets even more albumin out of this, otherwise, surplus product. While it has value, there is no critical shortage of albumin as there is of FVIII).

In July a teleconference was held in which the CHS, WFH, the World Health Organization (WHO), NBI, the International Plasma Fractionators Association, CBS and HQ all participated. During the call NBI agreed to provide CBS with its technical requirements document for plasma and indicated that they would take a test batch of Canadian cryo paste to manufacture into a single lot of FVIII. It was agreed that this test batch would serve as a feasibility study in terms of yield and quality. The cryo paste used would be derived from the new buffy coat plasma separation process that CBS is implementing this fall.

In September a face-to-face meeting was held at the WFH Global Blood Safety Forum in Montreal at which NBI and CBS confirmed their commitment to the feasibility test. CBS indicated that it was very committed to this project and is thoroughly reviewing the legal and regulatory issues related to the international shipment of any plasma fractions following initial processing. CBS is also working on the technical cryo manufacturing and collecting issues with Talecris, the current fractionator of CBS/HQ plasma located in the United States. The plan is that CBS will send a sample batch of buffy coat derived cryo paste to NBI in the spring of 2006.

There is growing international interest in this project. A representative of the Australian Blood Authority at the meeting indicated that current law prevents Australia from exporting blood products; however, the Australians are watching this project with great interest and envisage that something similar could be done with their domestic fractionator and blood agency. The WHO Director of Blood Safety also expressed her support at the meeting.

CURRENT MEMBERS OF BSSC

Michael King, (Chair) (Alberta)
Tom Alloway (Ontario)
Cyril Dubourdieu (Newfoundland & Labrador)
James Kreppner (Ontario)
Wilma McClure (Alberta)
Bill Mindell (Ontario)
Josie Sina (Ontario)
Bruce Ritchie (Alberta)
David Page (CHS staff support)

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perspective. But the current members of the committee will not always be there! The BSSC needs dedicated new blood!”

Michael King is also thinking about succession planning. “One of the more pressing considerations for the future will be how to encourage the interest of new participants. Given the rewards of participation—safeguarding one’s personal health, the opportunities for education and travel, and the camaraderie of a thoughtful and like-minded group of individuals—this committee should be able to attract candidates.”

All members agree that the most important work will continue to be the monitoring of the Canadian blood system so as to reduce the risk of any recurrence of the tainted blood tragedies of the past. The BSSC must continue to work to ensure the supply of safe blood and blood products so that Canadians need not fear the threat of shortage.

Bruce Ritchie feels the BSSC is crucial. “The BSSC must continue to monitor the blood system in Canada, and review the decisions made, so as to maintain everyone’s faith in the system.”

BSSC welcomes nominations

The BSSC is looking to renew its composition. It is looking for individuals who...

• are interested in making a contribution over several years;
• have an interest in gaining a basic understanding of technical and medical blood safety and supply issues;
• have the time to devote to one annual weekend meeting, monthly evening teleconferences and frequent reading to stay up to date;
• are interested in representing CHS on external committees.

Please send a letter of introduction and curriculum vitae to David Page, Director of Programs and Communications at dpage@hemophilia.ca or call for more information at (418) 884-2277.

Progress on Canadian surplus protein recovery for use in developing countries
In July a teleconference was held in which the CHS, WFH, the World Health Organization (WHO), NBI, the International Plasma Fractionators Association, CBS and HQ all participated.

Gynaecological and obstetric treatment guidelines published

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n July 2005, a milestone was reached in the campaign to obtain proper treatment for women with bleeding disorders. An article was published in the Journal of Obstetrics and Gynaecology Canada (JOGC) entitled Gynaecological and Obstetric Management of Women With Inherited Bleeding Disorders. It was based on the Association of Hemophilia Clinic Directors of Canada (AHCDC) Subcommittee on Women and Bleeding Disorders document entitled The Management of Women with Bleeding Disorders, published by the CHS in 2003, and contained recommendations for the treatment of bleeding disorders in women. A CHS Task Force composed of hemophilia doctors and nurses had made this a priority in the von Willebrand Disease awareness campaign. They realized that the medical profession needed to be educated on this topic. There was no use bringing this information to the public if women couldn’t find doctors with knowledge of the diagnostic tests required and the treatment options available to women with bleeding disorders.

In May 2003, the CHS organized a medical conference on von Willebrand Disease (VWD) in Montreal. A plenary session was held, chaired by Dr. Christine Lee, a specialist in VWD and women’s issues from the United Kingdom, and a workshop on obstetrics/gynaecology management was facilitated by Dr. Christine Demers, Hemophilia Program Director in Quebec City; Dr. Michelle David, hematologist from Montreal; and Dr. Christine Derzko, obstetrician/gynaecologist from Toronto. Following this workshop, internal recommendations for gynaecologists and obstetricians were developed based on a summary of the workshop in order to ensure that women with bleeding disorders would be able to obtain proper treatment. Joanne Douglas, anesthesiologist from Vancouver, joined the principal authors to develop the official recommendations. The final document was submitted to the Journal of Obstetrics and Gynaecology Canada in February 2004. Publication, however, was delayed as the article went through numerous revisions and editing before finally appearing in July 2005.

The reality of trying to simply diagnose VWD is difficult enough for hospitals with a full laboratory, but almost impossible for hospitals in outlying areas. Due to all the variants that can affect the VWF levels which include pregnancy, hormones and stress, to name only a few, as well as the transportation of the blood samples for testing, it is almost preferable for the patient to travel to a hospital that offers full testing. This is not always possible. Therefore, the recommendations were modified to make them more practical for doctors to follow. At times, this simply meant changing must to should.

Hopefully, these practice guidelines will increase awareness among gynaecologists and obstetricians of the importance of investigating the possibility of a bleeding disorder when a patient presents with menorrhagia, especially in the case of abnormal uterine bleeding with no known cause. Dr. Demers states that, while she has seen a slight increase in the number of women referred to the bleeding disorders clinic due to menorrhagia, these women are often at the point where they are already scheduled for a hysterectomy in the following days and have just found out that they have a bleeding disorder. At this point, they don’t want to put off the surgery, since it’s already scheduled and they’ve gone through the whole process of preparing for it both physically and psychologically, especially those who have reached menopause. With the publication of these recommendations, we can only hope that women will be diagnosed sooner and avoid unnecessary surgery. In the end, it is up to the doctors to decide on the option for testing by taking into consideration the patient’s history. The clinical practice guidelines published in the July issue of the Journal of Obstetrics and Gynaecology Canada are a major step in raising awareness of and treatment for this problem with gynaecologists and obstetricians in Canada.

You can download these guidelines from the CHS website under Educational Material www.hemophilia.ca/en/13.1.php

We wish to thank Dr. Christine Demers for her time in the elaboration of this article.
I am a severe hemophiliac, and I play sports for a living. Sports video games, that is.

As a child I had target joints in my ankles and elbows, so I ended up spending a lot of time playing at a computer. My family had a Commodore Vic-20. Back in those days, you didn’t just buy video games; you could also buy manuals with the code for games, and type them in yourself. So at the age of 6, I used to type in games from a manual letter by letter. I didn’t understand what the code meant, but I loved playing the games.

It wasn’t until years later that I decided I wanted to make games for a living. I still remember the day: it was when I bought my first Nintendo game and saw the list of developers in the credits. I guess it hadn’t occurred to me until that point that people actually had jobs creating video games.

I continued to teach myself how to program up until high school, when I finally took a course in computer programming. It was then that my high school computer teacher suggested I study computer science in university. I was awarded a scholarship by the CHS to attend the University of New Brunswick. I studied hard and worked every summer as a programmer at various co-op job placements. I even did my undergraduate thesis on a topic relating to 3-D perspectives in video games. Several months before I graduated, I received an offer from a video game studio, and started my first game job just four days after graduation.

The funny part is that the game studio that hired me specialized in sports games. I had hardly played any sports as a child, and here I was creating sports video games. And not just any sport—the first game I worked on was a rugby game!

I have since worked on a cricket game and another rugby game for PlayStation2, Xbox, and PC. The games are distributed all over the world and combined have sold over a million copies. Today, I am working on a freestyle soccer game for the PSP that will be released in early 2006.

Target joints are not my only health problem. Like many hemophiliacs, I was infected with hepatitis C. I contemplated treatment for years, but with school and work, there was just never time. Two and a half years into my game job, I decided to begin treatment. I knew that there was a risk I would miss a lot of time from work, but it was something I knew I had to do. I talked it over with my boss, and he said to go ahead and take as much time as I needed.

I finished my 48-week hepatitis C treatment in October 2005, and never missed a single day of work because of it. This was no small feat, as jobs in the video game industry are notorious for long hours. It is not unusual for us to work 12- to 16-hour days for weeks at a time! I won’t know for sure for a few more months if the treatment was successful, but so far, so good. It was not without side effects, but I do not regret the decision.

When I am not working, I love to camp. My family went on camping trips almost every summer when I was little. My Dad was a Boy Scout leader, so he used to come with me to Scout camps to help me with my infusions, and, well, just watch over me like the parent of a hemophiliac usually does. When I was 13, I started going to a summer camp on my own. There was a camp in Nova Scotia run by the Cancer Society that accepted children with hemophilia. When I became too old to be a camper, I volunteered as a counselor at the camp. The Hemophilia Society has since formed its own summer camp here in the Maritimes. My sister and I now spend our vacations volunteering every summer at both camps.

When I’m not working or camping, I can be found sailing the beautiful waters of Mahone Bay. One of the nice parts about my job is that it is located in Lunenburg, Nova Scotia—right on the Atlantic Ocean and some of the best sailing waters in North America. My other hobbies revolve around camp. I spend my spare time practicing guitar and magic tricks so that I can entertain the kids the next year. And of course I still play a lot of video games, but I now consider that research. I like to keep busy, and I don’t let hemophilia slow me down.

Editor’s Note: We invite you to submit your own story or the story of someone you think deserves to be better known. One story will be chosen to appear in each issue of Hemophilia Today.
Pam Wilton, R.N.
Vice-President, Canadian Hemophilia Society

“Are we there yet?” the man across the aisle asked.

I laughed and shook my head, “No, but we’re getting closer.”

That was the first sentence I had spoken since we left Atlanta eight hours earlier. I seemed to be the only person traveling alone in our part of the cabin and I was grateful for some conversation. We had just landed on the Island of Sol, a little dot in the Atlantic Ocean, off the coast of Senegal. The man told me that he was hunting “big game” and assured me that he would be able to keep up with his hunting buddies, despite his fractured ankle. I nodded and said a silent prayer for the animals.

I told him that I was a volunteer, headed to South Africa, where I would meet up with Stéphane Bordeleau, Executive Director of the CHS, and Eric Stolte, our President, to determine how we could work together with our new twin, the South African Hemophilia Foundation, to improve the lives of people with bleeding disorders.

Eight hours later our plane landed in Johannesburg where I transferred to a final flight into Cape Town. South Africa was even more beautiful than I imagined! It is about a tenth the size of Canada, with a population of about 43 million. There are 11 official languages, with cultural traditions different from ours. Most were adequately equipped and the level of staffing, human resources, extremely dedicated but limited language barriers, limited financial resources, an abundance of work to be done, dedicated medical teams, highly skilled volunteers and, of course, a common vision.

The following day our work began with an orientation meeting and warm welcome and dinner at the home of SAHF’s most dedicated volunteers, SAHF President, Bradley Rayner, and his wife, Cheryl. We were also joined by a handful of the volunteers from the Cape area. The food, the hemophilia talk, the laughter and the camaraderie reminded me of home, but when I looked out across the terrace of this lovely hillside house, past the twinkling lights of the town towards the Indian Ocean, I had to pinch myself just to make sure I wasn’t dreaming.

The hard work began the next day at a “2-hour” meeting, which stretched into 5, where we discussed more details about the work of SAHF and its challenges and successes. This time it was the Canadians asking lots of questions. We learned that the CHS and the SAHF have many things in common: long distances between cities, language barriers, limited financial resources, extremely dedicated but limited human resources, an abundance of work to be done, dedicated medical teams, highly skilled volunteers and, of course, a common vision.

Over the next 6 days, we visited 6 cities and 7 clinics. We participated in 3 workshops with members from the SA hemophilia community. We also met with the administrators from several hospital sites.

In many respects, clinics were not much different from ours. Most were adequately equipped and the level of staffing, hard and hoping to find employment. It was also startling to meet representatives from the pharmaceutical companies, who provide the factor, not only present in the treatment areas of the clinic but often assisting with hands-on care. One other interesting problem is that those who have insurance often have access to product as needed, but not necessarily hemophilia expertise, because their insurer dictates where they must receive care. In each clinic we met hemophilia nurses, called Sisters, who work endless hours providing their expertise and skill to help meet the needs of those they serve. They are also driving most of the SAHF work. These are truly amazing women. We met dedicated and overworked physicians. And we met physiotherapists with excellent skills who know how to do a lot with a little!

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SAHF gave him that with a used sewing machine.

On our final day together, Bradley and the leaders from the SAHF met the three of us to debrief and to begin to develop an action plan. We see huge potential for the two countries to work together to achieve our goals. Stéphane, Eric and I have developed a draft action plan. Once the plan has been approved by the SAHF and the World Federation of Hemophilia, we will be able to move forward. One of the first tasks is to help South Africa develop a strategic plan. We have much to learn from the South Africans, too. Bradley called our work together, “a journey of learning” and on that last day in South Africa, after an experience which Stéphane best summed up as “intense and fascinating”, Eric presented Bradley with a small Inukshuk. Inuit use the Inukshuk as a directional marker, signifying safety, hope and friendship.

So… are we there yet? No, but we’re getting closer.

World Federation of Hemophilia
4th Global Forum on Safety and Supply

Marius Foltea
CHSQ Board of Directors

On September 26-27, I had the opportunity to attend the World Federation of Hemophilia’s (WFH) Fourth Global Forum on the Safety and Supply of Treatments for Bleeding Disorders that took place in Montreal. During this meeting, where 150 researchers, doctors, blood system operators, regulators, pharmaceutical representatives and patients from around the world gathered, many themes were dealt with, including:

- Research into new products and new fractionation processes
- The WFH humanitarian donation program
- The Canadian project for the recovery of factor VIII from Canadian plasma
- The incidence of inhibitors
- Access to therapies for rare bleeding disorders (other than hemophilia A & B)
- Approaches of various countries for soliciting tenders and choosing therapeutic products
- The possibility of a variable price structure to facilitate access to factor concentrates in developing countries
- Safe treatment.

Several presentations were made by those responsible for the regulation of blood products. The conclusion was that expiration dates must be respected, even when products are donated for humanitarian aid, and even though it is known that products retain their efficacy long after the expiration date. A recommendation was also made that viral testing is useless on an end product since there is no test recognized for this purpose. Safety is solely dependant on donor selection procedures, virus detection in donations and good manufacturing practices, including viral reduction, during the production stages.

One doctor presented part of his research on factor VIII dosage. According to him, a dose smaller than that to which we are accustomed in Canada may be just as efficient. But there are many unanswered questions on this subject and research is ongoing. What’s more, many doctors doing research on the incidence of inhibitors lack data (the number of inhibitors or patients registered in the study is too low) to come to valid conclusions as to the association with a specific product, for example, recombinant factors. This led to a number of heated discussions between specialists.

The following items in particular caught my attention:

- 88% of recombinant products are used in North America and Europe (especially in the richer countries).
- Around the world, there is a great quantity of plasma that isn’t used for the production of factor concentrates and is, for all practical purposes, wasted. Many countries could benefit from this product. However, technical, legal and ethical questions have to be dealt with before this can happen.
- A number of countries are thinking about building their own plants to produce plasma-derived products in an attempt to minimize the cost.
- The way to identify the number of units on bottles of concentrates required by authorities is not consistent in Europe in comparison to North America (approximate amount versus exact calculation). This entails supplementary costs when products are exported from one continent to the other.
- The cost of the same therapeutic product is not consistent from one country to another.

I’d like to thank the CHSQ for giving me the opportunity to attend this very interesting forum. If you’d like to know more about it, you can consult the WFH website at www.wfh.org.