50 YEARS TO REMEMBER

2003 is a landmark year for the Canadian Hemophilia Society. In 1953, people with hemophilia and their family members and caregivers got together to create an organization that would lead to a better quality of life for Canadian hemophiliacs and also to some of the best medical treatment in the world. Celebrations to highlight our 50th anniversary will include a commemorative book, a public exhibit on the history of hemophilia and the CHS, a research symposium as well as a medical symposium, a poster exhibit of volunteers over the years and, finally, a celebratory banquet with a few surprises in store. These activities will all be taking place in Montreal on May 8-11th, 2003. You’ll find details on how you can take part in these celebrations on page 17 of this issue. Don’t miss out on this chance to join the biggest hemophilia-family gathering ever and to commemorate 50 years of tragedy and triumph in the care of people with bleeding disorders.
EDITOR'S KEYBOARD

Francois Laroche

Four days of information, testimonials and celebrations await attendees at the Canadian Hemophilia Society’s 50th anniversary, May 8 to 11. Exhibits, a medical research symposium, a commemorative book, a state-of-the-art conference on von Willebrand Disease and a sumptuous banquet are just some of the activities featured during the four days of festivities. The public display on the history of hemophilia and its treatment through the ages, with a link to hockey (after all, isn’t Mario Lemieux our Honorary President?), is not to be missed. All of this will take place in Montréal, where our society was founded in 1953.

In passing, we will all have a laudatory thought for the founder of the CHS — who was also the founder of the World Federation of Hemophilia (WFH) — Frank Schnabel, who did so much to improve the quality of life of people with hemophilia. This will be the ideal occasion to reminisce on the early days of the Society, in an era when treatment was nothing like it is today; some of you will remember only too well having lived through it yourselves.

This opens the door for me to point out once again the privilege we have here in Canada to be able to count on the latest treatments, efficacious and safe, while 75 percent of hemophiliacs in the world are completely deprived. The efforts deployed by the WFH to foster cooperation among hemophilia organizations both in industrialized countries and in developing countries deserve both mention and encouragement. Several international twinning partnerships have been set in motion in our provincial chapters. They are proof of the fact that together we can contribute to improving the quality of life of people with hemophilia around the world.

Please feel free to respond to this editorial or to any other article that has appeared in Hemophilia Today by writing to The Editor, Hemophilia Today, 119 Thomassin, Beauport, QC, G1B 2W6 or by Email at larochef@sympatica.ca.

LETTERS TO THE EDITOR

January 8, 2003

Dear members of the CHS Board of Directors,

I just read that you are preparing for your 50th anniversary.

It is my hope that it will be as great a success as the Society has been in the past 50 years. Your work has been appreciated, even in the small towns that are miles away from your office. Thanks to the work of your past and present directors, I will also be celebrating my 72nd anniversary a couple of weeks after your 50th.

I was born in 1931 in New Lisbon which at that time had a population of about 3,500. Included in that figure were four GPs and a small hospital. I spent a lot of my pre-teens in that hospital. When they could not handle my needs it fell upon my father to drive the 350 miles to Sick Children’s Hospital in Toronto. I was to learn that there was only a 10 percent chance that I would live until I reached 20 years of age. I have been given a few months to live twice and told I would never walk again.

I married at age 24, when advised by a doctor that my hemophilia would be passed on by my sister’s children but not mine. That was later proved wrong, of course, but by then I had 4 children. I think it was about the mid-60s that I heard about
Dear editor,

I want to congratulate Michael King on his excellent and informative article on “I Feel the Need...”. However, I would like to point out one small (perhaps editing) mistake. It appears twice—once in the second paragraph of the body of the article and in point 3 of “the Top Eight”—the minimum age recommended for the influenza vaccine is 6 months, not 6 years. (Reference: Canadian Immunization Guide, 6th Edition, 2002, page 124).

I have rambled on enough. My original idea was to let you know that much you have helped me through the rocky road of life and to wish you all the VERY BEST ANNIVERSARY possible.

Yours truly,

William J. Bond
New Liskeard, Ontario

LETTERS

Dear editor,

I want to congratulate Michael King on his excellent and informative article on “I Feel the Need...”. However, I would like to point out one small (perhaps editing) mistake. It appears twice—once in the second paragraph of the body of the article and in point 3 of “the Top Eight”—the minimum age recommended for the influenza vaccine is 6 months, not 6 years. (Reference: Canadian Immunization Guide, 6th Edition, 2002, page 124).

I look forward to the second vaccine article, and many more.

Best regards,

Bill Mindell
Director, Infectious Diseases Control Division York Region Health Services

This issue of Hemophilia Today contains articles on von Willebrand Disease (VWD) and other inherited bleeding disorders, topics which fit in well with the launch of the Bleeding Disorders Initiative, a programme which affirms the fact that the CHS is an organization which exists to improve the quality of life for Canadians with all inherited bleeding disorders. In addition, this spring in conjunction with our fiftieth anniversary celebrations, the CHS is hosting the world’s first international medical symposium on VWD. These events are very dear to my heart. They represent things that I’ve been working for since I first became active in the society in 1990.

In 1985, I met a man named Santo Caira, who was working for the Hemophilia Society in Toronto and told him over coffee one evening that, even though doctors had assured me that I was not a hemophiliac, I had nevertheless experienced a number of episodes of excessive bleeding. Indeed, once after surgery, I had almost bled to death. In addition, my mother died as a result of a hemorrhage when I was born. Santo suggested that I go see Dr. Jerry Teitel at St. Michael’s Hospital in Toronto; and Dr. Teitel diagnosed my von Willebrand Disease. It was comforting to know that my excessive bleeding could be controlled if the need ever arose. And arise it did in the fall of 1989 when I was unlucky enough to be standing next to a large mirror when it fell off the wall and cut me rather badly. That day it was very fortunate indeed that the comprehensive care team knew what to do. Afterwards, I realized that I owed a debt of gratitude not only to Dr. Teitel and the other doctors at St. Michaels Hospital, but also to the Hemophilia Society. If it hadn’t been for Santo Caira’s good advice, the aftermath of my encounter with the mirror would have been much worse than it was.

When I first started attending Hemophilia Society events in Toronto and eventually joined the boards of the Toronto and Central Ontario Regional Hemophilia Society (TCOR), Hemophilia Ontario and the CHS, I was a bit of a curiosity. Many of the people I met had never even heard of VWD; and those who had heard of it didn’t know much about it. I was the very first “von Willie” that most of the hemophiliacs had ever met.

In those days, the Hemophilia Society at all levels was heavily engaged in attempts to obtain compensation for people infected with HIV through the blood system. Then we realized that we needed to work for an inquiry into the Canadian blood system and obtain compensation for people infected with HCV. However, while working to make these extremely important things happen, a few of us also quietly worked to have the CHS gather and publish information about VWD and the other inherited bleeding disorders and to begin to reach out to people with these diseases through a VWD Education and Awareness Campaign. And this spring, the Medical Symposium on VWD and the launch of the Bleeding Disorders Initiative are making these efforts even more visible. I’m not a “lonely little von Willie in a hemo patch” any more.
NOTICE

The Annual General Meeting of the Canadian Hemophilia Society will convene as follows:

Saturday, May 10th, 2003 9:00 a.m.
at the Sheraton Hotel in Montreal, Quebec

1. To receive the report of the Nominating Committee
2. To acknowledge the designated Directors of each Chapter
3. To nominate candidates for the Director at Large positions on the CHS Board for 2003-2004
4. To receive the audited financial statements of the Canadian Hemophilia Society for the year ended December 31, 2002
5. To appoint an auditor for the ensuing year
6. To transact such other business as may properly come before this Annual General Meeting of the members of the Canadian Hemophilia Society

James Kreppner
Secretary

CHS SCHOLARSHIP AND BURSARY PROGRAMME

Applications for the 2003 CHS scholarship and bursary programme have been available as of February 1 on the CHS website at www.hemophilia.ca. Copies were also sent to chapters and clinics for distribution to interested people.

Annually, CHS awards one $4000 academic scholarship, one $4000 bursary, and one $4000 mature student bursary. The deadline for applications is April 30, 2003.

This programme is funded through an educational grant from Baxter.

NOW AVAILABLE!

HEPATITIS C:
An Information Booklet for People Infected With the Hepatitis C Virus, and Their Families and Friends, published by the Canadian Hemophilia Society.

Originally introduced in April 1995, the fourth edition of this extremely popular publication is now available. The revised edition provides updated information on: hepatitis C, diagnosis, symptoms, getting treatment and treatment options, hepatitis C and HIV co-infection, standards of care, healthy lifestyle, alternative therapies, psychosocial aspects, as well as a number of useful links to other sources of information.

Order yours today, for free.
Quantities are limited!

Place your order by FAX to 1-514-848-9661, or send us an e-mail at chs@hemophilia.ca. You may also order by phone by calling, in the Montreal area: 514-848-0503, or toll-free at 1-800-668-2686.

Order by mail by writing to: Canadian Hemophilia Society, 625 President Kennedy Avenue, Suite #1210, Montreal, QC H3A 1K2.

FDA PROPOSES NEW WARNING ON NONOXYNOL 9

In January 2003, The Food and Drug Administration in the United States proposed new warnings labels for over-the-counter contraceptive drugs that contain the spermicide Nonoxynol 9.

The warning would state that vaginal contraceptives containing Nonoxynol 9 do not protect against infection from HIV or other sexually transmitted diseases. The proposed label warnings would also tell consumers that the use of these contraceptives can increase vaginal irritation, which may increase the possibility of transmitting the AIDS virus and other STDs from infected partners. The proposals are based on recent studies using Nonoxynol 9, including data from a World Health Organization study of 991 HIV-negative sex workers in Africa and Thailand. The study showed Nonoxynol 9 to be ineffective in the prevention of HIV infection.

RENEWED SUPPORT FOR HTCS IN ONTARIO

The Ontario Ministry of Health has recently agreed to support the five provincial Comprehensive Care Clinics / Hemophilia Treatment Centres by providing funding for clerical support. The Ministry will also support the hiring of a Provincial Co-ordinator. Representatives of Hemophilia Ontario and the clinics have been asked to sit on the Steering Committee to oversee this initiative. Members of Hemophilia Ontario and the medical community look forward to working with the Ministry in this capacity to improve comprehensive care for people with bleeding disorders in Ontario. More in upcoming issues.

PATIENT NOTIFICATION SYSTEM

NEW SYSTEM FOR PLASMA PRODUCT RECALL INFORMATION

Canadian Blood Services is pleased to announce that the Patient Notification System is now available in Canada, in both French and English, at no cost to the consumer.

continued on page 14
AWARDS BANQUET held in November

CHS honours volunteers, health care providers and staff

Eric Stolte, Chair CHS National Awards Committee

Some might say that for altruism to be authentic, it must go unrecognized. If that were true, then an Awards Committee which honours altruistic service would be counter-productive. But when we see the selfless devotion of the people who receive acknowledgment, and whose sacrifice we deeply appreciate, we’re spurred on to greater service.

At the November 2002 Awards Banquet, the CHS recognized a group of dedicated volunteers, health care providers and staff who made a significant contribution to the bleeding disorders community during the year 2001. The Awards Committee trusts that by recognizing the following people, you’ll be inspired to even greater levels of service yourself!

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 fund-raising, patient services, education, or chapter/regional development.

Newfoundland and Labrador Chapter – for outstanding efforts to advocate, in collaboration with the clinic, for improved funding for comprehensive care.

Alberta Chapter – for outstanding efforts to provide peer support to members and to educate the general public about bleeding disorders.

AWARD OF APPRECIATION

This award honours individuals who have demonstrated outstanding service to the care of people with inherited bleeding disorders.

Dr. John J. Akabutu
Past Clinic Director, Edmonton, Alberta

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 and around the world.

Dr. John J. Akabutu (left), retired Director of the John J. Akabutu Bleeding Disorders Clinic in Edmonton receiving the Dr. Cecil Harris Award from Bruce Ritchie

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 who demonstrates outstanding qualities of devotion and support for volunteers and of his or her other staff members.

Clare Cecchini
CHS Program Development Coordinator

Frank Schnabel Award

This award was initiated to honour the outstanding service of Frank Schnabel, the founder of the Canadian Hemophilia Society. 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.

Michael McCarthy
Ontario

Maybe you know of more “hidden heroes” – people sacrificing their own time and energy for the greater good of improving the quality of life for ALL people with bleeding disorders. If you do and would like to nominate them for an award, we’re requesting people forward nominations to CHS for 2002 by June 30th, 2003.
FIVE PEOPLE... FIVE BLEEDING DISORDERS

In the coming months, the CHS will be launching its Bleeding Disorders Initiative, a programme intended to raise awareness among the general public, health care providers and decision-makers about the whole range of inherited bleeding disorders — von Willebrand Disease (VWD), platelet function disorders, rare factor deficiencies and, of course, hemophilia. The longer-term goal is improved care and treatment for all people with bleeding disorders.

The Bleeding Disorders Initiative is not a radical departure from the past mission of the CHS. People with VWD and the rarer factor deficiencies have been active members of the CHS for many years; indeed, a major element of CHS programming in recent years has been the VWD Awareness Campaign.

Hemophilia A and B are the most common severe bleeding disorders, and will remain a focus of the work of the CHS and the Hemophilia TreatmentCentres which treat bleeding disorders. However, they affect fewer than 3,000 Canadians. An estimated 300,000 Canadians suffer from other inherited bleeding disorders. These are usually, but not always, milder conditions. Many of these people remain undiagnosed; their lives can be in danger after serious trauma, surgery or even a banal event such as a nose bleed.

This article features five people describing the reality of five different bleeding disorders. Its goal is to raise awareness among the members of the CHS about the individuals we serve.

Six-year-old Albert can have intra-cranial bleeds

Sylvie Ferlatte is the mother of Albert Bourdages, a six-year-old boy with severe factor VII deficiency who this year started to attend kindergarten. Sylvie and her husband, Bernard Bourdages, and daughter Laurence, live in St-Siméon, a small town near the tip of the Gaspé Peninsula, and a nine-hour drive from Sainte-Justine Hospital in Montreal where Albert is now treated.

Albert’s deficiency in factor VII was discovered at the age of three weeks when a tiny intra-cranial bleed caused a blockage in his head, and a fluid build-up inside the skull. An operation was necessary to insert a valve; over the next 18 months, six more operations were performed to counter the build-up of fluids. Fortunately, there was no neurological damage.

Albert was treated in several hospitals in Quebec City. “It was hell,” Sylvie says today. “Each time we went to the hospital we saw different doctors. It was crazy — there were too many doctors at too many hospitals. Albert had to get his factor VII concentrate three times a week to prevent the intra-cranial bleeding. He had four or five Port-a-caths but they kept getting infected, and had to be changed.”

Four years ago, Albert was referred to the Hemophilia Treatment Centre at Ste-Justine Hospital in Montreal. “It is wonderful. I can’t compare it to what we went through before. All the services are in one place. Everything is connected together. Everybody knows Albert. They seem to know exactly what to do.”

At Ste-Justine, Sylvie and Bernard learned to infuse Albert with factor VII through IV injections. For the last four years, they have been successfully taking charge of Albert’s treatment with infusions every two days. “The goal,” says Sylvie, “is to completely prevent the intra-cranial hemorrhages. Albert accepts the infusions when we do them. He’s very brave.”

Albert is not affected by joint or muscle bleeds, or even bruising. The danger for people with factor VII deficiency is intra-cranial bleeding. “That’s why rough sports are forbidden for Albert. It’s just too dangerous,” says his mother. “But he has started school and he’s a normal little boy.”

Only 1 person in 500,000 has factor VII deficiency. Sylvie says, “We sometimes feel isolated. We’d love to talk to other parents with the same problem, but we don’t know anyone.”

Only 1 person in 500,000 has factor VII deficiency. Sylvie says, “We sometimes feel isolated. We’d love to talk to other parents with the same problem, but we don’t know anyone. There’s a lack of information about factor VII deficiency. The nurses recently wrote a booklet on the condition and that helps. We can show people what the condition is.”

Sylvie has a very positive outlook. “You can’t have pity for Albert just because he has this bleeding disorder. We see it as just one part of his life. We want to make sure he is not isolated because of it.”
Factor XI deficiency — much more common than believed?

Richard Yampolsky, a 46-year-old husband and father of two girls, is one of an unknown number of Canadians with factor XI deficiency, also called hemophilia C. He was diagnosed at the age of 12. “I had a tooth out and it bled for weeks. The resident suggested I be tested for hemophilia. My mother was appalled. Six months later, I had an eye operation. There was no problem post-op, but after I got home, I sneezed and the entire side of my face turned purple.”

Soon after, at the Royal Vic in Montreal, Richard was diagnosed with factor XI deficiency. But instead of referring him to the Hemophilia Treatment Centre, he was referred to the Jewish General. The doctor considered factor XI deficiency a “Jewish disease” because of its disproportionately high rate among Ashkenazi Jews. There is also a large population in Iraq.

“Factor XI affects 1 in 100,000 people in the general population. However, the defective gene affects as many as 8 percent of Ashkenazi Jews. This means it could affect more than 25,000 Canadians, most of whom don’t know they have it. This underlines the critical issue of proper diagnosis and referral to bleeding disorder clinics.”

“Jewish disease” developed in Richard after he was diagnosed with factor XI deficiency. It’s too bad, but the importance of factor XI deficiency is not even recognized in the Jewish community.”

To complicate matters more, the severity of bleeding is unpredictable. Some people with quite high levels of factor XI in their blood stream experience frequent, severe bleeding. Others with much lower levels have almost no problems. And levels seem to fluctuate,” according to Richard.

People with factor XI deficiency do not suffer from joint and muscle bleeds as do those with hemophilia A and B. In fact, Richard recently ran a 6.5 km leg of the Toronto Marathon. Bleeding after dental extractions, surgery and trauma are the main symptoms. Women can suffer from heavy, prolonged bleeding during menstruation and complications after childbirth.

Treatment is provided on-demand to stop bleeding. Fresh frozen plasma is still extensively used. Factor XI concentrates derived from plasma exist and are available in Canada, but have been associated with thrombosis, the formation of unwanted clots in the blood stream. In Israel, where many people are living with factor XI deficiency, research has tried to evaluate the effectiveness of desmopressin to treat bleeding; however, the results are not convincing. Fibrin glue is used during dental work. The small numbers of patients makes it unlikely that recombinant factor XI concentrate will ever be developed.

“I was lucky,” recounts Richard. “I happened to read about the opening of the St. Michael’s Hemophilia Clinic in 1983 in the newspaper and have been going there ever since. It seems that doctors and hospitals just don’t think to refer patients to where they should be treated — in a specialized centre like St. Mike’s. I know one woman with factor XI who was treated in another Toronto hospital. She went into cardiac arrest from circulatory overload with fresh frozen plasma and almost died.”

Richard says having factor XI deficiency has its positive side. “I’ve learned a lot more about my body and my own care and treatment than most people. And I’ve had the privilege to be involved in the bleeding disorders community over the years.”

Type 2B VWD can cause life-threatening bleeds

France Drapeau, 44, and her two children, aged 12 and 3, have Type 2B von Willebrand Disease, a type of VWD in which the von Willebrand factor in the blood stream binds to platelets. The clumping together of platelets causes low levels of platelets which, in turn, contributes to bleeding.

Type 2B VWD represents about 5 percent of all the cases of VWD, or approximately 15,000 Canadians. Some cases can be associated with serious, life-threatening bleeding. As is often the case, it’s a family affair; France’s four brothers also have VWD. One of them died from complications caused by contaminated blood products.

“I’ve always been treated at Ste-Justine in Montreal,” says France. “People are always complaining about hospital services these days; I have only praise. I can’t find the words to express all my gratitude for what they have done for me over the years.

“Von Willebrand Disease is not well known outside the hemophilia clinic. If I see other health care providers and say I have VWD, they don’t say anything. Maybe they don’t want to seem ignorant. As soon as I say it’s a type of hemophilia, they know what it is, they know it’s a bleeding problem.”

France was treated with cryoprecipitate in her youth. Dental extractions were often a cause of bleeding. Both her children were born by Caesarian section and each time she suffered extensive bleeding. “The last time the doctors were very worried because I lost a lot of blood,” she remembers. Nowadays, she is treated with Humate-P, a concentrate of factor VIII and von Willebrand factor. France is no longer able to use desmopressin to prevent bleeding as she has angina and the side effects of the med-
icardial cord after the stump fell off, a classic sign of factor XIII deficiency. There was no history of abnormal bleeding in the family.

As a 7-year-old, the main symptoms of his condition are prominent bruising and poor wound healing. "Cuts and scrapes take forever to heal," says Gwenn. "First, the bleeding lasts longer than normal, then a large scab forms and stays for a long period and finally, scar tissue can form."

The other danger is the potential for intra-cranial bleeding. "He receives a preventative infusion of factor XIII concentrate, Fibrogammin P, every four weeks. Fortunately the half-life of factor XIII is long, 19 days, so frequent infusions are not necessary," says Drake's mother.

"He went to the ER for treatment for the first three and a half years, but then the staff at the hemophilia clinic in Winnipeg taught us to home infuse. He never had a port.

There were times at the beginning when it took two of us to hold him down. Drake didn’t understand why he was getting a needle. But it’s much better now. He has great veins and we have to insist. He’s at the point now where he often does all the preparations for the infusion, except the poke. That’ll come when he’s a little older.

Drake doesn’t experience joint or muscle bleeds so, with his prophylactic therapy, he is able to play sports. "We follow the physical activity guidelines developed for hemophilia A and B," says Gwenn. "He plays hockey but without contact."

"His condition could have been overwhelming. It’s an 8-hour drive to the hemophilia clinic in Winnipeg. There was no one to talk to about it and we felt so alone, so isolated. But I’m an RN and that has helped with the hospital situations. Our reaction was to get all the information we could find. In the end we had so much the physicians asked us what we knew. And home treatment has made it so much easier."

"I think this has opened a lot of doors for us as a family," concludes Gwenn. "We’ve met so many nice people at Hemophilia Manitoba and at the clinic. We go to the family camp and really enjoy that. Once Drake learns to manage his own disease, he’ll benefit from his condition in a lot of ways.

Nor are mucosal bleeds from the nose or mouth a problem in Drake’s case.

"His condition could have been overwhelming," says Gwenn. "When he was a baby, we lived in Terrace, BC, and now Thompson. It’s an 8-hour drive to the hemophilia clinic in Winnipeg. There was no one to talk to about it and we felt so alone, so isolated. But I’m an RN and that has helped with the hospital situations.

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An inherited bleeding disorder... but which one?

Inherited bleeding disorders are not always easy to diagnose. Just ask Marlene Permanand of Winnipeg, Manitoba.

"For years I was told I had a platelet function disorder," says Marlene. "That’s even what’s written on my MedicAlert bracelet. But after a recent lab work-up, the doctors can no longer say I do. The lab work just doesn’t match my symptoms."

Those symptoms started at a very young age. “I had horrible lengthy nose bleeds as a child. I bled on-and-off for two or three days. My mother remembers I was anemic. I used to chew on the coal delivered for the neighbour’s furnace. My body craved the iron."

Marlene continues to have problems as an adult. “I’ll bleed into the tissues of my fingers just from carrying groceries,” she says. Her most serious problems have resulted from bleeding after surgery. One time after back surgery, bleeding damaged the sciatic nerves. As a result, she lives with chronic pain. The pain forced her to shorten her nursing career.

Marlene wasn’t the only person in the family with bleeding problems. “My mother and six or seven of her brothers bled after tooth extractions or surgery.

Drake is a pretty awesome boy," says his mother, Gwenn Bodie of Thompson, Manitoba. Drake has severe factor XIII deficiency. The family learned of his condition when he was 13 days old. Bleeding began from the umbilical cord after the stump fell off, a classic sign of factor XIII deficiency. There was no history of abnormal bleeding in the family.

As a 7-year-old, the main symptoms of his condition are prominent bruising and poor wound healing. "Cuts and scrapes take forever to heal," says Gwenn. "First, the bleeding lasts longer than normal, then a large scab forms and stays for a long period and finally, scar tissue can form."

The other danger is the potential for intra-cranial bleeding. "He receives a preventative infusion of factor XIII concentrate, Fibrogammin P, every four weeks. Fortunately the half-life of factor XIII is long, 19 days, so frequent infusions are not necessary," says Drake’s mother.

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Marlene wasn’t the only person in the family with bleeding problems. “My mother and six or seven of her brothers bled after tooth extractions or surgery.
One time, one almost died. My mother’s mother also bled abnormally. But since everybody had it, they thought it was normal.

“In the 1980s,” Marlene recounts, “my son was diagnosed with von Willebrand Disease. He went back recently to be re-assessed and now they’re not so sure. We’re a real mystery.”

Marlene’s difficulties in getting a definite diagnosis, even in a specialized bleeding disorders clinic, underline the need to continue to conduct research in this area. “I’m close to retirement. We’re going to be traveling a lot. What do I put on my MedicAlert bracelet?” Marlene asks. “I want people to know what I have and what to do if I’m in an accident.”

Despite the lack of a definite diagnosis, health care providers have found effective treatments. “I’m treated with desmopressin before surgery. The times I didn’t have it, I had bleeding complications. The times I took desmopressin, the problems were much less severe. I don’t know what would’ve happened the last time without it.”

“I’ve had to become very knowledgeable about my body. A few years ago, I started taking vitamin E and noticed I was getting increased bruising. I called the bleeding disorders clinic and the nurse said to stop taking it – the vitamin was the cause.

“I’ve also made a point to inform everybody in my family of the symptoms through a family letter. That’s how my sister and her sons were diagnosed with VWD. Family awareness about our bleeding tendency has really improved.”

Marlene says her links with Hemophilia Manitoba and the local bleeding disorders clinic are excellent. “And,” she concludes, “I’m so grateful for universal health care.”

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**Von Willebrand Disease**

The inherited bleeding disorder von Willebrand Disease (VWD) is extremely common, particularly in its mildest form, called Type 1. In fact, it’s thought that one in 100 people have VWD, though the vast majority are undiagnosed. On the other hand, the more severe form, Type 3, occurs in only one in 500,000 people. I’m one of those rare Type 3s.

I was diagnosed as a child, but I didn’t realize until adulthood that I have Type 3. It’s funny to think of it now. All those bleeds into muscles and joints, Emerg visits, hospital stays, missed school-days, crutches, tears, never-ending bleeding times... and I thought I had a mild disorder.

Although the treatment back then was a far cry from today’s options, I coped and my family coped, so I thought everything was close to normal.

My experience helps me understand how so many can have VWD and yet be unaware of their condition. The main symptoms of VWD are easy bruising, heavy menstrual periods, frequent or prolonged nosebleeds, and prolonged bleeding after injury, surgery, childbirth or dental work. Both males and females can have VWD and exhibit symptoms. Sounds straightforward; you might expect people to be getting diagnosed in droves. It seems that most people with undiagnosed VWD don’t realize that their symptoms are symptoms of anything. But just because someone doesn’t realize that, say, her period is much heavier than normal (after all, flow volume is not a common topic of conversation) doesn’t mean that she shouldn’t be relieved of the burden of excessive bleeding, if possible. Even someone with mild VWD can experience significant bleeding. It’s always better to have a proper diagnosis and know the facts so that one can prevent or treat problems.

For Type 1s, treatment is often desmopressin, also known by the brand name DDAVP, a pharmaceutical product which causes the body’s stored von Willebrand factor (VWF) to be released into the bloodstream where it can get to work in clotting — VWF carries and stabilizes Factor 8. DDAVP can be used preventatively or to treat bleeding. There are several ways to administer it. My children, who have Type 1, have received it only intravenously. Fortunately, they’ve had few problems, but they have received treatment before significant dental work as well as after a head injury.

Type 3s don’t respond to DDAVP. We have little VWF, and not enough is warehoused in our cells to make a difference when it gets released. When I need to prevent or stop bleeding, I sometimes use Humate P. It’s a heat-treated, virally inactivated blood product. There is also Type 2 VWD. Unlike 1s and 3s, 2s have normal amounts of VWF in their bloodstreams, but their VWF doesn’t function properly. Type 2s may use Humate P or other treatment options (excluding DDAVP.)

For all of us, prevention is obviously the best medicine. My kids and I wear helmets to ride and skate, and our sports activity is low impact. But there are some things that can’t be prevented. One of my worse bleeds occurred from ovulation. It may sound trivial; it was bad. But I knew where and when to get treatment, and the treatment worked well. That’s what I wish for all girls, boys, men and women with VWD: knowledge, right off the bat, and effective treatment if and when they need it.

(The writer’s name has been withheld on her request.)
# Bleeding Disorders at a Glance

<table>
<thead>
<tr>
<th>CONDITION</th>
<th>OTHER NAMES</th>
<th>INCIDENCE</th>
<th>TYPES OF BLEEDING</th>
<th>TREATMENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Factor I</td>
<td>Fibrinogen deficiency</td>
<td>1 in 1,000,000</td>
<td>- bleeding from the umbilical cord; urinary tract bleeding; intra-cranial bleeding.</td>
<td>· fresh frozen plasma · cryoprecipitate · fibrinogen concentrate</td>
</tr>
<tr>
<td>Factor II</td>
<td>Prothrombin deficiency</td>
<td>Only 30 cases identified in world</td>
<td>- bleeding from the umbilical cord; nose bleeds; easy bruising; heavy or prolonged; menorrhagia; abnormal bleeding after giving birth; bleeding after trauma or surgery; occasional muscle bleeds; nose bleeds; easy bruising; menorrhagia; bleeding after trauma or surgery.</td>
<td>· fresh frozen plasma · prothrombin complex concentrate</td>
</tr>
<tr>
<td>Factor V</td>
<td>Parahemophilia</td>
<td>1 in 1,000,000</td>
<td></td>
<td>· fresh frozen plasma</td>
</tr>
<tr>
<td>Factor VII</td>
<td>Alexander's Disease</td>
<td>1 in 500,000</td>
<td>- menorrhagia; nose bleeds; bleeding from the gums after tooth extractions; easy bruising; bleeding in the joints; bleeding in soft tissues and, more rarely, in muscles; blood in the urine; intracranial bleeding; bleeding in the mother after delivery; bleeding during and after trauma or surgery.</td>
<td>· Factor VII concentrate</td>
</tr>
<tr>
<td>Factor VII</td>
<td>Classical Hemophilia</td>
<td>1 in 10,000</td>
<td>- joint bleeding; muscle bleeding; bleeding after dental work; bleeding after trauma or surgery.</td>
<td>· Factor VIII concentrate</td>
</tr>
<tr>
<td>Factor IX</td>
<td>Christmas Disease</td>
<td>1 in 35,000</td>
<td>- joint bleeding; muscle bleeding; bleeding after dental work; bleeding after trauma or surgery.</td>
<td>· Factor IX concentrate</td>
</tr>
<tr>
<td>Factor X</td>
<td>Stuart-Prower deficiency</td>
<td>1 in 500,000</td>
<td>- umbilical cord bleeding; bleeding after circumcision; bleeding into the joints; nose bleeds; easy bruising; bleeding in soft tissues and in muscles; gastrointestinal bleeding; menorrhagia; blood in the urine; intracranial bleeding; first-trimester miscarriage; bleeding in the mother after delivery; bleeding during and after surgery or trauma.</td>
<td>· fresh frozen plasma · thrombin complex concentrate</td>
</tr>
<tr>
<td>Factor XI</td>
<td>Hemophilia C</td>
<td>1 in 100,000, 1 in 12 are carriers among Ashkenazi Jews</td>
<td>- persistent bleeding after surgery or trauma; - bleeding after tooth extractions; menorrhagia.</td>
<td>· fresh frozen plasma · Factor XI concentrate</td>
</tr>
<tr>
<td>Factor XIII</td>
<td></td>
<td>1 in 3,000,000</td>
<td>- umbilical cord stump bleeding; severe bruising; bleeding in soft tissues and in muscles; intracranial bleeding; miscarriage; bleeding in the mother after delivery; bleeding after surgery or trauma.</td>
<td>· fresh frozen plasma · Factor XIII concentrate</td>
</tr>
<tr>
<td>Type 1 VWD</td>
<td></td>
<td>~ 1 in 150</td>
<td>- bleeding from the gums; nose bleeds; minor bruises; prolonged bleeding from cuts; menorrhagia; bleeding after surgery or trauma.</td>
<td>· desmopressin · anti-fibrinolytics · thrombin · hormone therapy</td>
</tr>
<tr>
<td>Type 2A VWD</td>
<td></td>
<td>~ 1 in 500</td>
<td>- bleeding from the gums; nose bleeds; minor bruises; prolonged bleeding from cuts; menorrhagia; bleeding after surgery or trauma.</td>
<td>· VWF concentrate · anti-fibrinolytics · thrombin · hormone therapy · desmopressin (in some cases)</td>
</tr>
<tr>
<td>Type 2B VWD</td>
<td></td>
<td>~ 1 in 3,000</td>
<td>- bleeding into joints and muscles; bleeding from the gums; nose bleeds; minor bruises; prolonged bleeding from cuts; menorrhagia; bleeding after surgery or trauma.</td>
<td>· VWF concentrate · anti-fibrinolytics · thrombin · hormone therapy</td>
</tr>
<tr>
<td>Type 3 VWD</td>
<td></td>
<td>1 in 500,000</td>
<td>- bleeding into joints and muscles; bleeding from the gums; nose bleeds; minor bruises; prolonged bleeding from cuts; menorrhagia; bleeding after surgery or trauma.</td>
<td>· VWF concentrate · anti-fibrinolytics · thrombin · hormone therapy</td>
</tr>
<tr>
<td>Platelet function disorders</td>
<td>Many sub-types</td>
<td>~ 1 in 100</td>
<td>- nose bleeds; easy bruising; bleeding from the gums when baby teeth fall out or after tooth extraction; menorrhagia; bleeding into the stomach or intestine; bleeding after trauma or surgery.</td>
<td>· desmopressin · anti-fibrinolytics · thrombin · hormone therapy · platelet transfusions</td>
</tr>
</tbody>
</table>
Reaching Out

This isn’t the first time this column has been devoted to the theme of supporting each other nor, I venture, the last. It is one of the founding principles of our national, provincial and local chapters. Much good has come over the years from talking and sharing our experiences with each other. We have the challenge of bleeding disorders in common. Our family is comprised of those who have a bleeding disorder and those of us who are parents, siblings, grandparents, friends and family of people with bleeding disorders. It seems fitting to highlight a new pilot project being planned in London, Ontario as we celebrate the anniversary of 50 years of caring and support.

At SWOR (South Western Ontario Region), this age-old tradition of support between families is getting an overhaul! Julie Serrard is the Regional Service Coordinator at SWOR. She joined SWOR this fall and has taken over the challenge of launching a pilot project to pair families together, one a newly diagnosed family and the other a family with some living experience with a bleeding disorder. (Watch out, Julie, the “It’s a Boy/Girl Programs” are in need of an overhaul and your initiative fits in nicely with that goal, too!)

Julie is setting up a pilot project to pair families together. She is able to do so, through the financial support of Bayer Inc. Julie has an extensive non-profit background. She has worked as an education and service coordinator, run community outreach programs and even worked at a camp for kids with sight and hearing disabilities. She is enthusiastic about the new pilot project.

“It’s a great opportunity for me to get to know the bleeding disorder community and the need for this type of program is strong. I’ve had great feedback so far and look forward to getting the project off the ground.”

The pilot project will start off with 10 pairs of families from across the country. One of the challenges of the project is to identify host families to work with the new families. For the pilot project, SWOR families will be trained to work with families from across the country. Once the pilot phase is completed the ideal situation will be to recruit host families from across Canada to draw on their diverse experiences and expertise to provide the best-suited match for the newly diagnosed family. The host family will be trained in preparation for their role as mentor. Training will include what families should and should not say, what the host/mentor role is meant to be, active listening, how involved to get and not to get, when to refer matters back to Julie, and participant feedback.

Julie has researched 12 other programs in operation including those at The War Amps and at the AIDS Committee of London. These programs have very successfully provided support amongst families in similar situations. Like these programs, this pilot project will provide support and reassurance to new families and provide them with a connection to our community.

Many of us have worked with families who are dealing with a newly diagnosed case of hemophilia or von Willebrand Disease. I think the participants in this project will find they are not only helping the new families, but they will also receive great satisfaction and support from their buddy family. Many of us have benefited from the support, kindness and interest of families with older children or from the same support from adults with bleeding disorders.

Funds raised are going to awareness and educational workshops/events for adults and youth. We received “in-kind” donations from NEXT Communications, the company that designed and printed our display boards and tickets. Our other sponsors were: Audio-Warehouse, Baxter Pharmaceuticals, NovoNordisk, Wal-Mart and Wyeth.

Thank you to each volunteer who sold tickets and to our wonderful sponsors for their generous contributions!
PAIN – THE FIFTH VITAL SIGN

Dr. Peter Leung
Pain Management Service
St. Michael’s Hospital

Most health care providers and consumers are used to having the four routine vital signs recorded. Blood pressure, pulse rate, temperature and respiratory rate are documented every time a patient presents for a medical assessment. Yet the most common reason for seeking medical care is pain. In 1995, the President of the American Pain Society, Dr. James Campbell, coined the above captioned title suggesting that “quality care means that pain is measured and treated”. When we add the measurement of “pain” as one of the essential records for all patients, then we are finally focusing on the main cause for access to medical care.

Health Regulatory Boards in many U.S. states have legislated guidelines to mandate pain assessment with all patient contacts. Pain is now officially considered the fifth vital sign by the Joint Commission on Accreditation of Healthcare Organizations; in other words, all health facilities have to include pain as the fifth vital sign for that facility to be accredited. The California Governor recently signed into law the Health and Safety Code (HSC). As part of this bill, HSC 1254.7 reads:

(a) It is the intent of the Legislature that pain be assessed and treated promptly, effectively, and for as long as pain persists.
(b) Every health facility licensed pursuant to this chapter shall, as a condition of licensure, include pain as an item to be assessed at the same time as vital signs are taken. The health facility shall insure that pain assessment is performed in a consistent manner that is appropriate to the patient. The pain assessment shall be noted in the patient’s chart in a manner consistent with other vital signs.

Surveys report 14% of the population have sick days due to pain, 75% use over the counter pain medications and 35% use prescription pain medications. Chronic pain accounts for more total annual costs than other chronic conditions such as heart disease, high blood pressure and diabetes. In the hemophilia community, a new bleeding episode is recognized primarily because it causes pain. Hemarthrosis — bleeding into the joint — is most common. The pain from the inflammatory reaction of blood in the joint can become severe; the joint swelling then further aggravates the pain. Bleeding into the muscle also gives rise to pain and swelling and, if unabated, can damage nerves, tendons or other structures. Other sites may or may not be as painful and each person with hemophilia will have different common sites.

What then is pain? Pain is very difficult to define in words but the International Association for the Study of Pain did try. “An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage.”

Pain is always subjective. The person with pain is the one who decides if there is pain or not. It is always unpleasant and since we learn of pain from injury in early childhood, it is described in “damage” terms. Lastly, it is an emotional experience. We should note that there does not have to be actual damage to specific areas of the body to cause pain. In other words, when pain becomes chronic, we may not see the actual injury or the physical response such as changes in heart rate, blood pressure or even grimacing and crying out.

Some books or pamphlets on hemophilia might talk about individual differences of pain perception but the pain level is yours and yours alone. Do not feel that your pain is less significant than that of others, and certainly you must not feel guilty or embarrassed because you need medication or treatment for both acute and chronic pain. Actually, inadequate initial pain management may be a cause for future abnormal pain behaviour.

The aim of pain control within the first few hours of a bleeding episode is relief of suffering. With chronic pain control there is the added aim of maintaining daily function. The balance between the efficacy of pain relief, the side effects if any, and the ability to be as functional as possible is the final goal of management. Any and all modalities of pain management — physical, pharmacological and psychological — should be incorporated into the scheme if beneficial.

How do we measure pain?

Unlike its vital sign counterparts, however, there is no gadget to measure pain; it must be evaluated by asking questions and observing behaviour. And unlike temperature or blood pressure, getting accurate data about pain depends on two-way communication between the health care provider and the patient. These are some helpful tools:

**Numeric Rating Scale:**
Instructions: Choose a number from 0 to 10 which indicates how strong your pain is right now.

- No pain at all = 0
- 1 2 3 4 5 6 7 8 9 10

**Visual Analog Scale:**
Instructions: Mark on the line below how strong your pain is right now.

- No pain at all ——————————— The worst pain imaginable

**Category Scale:**
Instructions: Choose the word below which best describes how your pain feels right now.

- Mild
- Disconforting
- Distreeing
- Horrible
- Excruciating
For children aged 3 and older, a range of tools is available for self-reporting and behaviour observation; children from approximately age 5 are able to reliably complete a VAS (Visual Analog Scale) score. One useful tool might be the “Face Scales”.

Once we measure the level of pain, we can go ahead with the treatment plan. The clinician may quantify it on a single dimension using, for example, a single VAS, but this approach risks being too simplistic. Pain has sensory, emotional, motivational, cognitive, and behavioural dimensions. We must be aware that clinical pain intensity does not necessarily vary directly with the extent or severity of clinical pathology. Hence the individual’s subjective response overrides the clinician’s bias of labeling the patient. Every patient deserves the most effective treatment, not what the provider feels he/she should have. Many barriers impede humane and competent assessment and management. Patients and health care professionals also often differ culturally and socially. Treatment for chronic pain and chronic illness may be unavailable, unaffordable, or not covered by health insurers. The variability and unpredictability of pain in hemophilia make effective coping difficult, and thus contribute to an adversarial relationship so often observed between patients and health care professionals.

Fortunately, there is already a major shift in attitudes toward pain medications. Not so long ago, there was a reluctance to prescribe pain killers because they might cause addiction or interfere with recovery. Research has shown that the risk of clinical addiction is overestimated and, in fact, quite rare at the dosages used for pain management. What’s more, recovery takes place faster when pain is properly managed. Unrelieved pain can actually interfere with healing and turn acute pain into a chronic problem.

I believe that recognizing the 5th vital sign puts assessment at the forefront and sets the tone for cooperation. “What level is your/your child’s pain?” brings the family and the provider into an alliance against the suffering.

Once we have all parties on the same side, the therapeutic plan can be developed for future episodes and daily chronic pain. Then, there is no fear of the agony of the next episode because the patient can assume “control” and knows there is a path to follow with back up plans in place.

This all stems from a simple assessment tool, what we refer to as the “vital signs”.

### The Blood Factor

**David Page, CHS Blood Safety Coordinator**

### Preparations for summer

**West Nile Virus season underway**

In the summer of 2002 at least one Canadian was infected with West Nile Virus (WNV) through a blood transfusion. At least thirteen cases occurred in the U.S. As the 2003 mosquito season nears, concerns mount about the integrity of the Canadian blood supply should the West Nile Virus epidemic in mosquitoes, birds, horses and humans continue, or worsen.

Huge efforts are underway to develop a test to screen blood donations for WNV and introduce it across Canada by July. Fresh frozen plasma and cryoprecipitate collected during the winter months are being stockpiled in case the test is not ready. Other creative strategies are being evaluated in an effort to reduce the risk to patients.

WNV can be transmitted through red blood cells, platelets, fresh frozen plasma, cryoprecipitate and cryosupernatant. Risks in 2002 were extremely small, but real. Risk estimates for 2003 are difficult to make as the scope of the epidemic cannot be predicted.

Products manufactured from plasma such as factor concentrates, immunoglobulins and albumin have been shown not to transmit WNV.

### Baxter announces ADVATE as brand name for its third-generation FVIII recombinant product

Baxter International Inc. announced in February that ADVATE is the proposed proprietary name for its investigational factor VIII therapy - Antihemophilic Factor (Recombinant), Plasma/Albumin-Free Method (rAHF-PFM). This announcement follows the provisional acceptance of the brand name by both the U.S. Food and Drug Administration (FDA) and the European Medicines Evaluation Agency (EMEA).

Hemophilia Today reported on the early results of clinical trials with ADVATE in the spring 2002 issue (Vol 37, No 1). ADVATE is expected to be the first FVIII recombinant product made without the addition of human or animal proteins at any stage of the production process to come to market.

### Reports of cyro being used to treat hemophilia A

At the January 25-26 meeting of the CHS Blood Safety Committee, it was reported that cryoprecipitate is still being used to treat some people with hemophilia A. These unconfirmed reports came to light at the time of the plasma and cryoprecipitate recalls for West Nile Virus in late December. The provinces mentioned were Quebec and Ontario.

Note that cryoprecipitate continues to be supplied to hospitals by both CBS and Héma-Québec to treat certain conditions; however, since the arrival of enhanced viral-inactivated factor concentrates in the late 1980s, cryoprecipitate has not been the recommended treatment for hemophilia A both because of its lesser efficacy and continued very small risk of transmitting human viruses. In addition, with the availability of enhanced viral-inactivated von Willebrand factor, physicians have preferred to use factor concentrates, such as Humate-P®, in those situations where desmopressin and other hemostatic agents are not effective for VWD.

After discussion, the following motion was made: “In the opinion of the Blood Safety Committee, notwithstanding exceptional circumstances and patient preferences based on informed choice, given the safety record of high-purity factor concentrates over the last ten years, cryoprecipitate represents a sub-standard form of care for hemophilia A.”

If chapters are able to identify any physicians continuing to prescribe cryoprecipitate, the following actions are suggested:

i) provide them the AHCDC guidelines (http://ahcdc.medical.org/)
ii) refer them to specialists in the nearest Hemophilia Treatment Centre.
In February Health Canada approved the release of individual lots of ReFacto®, a second-generation recombinant factor VIII concentrate used to treat hemophilia A, manufactured by Wyeth. ReFacto obtained its Notice of Compliance in June 2002.

This brings to four the number of recombinant factor VIII products on the Canadian market: Kogenate® FS, manufactured by Bayer; Recombinate®, made by Baxter; Helixate® FS, from Aventis-Behring; and now ReFacto.

Note that Kogenate FS and Helixate FS are identical products manufactured by Bayer. Under a licensing agreement, Aventis-Behring distributes a significant percentage of the production of Bayer’s Berkeley manufacturing facility.

Both Wyeth and Aventis Behring are continuing talks with the Canadian Blood Services and Héma-Québec in efforts to have their products made available on a regular basis.

The Canadian Hemophilia Society has consistently made known its position to the operators: physicians and patients should have freedom of choice in selecting the most appropriate therapy. In addition, the Canadian blood system should establish permanent relationships with multiple distributors so as to minimize risks to supply.

Bayer, Aventis Behring merger off, Aventis starts talks with CSL

Bayer and Aventis Behring have cancelled plans to combine their plasma products units after a year of talks. Bayer has said that it will continue to run its biological products unit on its own. Aventis said in a statement that it is “proactively exploring alternative options for the future of Aventis Behring.”

Only weeks later, Aventis Behring announced that it had entered into preliminary negotiations with CSL Limited regarding the acquisition of Aventis Behring.

CSL is an Australian company which manufactures products derived from human plasma. The company has grown dynamically over the last few years through the acquisition of ZLB in Switzerland in 2000 and the NABI plasma collection centres in the United States in 2001. Today, CSL is ranked number three in fractionation volume and number four in sales revenue in the plasma protein industry, with a strong focus on immunoglobulins.

In the hemophilia field Aventis Behring manufactures and/or distributes these products in the Canadian market: Helixate® FS, a recombinant factor VIII; Monoclate® P, a monoclonal antibody purified plasma-derived factor VIII; Mononine, a monoclonal antibody purified factor IX; and Humate-P® to treat von Willebrand Disease.

More data on prion removal

Aventis Behring has announced that studies show its procedure for cleaning the production equipment for plasma-derived therapies has the capacity to eliminate the theoretical risk of prion contamination. Although prions have never been found in the blood or plasma of people with CJD or vCJD, a study published in a supplement of Blood, suggests that even if prions did contaminate equipment, they would not adhere to the surface of the equipment and would be removed by standard cleaning procedures.

Reaching Out continued from page 12

disorders. Families In Touch was started as a support group at TCOR (Toronto Central Ontario Region), over 5 years ago for the very same reasons Julie is undertaking this project.

On the day we founded FIT (Families in Touch), mostly as a group of moms, Margaret Plater joined us. Margaret is a founding member and long time supporter of our associations. She is, of course, John Plater’s mother. On that day Margaret talked about sending a child to camp for the first time, the interaction of siblings with and without a bleeding disorder and about the day she was left outside the doctor’s office at John’s first appointment at St. Michael’s Hospital. I’ve already sent kids to camp, although I have a few years left before we graduate to St. Mike’s. I do know that every hug and shared experience from all the moms and dads I have met will help me along the way.

Good luck, Julie. Keep up the great work. You have a wonderful opportunity to do something outstanding. If anyone has any suggestions on what to call this project, or if you are interested in being a part of it, please contact Julie at the SWOR office.

jserrador@hemophilia.on.ca
SWOR: 519-432-2365

continued from page 4

The Patient Notification System is a confidential, 24-hour communication system providing information on plasma-derived and recombinant product withdrawals and recalls. It was created to provide a single, convenient source for up-to-date product withdrawal and recall information.

The Patient Notification System was developed in the U.S. by the Plasma Protein Therapeutics Association of Washington, D.C. (made up of 11 manufacturers), in conjunction with relevant consumer groups. NNC Group, based in Indianapolis, Indiana, is the System Operator. It has been adapted for Canadian use by an advisory panel of Canadian companies, and relevant medical and patient groups who worked with Canadian Blood Services and Héma-Québec. In Canada, the system is offered with funding from plasma and protein therapy producers and distributors.

The system is entirely voluntary. In Canada, notification of a recall or withdrawal of blood or blood products is the primary and legal responsibility of the treating physician and/or hospital officials. Registering or choosing not to register with PNS does not alter current patient notification by treating physicians and hospitals.

If you would like to register, you can do so by visiting the Web site at www.patientnotificationsystem.org, calling the toll-free phone number (1-888-UPDATE-U), or by sending an application form by mail to NNC Group, Attention: PNS Manager, 5250 West 76th Street, Indianapolis, IN, 46268. There is no cost to the consumer and you will be asked to provide your name, contact information, password, password hint and a list of the product(s) you would like information on. You can choose to be contacted by U.P.S. Express, telephone, fax or e-mail. You will also receive a follow-up notification by regular mail. Detailed information can be found on the Web site. Please note that promotional pamphlets containing application forms are available upon request by sending an email to ippo@bloodservices.ca or calling 613-260-6800.

The Patient Notification System is completely confidential. It is operated by NNC Group, an independent organization that specializes in pharmaceutical notifications. All patient information is held in strict confidence by NNC Group. Every attempt will be made to reach you within 24 hours of any recall or withdrawal.
TCOR Twins with Jordan

Candace Terpstra

Jordan is a small country — 100,000 square kilometres of land, mostly desert — sandwiched between Israel and Saudi Arabia and also bordering on Syria and Iraq. It is not an oil rich country. The population of the country is five million and, just like every country in the world, some people have hemophilia. There is no hemophilia treatment centre in the entire country of Jordan and factor concentrates are extremely scarce.

On November 8th, 2002, the World Federation of Hemophilia officially recognized the partnership between the Toronto and Central Ontario Regional Hemophilia Society and the Jordan Blood Diseases Patients Friends’ Association (Hemophilia Committee). When you learn that hemophilia affects 400,000 people worldwide, seventy-five percent of whom have little or no treatment, and when you know that national hemophilia care programs have been proven to increase the life expectancy of people with hemophilia, you realize there is much to be done. The World Federation Twinning program is one way of supporting local hemophilia organizations to improve national hemophilia care programs in their own countries.

In the fall of 2002, Karttik Shah and I traveled as representatives of TCOR to Amman, Jordan. It was a pleasure to meet the members of the Jordan Hemophilia Committee: Arafat Awajan, Wael Hudhoud, Mohammed Jaber, Alla, and Mahera Hamza. Without realizing it, they form quite a dynamic little group. They remind me of the early days of the Canadian Hemophilia Society when passion and commitment kept members going, working, moving forward, one step at a time to the next task. Already they have formed a Committee, part of a larger organization officially recognized by the Queen of Jordan. More recently, they rented separate office space in Amman and the office was freshly painted just prior to the visit. They have been in contact with about 350 members thus far and are reaching out to find more. And so it continues.

As for my impressions, there are no words to describe the incredible hospitality with which we were treated. We were personally greeted at the airport at 3:00 a.m., met families in their homes, attended a packed members’ meeting in the new office, were personally accompanied on all visits and shared many wonderful meals with members of the Committee.

The assessment visit also included more formal activities such as meeting with key personnel in local hospitals and the blood bank, as well as a meeting with the Minister of Health. As part of the Fourth International Biotest Hemophilia Forum for physicians, we were able to visit the site of the ancient city of Petra and the Dead Sea. This was especially enjoyable as our hosts from the Jordanian Hemophilia Committee accompanied us on these trips.

Twinning is a two-way street and already we have learned a tremendous amount about Jordanian culture and religious customs in the Middle East. There will be lots more to come as we continue to work together at educating families through meetings and newsletters, and planning a symposium for the fall of 2003. These initial activities will set the stage for later advocacy efforts to improve hemophilia care and treatment in the country of Jordan.

I invite all our members to think about what they can do to support World Federation Twinning Programs. It is surely a worthwhile endeavour.
Endometrial Ablation

Menorrhagia (heavy or prolonged menstrual bleeding) often leads to problems including severe anemia. When the problem cannot be controlled with hormone therapy or other medication, surgical options may be the only way to control blood loss.

In the past only a hysterectomy could stop menstrual bleeding altogether. Today, for many patients, a simple safe outpatient procedure called uterine or endometrial ablation (EA) in which the uterine lining is removed will often alleviate excessive menstrual blood loss. In contrast to a hysterectomy which may violate excessive menstrual blood loss. In contrast to a hysterectomy which may require up to 8 weeks for recovery, most women who have EA are able to return to most normal activities within 2-3 days. Gynecologists have been successfully performing endometrial ablation since 1990.

Preparations

Before undergoing any procedure, a woman should be examined to eliminate any other mechanical disorder such as a fibroid tumor or a polyp in the lining of the uterus which could cause bleeding to occur. The existence of a bleeding disorder does not rule out these problems. Other tests could include blood tests, uterine lining sampling (biopsy), and a saline sonohysterogram or office hysteroscopy to evaluate the size and configuration of the woman's endometrial cavity. These procedures are usually done in the physician's office and are quick and relatively painless. Proper treatment precautions should be taken to prevent further bleeding in women with a bleeding disorder.

For 1 to 2 months before the procedure anti-hormones may be prescribed to decrease the thickness of the endometrium. Thinning the uterine lining exposes the lower (basal) layer of endometrial cells; this is the tissue that will be removed.

Procedure options

Hysteroscopic endometrial ablation or “RollerBarrel system”: Developed in the early 1990s, this is a first-generation EA technique and an experienced gynecologic endoscopic surgeon is required. The patient receives a general anesthesia. Endometrial ablation is performed by inserting a narrow viewing tube through the vagina and the cervix into the uterus. A tiny camera attached to the viewing tube (hysteroscope) allows the uterine cavity to be shown on a TV monitor. The uterus is filled with a harmless liquid to make the procedure easier. The lining of the uterus is then burned away or vaporized, using a laser or electrosurgical tool inserted through the viewing tube.

Second-generation EA devices have now been developed including uterine balloon technique (UBT) and the Microwave technique, among others. Benefits of these procedures are that they are easier to perform, easier to learn by physicians, have very high success rates, are safer than first generation devices, and in contrast to first generation devices, can often be performed in your doctor’s office, taking less than 15 minutes, and requiring only local anesthesia.

These second-generation devices require less operator skill than for hysteroscopic endometrial ablation and no irrigant or distending solutions. All utilize heat to destroy the endometrium. Both UBT and Microwave techniques avoid the use of laser or electrosurgical energy, liquid uterine distention media, and their associated complications. The woman will normally stay in the recovery area for 1-2 hours, and then be discharged. There may be some mild menstrual cramping and vaginal bloody discharge for the next few days.

Potential risks

Most potential complications of EA involve use of the hysteroscopic endometrial ablation devices. These include the risks of anesthesia, uterine perforation, and absorption of large volumes of fluid used during the ablation procedure (fluid overload).

The global endometrial ablation procedures have the advantage of not using high volumes of, or dangerous, fluids, requiring less anesthesia, requiring less time to complete, and in many cases, can be performed in a gynecologist’s office rather than a hospital.

Post ablation

Most women cannot have children after endometrial ablation. However, because there is still a slight possibility of pregnancy, contraceptive methods should continue to be used until menopause.

It’s important to realize that these procedures are not guaranteed to produce amenorrhea (cessation of menses). Most studies have shown that the rate of absolute stoppage is 50%, while another 25% of patients have very little bleeding.

Approximately 10 percent of women will move on to hysterectomy and 10 percent will require a repeat endometrial ablation for failed initial treatment. Reoperation rate at five years may be up to 40 percent with rollerbarrel ablation. Patients undergoing surgery after the age of 40 appear to have a better outcome.

2. www.ivf.com/eablate.html

This section is related specifically to women with bleeding disorders and their families. All articles are reviewed by physicians to ensure medical accuracy. If you have any questions, comments or ideas, feel free to contact me, Patricia Stewart, at the following addresses: Phone & Fax: 418-884-2208 or e-mail: stewart.page@globetrotter.ca or simply put pen to paper and mail to: 389, R.R. # 4, La Durantaye, Quebec G0R 1W0
CHS 50th Anniversary Celebrations

Patricia Stewart, Chair, CHS 50th Anniversary Celebrations

Celebrations for the 50th Anniversary of the founding of the Canadian Hemophilia Society will be taking place May 8-11th, 2003, at the Centre Sheraton Hotel in Montreal. The CHS is planning a number of activities to highlight this important occasion.

- **Public exhibit on bleeding disorders**

  Located in the Complexe Desjardins in downtown Montreal, the CHS will present a public display on the history of hemophilia, its treatment and the achievements of the CHS. Mario Lemieux, the CHS Honorary President, and M.J. O’Grady, will be the virtual guides for visitors along this fifty-year timeline. Mario’s family has graciously offered some Mario Lemieux memorabilia to make the exhibit even more attractive. At the same time, Héma-Québec is working with the CHS and is setting up a blood donor clinic beside our exhibit. We’re looking for volunteers to man the exhibit and to thank donors for giving blood. Buses have been arranged on Thursday night and Sunday morning to take you to the exhibit. The exhibit itself will later be available to travel across the country to be shared with all chapter members.

- **Commemorative book – 50 Years to Remember**

  In order to have a written and pictorial history of the CHS, a commemorative book will be distributed during the weekend. People active in the Society over the last five decades will be contributing their memories of living with hemophilia. Many volunteers and health care professionals who have made major contributions will also be included. This limited edition book will be available to all members.

- **MSAC research symposium**

  Medical personnel will give an update on the most recent research in hemophilia-related areas and answer questions. This will take place Friday afternoon.

- **Youth dinner**

  Young people from 18-25 years of age will be attending a dinner on Friday evening giving them a chance to get together and discuss their vision of the future of the CHS. It’s also a chance for them to meet others from across the country who will eventually become the lead volunteers in the CHS.

- **Medical Symposium**

  During the weekend there will a medical symposium for patients on a variety of topics including pain management, visiting the ER, the safety and supply of blood and blood products, and the latest in HCV treatment and women’s issues. This is a chance to get the latest information from specialists and find answers to your questions.

- **Poster exhibit**

  One of the strengths of the CHS is the dedication of its volunteers. A poster exhibit will be displayed at the hotel during the weekend on a variety of topics. You may find faces from the past and perhaps even see yourself in this exhibit. This will be the CHS giant family photo album and a reminder of much that has happened in the fifty years since its founding.

- **Pioneer Award**

  This award was created to acknowledge the founders of each chapter, people who had a dream of improving care for the hemophiliacs in their own province. This award is to be presented by each Chapter to the recipients during the year.

- **50th Anniversary Banquet**

  No celebration would be complete without a feast. The banquet will take place on Saturday evening. This is a chance for people to renew acquaintances and see old friends. All Past-Presidents and Honorary Life Members have been invited making this a truly multi-decade celebration.

Make sure you send in your registration as soon as possible. Don’t miss out on this once-in-a-lifetime opportunity to commemorate 50 years of tragedy and triumph in the care of people with bleeding disorders.
CHS to host 1st Canadian State of the Art Conference on von Willebrand Disease

1st Canadian State of the Art Conference on von Willebrand Disease

Dr. David Lillicrap, Chair, Conference Steering Committee

On May 8th and 9th 2003 in Montreal, the CHS will be hosting the 1st Canadian State of the Art Conference on von Willebrand Disease to coincide with the 50th anniversary celebrations for the Society. The conference promises to be an excellent forum for reviewing the diagnostic, treatment and patient-related issues associated with this condition, in light of recent advances in knowledge.

Despite the fact that von Willebrand Disease (VWD) has been recognized as a distinct clinical condition for more than 75 years, there are still many unresolved questions about its genetic basis, the most effective way to diagnose it and the optimal forms of treatment in different clinical settings. Furthermore, until very recently, critically important issues such as quality of life measurements have not been investigated in the context of VWD. There even remains uncertainty about the population prevalence of the condition, with figures ranging from 1 in 100 to 1 in 100,000 being quoted in the medical literature. Overall, these remaining questions, along with recent advances in our understanding of the biology of von Willebrand Factor (VWF), suggest that this conference comes at a time when a comprehensive reassessment of VWD will be very informative for the professional and patient communities alike.

In considering the best way to review this topic, the Steering Committee for the conference has developed a program that we hope will be informative and engaging to all attendees, whether they be a professional care giver or a patient. The meeting will begin with a series of four “stage-setting” plenary talks by international experts in this area. Drs Bob Montgomery and David Ginsberg will talk about the clinical and laboratory presentation, and genetic basis of the disease, respectively, and will, in particular, address the challenging questions of how to diagnose and sub-classify patients with this disorder. The third presentation, by Dr. Craig Kessler, will focus on treatment issues, and will consider the best forms of therapy for specific hemostatic challenges as well as suggesting optimal ways to evaluate treatment outcome. Finally, Dr. Christine Lee will address the issue of clinical management of VWD in women, the patient group in which the most adverse quality of life outcomes have now been documented in VWD.

For the remainder of the meeting, the challenge for the attendees will be to place the information presented by the plenary speakers into the context of a series of “Conference Recommendations” relating to VWD diagnosis, treatment, specific management issues in women and patient advocacy matters. These recommendations will be developed through a series of interactive forums that will be overseen by members of the Planning Committee. Finally, the conclusions of each of the four forums will be presented to all conference attendees at a summary session on the Friday morning of the meeting. This will enable input and discussion by all attendees on each of the forum topics and recommendations.

We hope that you will be able to attend this conference for what we think will be an outstanding review of this, the commonest inherited bleeding disorder in humans. Further details about the 1st Canadian State of the Art Conference on von Willebrand Disease including the registration form are available on the CHS website at www.hemophilia.ca.

Managing the Bleeding Patient: von Willebrand Disease Diagnosis, Treatment and Gynecological Considerations

May 8-9, 2003 • Le Centre Sheraton Hotel • Montreal, Quebec

A 2-DAY CONFERENCE for physicians, nurses and other medical professionals in the fields of:

- Inherited bleeding disorders
- Hematology
- Obstetrics / Gynecology
- Nursing
- Family Practice

We invite you to attend this conference in order to increase your understanding of the diagnosis and clinical management of the bleeding patient with von Willebrand Disease.
As a young boy with hemophilia in Montreal in the 1950s, whose parents and grandparents were active in the Canadian Hemophilia Society, I grew up hearing about ‘Frank’. In my house he was portrayed as a sage. I knew he wasn’t a doctor, yet he was the one whose words counted. “Frank says there’s a new blood product. It means surgery could be safe.” “Frank says he’s getting his plasma as an out-patient—he’s not being admitted to hospital anymore.” “Frank says we need to push for comprehensive care.”

I knew Frank had hemophilia like I did, yet he was doing the most amazing things. He was the Consul-General for Costa Rica—this was very mysterious—and was always traveling around the world. He had a huge office at the top of Montreal’s tallest skyscraper—even more impressive—which I visited on occasion. (I now know he worked as an investment analyst at The Imperial Trust.) And, best of all, he had season tickets for the Montreal Canadiens hockey team and, when I was very lucky, invited me to go with him. Watching the game, we discussed everything under the sun, including hemophilia. It was in researching this article that I came across these words of Frank’s from the 1960s.

“I wanted to be like everyone else. I didn’t want to be different. So I never told anyone what was wrong with me. Then it occurred to me that if all hemophiliacs hid their problem, how could we ever expect to make any progress? I felt we had to educate people about hemophilia, and then push, and push hard, for better treatment and more career opportunities. So I went to the other extreme and just refused to stop talking about hemophilia.”

I remember my parents’ pride that this young Montrealer, who had rounded up patients, parents and physicians to found the Canadian Hemophilia Society in 1953, went on to create the World Federation of Hemophilia ten years later, with six founding National Members—Argentina, Australia, Belgium, Canada, France and United Kingdom. And, only five years later, he brought many more countries to our city for one of the first World Congresses. Imagine how proud Frank would be today to see the number of WFH National Member Organizations surpass one hundred!

As I grew up, Frank’s youthful face, with the dark horn-rimmed glasses, was the face of hemophilia. It looked out at me from newspaper and magazine articles which my mother carefully preserved in scrapbooks. Words like these influenced my parents and parents around the world in rearing children with hemophilia.

“My parents decided that they didn’t want me to live in a cotton wool existence and they did everything possible to allow me a normal childhood. My mother later told me it was the hardest thing she ever had to do—to stand back and let me do all the things kids normally do—and then rush me to hospital when I got hurt.”

In these newspaper and magazine photographs, Frank was often flanked by prominent physicians in hemophilia care. Such collaboration was unheard of at the time. Chris Tsoukas, Frank’s Montreal physician, once said:

“Frank was the one who dared break into the medical establishment and propose a meeting of minds, a cooperation between the care givers and the care receivers. He was the one who by organizing and bringing together hemophiliacs made them feel they were not alone.”

Frank’s contribution was more than that of a patient advocate. He became as competent on hemophilia issues as any of the trained medical personnel. Again, in the words of Chris Tsoukas.

“Professionally, he was invaluable to me, in helping me begin my research career. He was my sounding board, the person I knew I could talk freely and openly with. He was a great listener and always gave me good advice and encouragement. He helped me to keep my enthusiasm for my work, even during times of gloom.”

Frank’s contribution was recognized outside the hemophilia community. Among many other decorations, he was awarded in 1967 the Centennial Medal by the Government of Canada. In 1970 the International Society for the Rehabilitation of the Disabled designated Frank ‘Representative to the Assembly’ in recognition of distinguished service rendered to advance the welfare of disabled persons throughout the world.

It is without doubt that Frank’s most important achievements were on the world stage. One observer commented, “To most people the world is a big place to live in; to Frank Schnabel, the world was his backyard. He used the newspapers, telex and the telephone to shrink the world to manageable size.” Imagine what he would have accomplished in the era of E-mail and Internet!

Frank’s extensive travel on behalf of WFH could not have been without sacrifice. The Reverend Alan Tanner, former Chairman of the WFH, said of Frank:

“I think he must have been one of the most widely traveled people ever. And on all those occasions I have seen his single minded devotion to the national member organizations and to individuals who came to him for advice and guidance. He was the pioneer in establishing this great blood brotherhood. And all of this was achieved at great personal cost to himself, because he never spared himself. Lesser men would not have started the journey.”

I happened to be in hospital in Montreal at the same time as Frank just before his death in 1987 at the age of 61. His hospital room had become the nerve centre of the WFH. Frank was summoning people to his bedside so that his work could continue. Few of us could tell how ill he was. Only weeks later, The Reverend Tanner spoke these words in Frank’s eulogy.

“For many years to come, the names of the World Federation of Hemophilia and Frank Schnabel will be synonymous; and many boys and men throughout the world look to Frank Schnabel as their model and their hero because he demonstrated so clearly that they could rise above the complications of hemophilia and turn adversity into triumph.”

This tribute to Frank Schnabel first appeared in the March 2003 issue of Haemophilia World, on the occasion of the 40th anniversary of the World Federation of Hemophilia.
REGISTRATION FORM

FIFTY YEARS TO REMEMBER! • MAY 8-11, 2003
CANADIAN HEMOPHILIA SOCIETY 50TH ANNIVERSARY CELEBRATION

Please fill in the form below and return it as soon as possible to:
Canadian Hemophilia Society, 625 President-Kennedy Ave, Suite 1210 Montreal, Quebec  H3A 1K2

NAME:

ADDRESS:

CITY: PROVINCE: POSTAL CODE:

TELEPHONE NUMBER: E-MAIL ADDRESS:

ARRIVAL DATE: DEPARTURE DATE:

Registration fees:

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*Full conference includes Research Symposium, Consumer Workshops, Tour of CHS Public Display and Banquet. (Please be advised that these registration fees do not include registration for the 1st Canadian State of the Art Conference on von Willebrand Disease).

Cheques should be payable to the Canadian Hemophilia Society.

I would like to register for the following consumer workshops. Please print name of participant(s) beside your choice (The following sessions will only be offered depending upon sufficient registration.)

Navigating the Emergency Room

☐ English  ☐ French

Name(s)

Treatment Update on Hepatitis C

☐ English  ☐ French

Name(s)

Women with Bleeding Disorders

☐ English

Name(s)

Current Issues in the Safety & Supply of Blood Products

☐ English  ☐ French

Name(s)

Pain: The Fifth Vital Sign

☐ English

Name(s)

Hotel Accommodation

Le Centre Sheraton Montreal is the site of all meetings. For your convenience, arrangements have been made with Le Centre Sheraton Hotel as well as with the alternative hotels listed below. As shown on the map, all these hotels are at a walking distance or accessible by bus from the Conference site. Please reserve directly with these hotels where rooms are set aside until the dates indicated. Late reservations are subject to availability and Conference rates may not apply. When making your reservation, make sure to identify yourself as a participant at the CHS 50th Anniversary Celebrations. Space is limited so reserve early.

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<td>$189</td>
<td>1-800-325-3535</td>
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<tr>
<td>Le Nouvel Hotel</td>
<td>$139</td>
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<td>Days Inn Metro Centre</td>
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