PASSPORT to well-being LAUNCHED

empowering people with bleeding disorders to maximize their quality of life
WORD
FROM THE
EDITOR-IN-CHIEF
François Laroche
This issue of Hemophilia Today that you’re holding is particularly chock-full. The subjects covered are as varied as they are interesting, especially the Passport to Well-Being Program, which is the special feature. And justly so, since this initiative, financed by Baxter and initiated during the CHS Annual General Meeting held in Toronto last May 29, promises to be highly enriching for anyone who participates. The four modules that make up the passport are at the heart of the lives of people living with a bleeding disorder. In fact, home care, along with adequate follow-up, a personalized physical exercise program and healthy management of pain make up a winning recipe that allows people with a bleeding problem to optimise their quality of life. I highly encourage you to get a passport, take part in the training workshops that will let you gain knowledge, aptitudes and strategies in these four categories... and get your visas stamped.

The second Canadian Conference on Hepatitis C, held from April 27 to 30, 2004, also catches our attention. Under the theme New Knowledge, New Hope, over 700 people from across Canada—health professionals and social workers as well as people infected with the disease—gathered in Vancouver. As a representative from the Quebec Chapter, I was among the CHS delegation. It was no surprise when experts confirmed that the treatment with peg-interferon and ribavirin is the current treatment of choice for chronic carriers of the virus, including people co-infected with HIV. We did learn, however, that we’ll still have to wait five to ten years for the creation of an effective vaccine. Researchers are, in fact, still confronted with a number of challenges. Since hepatitis C is a chronic disease and has numerous forms (many genotypes), it’s difficult to find an adequate cellular host and a distinct antigen to properly block the replication of the virus. Moreover, non-human models react differently to the disease. A bit farther on in these pages, you can read the announcement of the Health Canada Research, Support and Prevention of Hepatitis C Program, including the renewal of funding, that was made at the opening of the Conference.

I want to remind you that the World Federation of Hemophilia (WFH) Hemophilia 2004 World Congress will take place in Bangkok, Thailand, from October 17 to 21. There’s still time to register by visiting the WFH website at www.wfh.org or by requesting a registration form at (514) 875-7944.

I can’t end this column without talking about the departure of Daniel Lapointe, now former Executive Director of the CHS. During his tenure, from July 1999 to April 2004, the organization made major progress in a number of fields, due to his good judgement, his leadership, his dedication to the cause and his helpful experience. Supported by volunteers and by the rest of the staff, he made a major contribution to raising the level of awareness in the Canadian public about hereditary coagulation problems (von Willebrand Disease, in particular) thanks to the Bleeding Disorders Initiative campaign. He also worked to improve relations between the provincial chapters and the national level, as well as those with our pharmaceutical industry partners. These are only a few of his achievements. As well as wishing all the best to Daniel in his new position as the Executive Director of the Canadian Institute of Actuaries, I’d also like to welcome the new Executive Director, Stéphane Bordeleau, to our organization.

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OUTGOING PRESIDENT’S
MESSAGE

Tom Alloway, Ph.D.

If we are not willing to give to the CHS, who will?

The past three years have been a busy and rewarding time for I’ve had the opportunity to visit most CHS chapters and meet a substantial proportion of our members from coast to coast. I particularly treasure my memories of family weekends and annual meetings in Saskatchewan, Manitoba, Ontario, the Maritimes, and Newfoundland. Meeting and talking to people at these get-togethers has impressed me with both the diversity of our membership and the extent to which, despite the diversity, we share the same issues when it comes to the management of our inherited bleeding disorders.

During my time as President, I have striven to increase the inclusiveness of the CHS by making it a more welcoming organization to individuals of both sexes and to the families of Canadians with all inherited bleeding disorders. As part of this effort, we have completed the von Willebrand Disease Awareness Program and launched a new “brand” that we call the Bleeding Disorders Initiative. As part of these programmes, we have not only updated our informational material on factor VIII and factor IX hemophilia but also created and disseminated some of the most comprehensive information to be found anywhere in the world on von Willebrand Disease and other inherited bleeding disorders. We can all be proud of the pamphlets and informational brochures that we have published and of our website (www.hemophilia.ca) which contains perhaps the most encyclopaedic information to be found anywhere on rare bleeding disorders. These programmes and educational materials have helped thousands of Canadians to understand their bleeding disorders more fully and greatly increased the number of people who are being diagnosed with von Willebrand Disease and other bleeding disorders.

A major challenge that began in the recent past and which we must face more effectively in the years to come is assuring the financial future of the CHS. During the tainted blood crisis of the 1980s, the CHS for the first time obtained substantial government funding to assist us with our programmes for people who had been infected with HIV and hepatitis C. In the 1990s, before and during the Krever Inquiry, heightened public awareness of the CHS enabled the organization to launch successful direct-mail and telemarketing campaigns. Our sources of government funding are now “drying up,” and the public is less and less aware of the CHS’s vigilant role as a guardian of the Canadian blood system. These circumstances mean that we must either find new ways of funding the CHS or face substantial reductions in the services which the CHS, both nationally and locally, will be able to offer. During the past several years, the decrease in government funding has to a degree been offset by increases in funding from the pharmaceutical industry. We greatly appreciate the help that our pharmaceutical partners have provided; however, in order to maintain our ability to be independent commentators on the blood system and on the safety and efficacy of treatments offered people with bleeding disorders, the CHS cannot afford to be seen as too dependent on pharmaceutical funding. To a large extent, the future funding of the CHS and its chapters is going to have to depend upon the community of people with inherited bleeding disorders. They and their families are the principal beneficiaries of the programmes that the CHS and its chapters provide. If we are not willing to give to the CHS, who will?

In closing, I want to thank each and every one of you who has offered me your support, your encouragement, and your friendship. This summer, the CHS will have a new President and a new Executive Director. I am confident that you will give them the support that they will need to move the organization forward.

PRESIDENT’S
MESSAGE

Eric Stolte

Same Journey, New Phase

The CHS has been on a 51-year journey to find a cure for hemophilia. Along that journey, we have improved the quality of life for thousands of people with hemophilia. Recently, we have engaged the entire bleeding disorder community in our journey and are now traveling together. Until a cure is found, our journey will be one of vigilance in ensuring an ever improving, quality of life for all people with bleeding disorders.

As the new CHS President, I have the privilege and responsibility to give volunteer leadership to this journey. But it is truly a journey we travel together, each one of us playing an important role. No single role is all-encompassing. I desperately need the contribution of each one in our society, from the “least” to the “greatest”, if our journey together is to be one of progress and not regress.

Right now, a critical challenge to this progress is our ability to acquire sufficient public funding for our mission. Our industry partners are to be congratulated for their contribution of resources. But raising public funding is like swimming upstream. If you look at the current alone, you think you’re making progress. But if you’re not swimming vigorously enough, when you look at the shore line, you see that you’re actually losing ground. This is our situation. The current decrease in public funding threatens our missional strength. This, in turn, threatens the level of quality services we’ve been able to achieve. Ultimately, this can even threaten not only quality of life, but life expectancy itself.

Although we’re far from this threat at the moment, we must generate new energy and momentum in the development of resources so that a situation of compromised care never becomes our reality. We can only do this as one strong organization whose regional, provincial and national levels pull in the same direction. Then we can tap in to the enormous abundance of as yet untapped philanthropic dollars that are available in Canada.

The CHS’s energy to effect change in response to vast threats in the past resulted in a changed blood system in Canada. Now, not in response but with proactive action, we can change our funding future. We can bring about a new day of coordinated effort to take advantage of opportunities which now lie beyond our grasp. Opportunities which are not only funding based, but program based as well. Opportunities which will bring us along this next leg of our journey together to a place of quality care and maybe even a cure!

I deeply believe in the power of all members of our society in helping to find our way forward to this new day of increased public funding. We will be launching a national effort to ensure as many members as possible can make their contributions to a national public funding strategy. I look forward to seeing many of you in this process and devoting my efforts to see that this comes to pass in a way that will ensure a confident resource development future.
PETER WACHTER
The hemophilia community was saddened to learn in May of the passing of Peter Wachter of Montreal.
Rich with his years of experience as a financial analyst at Bell Canada Enterprises, Peter joined the Quebec
Chapter Board in 1985 and became CHS Treasurer in 1986, when the organization’s serious financial
difficulties demanded his considerable skills.
Peter was a stalwart member of the Compensation Task Force lobbying the federal government in the late 1980s and a member of the CHS negotiating team in Ottawa. With Peter in the room, there was little danger the
government would succeed in discrediting CHS actuarial projections of the financial impact of HIV!
Peter became CHS President in 1990, a difficult time when attempts to complete the drive for fair compensation had to be carried out in ten provincial capitals. During Peter’s term, national programming to support those with HIV was increased considerably. The Women Helping Women Network was established. An international conference on recombinant factor VIII was hosted by CHS, which laid the groundwork for its introduction in 1993. He and his wife, Jackie Marin, were instrumental in securing Opening Nights of The Phantom of the Opera, with significant benefits coming to the CHS.
Later in the 1990s, Peter remained active within the CHS as a strong supporter of fundraising efforts and as a trustee of the Million Dollar Club. In all of his volunteer efforts with the CHS, Peter demanded the integrity and dedication of those he worked with. He was even more demanding of himself.

KARTTIK SHAH
Karttik Shah died on March 18th, 2004 after a valiant year-long battle with cancer. He is survived by his parents, Fulchand and Amrit Shah, his sister Minashi and her husband Ravi Varma, his niece Sohum and nephew Akshay Varma.
Karttik first developed visibility within the CHS in 1995, when he was appointed Chair of the Hemophilia Ontario Youth Committee. With characteristic dedication and drive, he called monthly meetings resulting in a youth retreat, publication of the Youth News, and an annual canoe trip, initiatives recognized with a Chapter Recognition Award by the Canadian Hemophilia Society. A weekend symposium was organized in 1997, under Hemophilia Ontario auspices with CHS funding, for young people with hemophilia and von Willebrand Disease. Within a few years, Karttik was also heading up youth committees at national and international levels.
By 2000, he was serving on regional, provincial, and national boards of directors and committees within the Canadian Hemophilia Society. By then, he had enlarged his scope to also embrace AIDS and hepatitis C concerns, international projects, and blood safety issues, most notably with regards to the latter appearing as a panelist on the CHS Consumer Forum on Safety, CJD and Blood Products in Toronto (1999). He was actively involved in the organization of Hemophilia 2000 in Montreal, including an international youth retreat prior to the Congress, as well as Chair of one of the sessions at the symposium. In 2001 Karttik became President of the Toronto & Central Ontario Regional Hemophilia Society (TCOR), a position he held until his death, fulfilling his responsibilities, at times, from his hospital bed. During his presidency, he further broadened his international vision, promoting twinning between TCOR and the Kingdom of Jordan. In September 2002, he and Candace Terpstra met with the Jordanian Hemophilia Society (JHS) to inaugurate the twinning relationship. By the time of the second visit a year later, he was no longer able to travel and Candace has very capably carried on his work. A tribute to Karttik personally and to the region, TCOR and the JHS were recognized with the WFH Twins of the Year Award for 2003.
This is the legacy that Karttik Shah has left in the few years he was with us. While the recitation of these achievements touches on his energy, drive, and dedication, it does not do justice to the spirit, personality, and intellect of this remarkable young man who did more in his shortened years on behalf of people with bleeding disorders than many do in a lifetime.
This tribute is abstracted from an article by the author written for the Spring 2004 edition of the TCOR Community News.

EMERY MARTIN
After a courageous battle, Emery Martin passed away on March 18th, 2004. Those who knew Emery well will remember him as a person with strong convictions and a warm, fun-loving man who had a great sense of humour. He loved to spend time with his family and friends, and that time was often spent laughing and telling some hilarious stories of his youth; he had a great way of looking at life.
Although he did not have a bleeding disorder, Emery worked energetically for the British Columbia Chapter of the Canadian Hemophilia Society. For 10 years, Emery was the Chapter’s vice-president and the publisher/creator of their award-winning newsletter. He generously spent many hours every week handling all the details that needed attending to. At times, he almost single-handedly ensured the survival of the Chapter. For many years he also served on the National Board of Directors that required travel and time away from his family. His friends at the chapter will always be grateful for his contributions and we will miss his presence profoundly.
Emery will be especially missed by his wife Julianna and his 2 daughters, Julia and Judith, who loved and respected him deeply.
NEW EXECUTIVE DIRECTOR AT CHS

The CHS Board of Directors announced on May 25 the arrival of Stéphane Bordeleau as the organization’s new Executive Director. Stéphane, a bilingual Montrealer, begins his new duties on June 14.

Stéphane comes to the CHS with more than ten years of experience in the not-for-profit sector. Most recently, he served for five years as Executive Director of the Quebec Chapter of the Parkinson’s Society of Canada. He has also worked in a fundraising capacity with Leucan, the University of Montreal and the Canadian Red Cross.

On behalf of the entire bleeding disorder community, welcome to Stéphane!

Mr. Bordeleau succeeds Daniel Lapointe who announced his resignation in April to take on a new challenge with the Canadian Actuaries Association in Ottawa. During his five-year tenure at the CHS, working with two Presidents, Erma Chapman and Tom Alloway, Daniel worked extremely hard to broaden the scope of CHS activities to include services for people with all types of bleeding disorders, in addition to hemophilia A and B. The organization launched the von Willebrand Disease Awareness Program and held a world-class medical symposium on VWD. It also adopted a new brand, the Bleeding Disorders Initiative, to reflect its expanded focus. Under Daniel’s wise guidance, the CHS solidified its role as the principal community voice in the blood system, placing members on all major blood system committees and producing two report cards on progress in implementing the Krever Commission recommendations. In an era when funds from both government and the general public are harder and harder to find, he has left the CHS with some roads forward to a more solid financial foundation. In addition, thanks to his professionalism, the organization is better administered than ever before.

All those who have worked with Daniel since 1999 wish him the best in his new endeavours.

PASSPORT TO WELL-BEING PROGRAM LAUNCHED!

The Canadian Hemophilia Society and Baxter Bioscience have launched an exciting new program aimed at empowering people with bleeding disorders, at all stages of their lives, to maximize their quality of life. The new program was officially presented to the bleeding disorders community at a reception held on May 29th at the Toronto Airport Renaissance Hotel. Attending the launch were members of the CHS Board of Directors and other key volunteers as well as representatives from Baxter.

The Passport to Well-Being Program has been designed around 4 modules:

- Charting Your Course — promoting accurate patient record keeping and monitoring of product usage
- Destination Fitness — promoting the benefits of physical activity, fitness and sports
- Home Care: the Road to Independence — helping patients take greater control of their disease through home treatment.
- Roadmap for Managing Pain — raising awareness of ways to manage pain

Key messages relating to these themes will be communicated through educational booklets, newsletters and workshops targeted at children, adults and caregivers of people with bleeding disorders. Participants in the program will each receive a personal passport which they will have stamped with a visa when they take part in a workshop or related activity.

For more information about how to get involved in the Passport to Well-Being Program please see the special bulletin included with this issue of Hemophilia Today.
CHS PHYSIOTHERAPY GROUP UPDATE

Fourteen physiotherapists from across Canada involved in the treatment of people with bleeding disorders met in Edmonton April 23 – 25, 2004 to share their knowledge and expertise. Back row: Betty Hale, Kathy Mulder, JoAnn Nilson, Andrea Hahn; Middle row: Nick Zourikian, Danielle Levac, Greg Blamey, Brenda Elliott, Catherine van Neste; Front row: Mary Jane Steele, Cathy Walker, Pam Hilliard, Jenny Aikenhead; Missing: Nicole Graham.

Mary Jane Steele, BScPT, South Western Ontario Regional Hemophilia Program

Fourteen physiotherapists from across Canada, affiliated with Hemophilia Treatment Centres (HTC), had an active, yet highly productive weekend April 23 – 25, 2004. With the generous support of Baxter Corporation, Bayer Healthcare, the Canadian Hemophilia Society (CHS) Physiotherapy Group was able to meet in Edmonton, Alberta in conjunction with the Association of Hemophilia Clinic Directors of Canada (AHCDC) and the Canadian Association of Nurses in Hemophilia Care (CANHC) annual general meetings. Most HTC physiotherapists have very limited clinical time dedicated to the care of individuals affected by inherited bleeding disorders. Therefore, the opportunity to get together to share experiences, exchange information and to promote best practices in a collaborative way is highly valued and greatly appreciated.

Topics of discussion at the meeting included an update from Dr. B. Feldman on the Canadian Hemophilia Prophylaxis Study, as well as an update from P. Hilliard and N. Zourikian, members of the physiotherapy group, regarding the ongoing refinement of an international physiotherapy assessment tool. There was consensus among the Canadian Hemophilia Physiotherapy Group to work toward integrating the current Canadian assessment tool with the international guidelines. The ultimate goal is to incorporate findings from regular physiotherapy clinic assessments into the Canadian Hemophilia Assessment Resource Management System (CHARMS), in a nationally consistent manner. This will in turn provide access to important data for research and clinical management purposes. For this reason, the group received an orientation to the data gathering possibilities of CHARMS. The group intends to investigate efficient and effective methods of data collection, and plans to provide hands-on orientation to all clinic physiotherapists to ensure consistency in assessment techniques and data entry across the country.

Other topics of discussion included: review of the Physiotherapy Resource Binder and other recently published resource materials; a proposed physiotherapy link from the CHS website; individual therapists’ experience with the WFH twinning program; and upcoming educational opportunities, including the XXVI International Congress of the World Federation of Hemophilia, Bangkok, Thailand from October 17-21, 2004. Members of the group had the opportunity to present challenging case studies for consideration on Sunday morning. This provided the opportunity for some extremely helpful exchanges of clinical information.

Of course, physiotherapists do like to engage in physical activities. Saturday evening, members of our group proved to be leaders on the dance floor.

The group unanimously and appreciatively agreed to continue working under the leadership of K. Mulder, P. Hilliard, and N. Zourikian. There was consensus that these meetings are extremely important to furthering clinical competence and expertise. Meeting in conjunction with the AHCDC and CANHC helps to foster an increased sense of collegiality and comprehensive care. The Physiotherapy Group intends to work diligently to ensure that these meetings continue on an annual basis.

DECENTRALIZATION OF BUDGETS FOR BLOOD AND BLOOD PRODUCTS IN QUEBEC

A threat to the quality of care offered to people with bleeding disorders

François Laroche, Past-President, Quebec Chapter

Over the past 12 months, the Quebec Chapter (CHSQ) has been working to find a solution to problems posed by a Quebec Minister of Health and Social Services (MSSSQ) plan to decentralize budgets for blood and blood products from the supplier, Héma-Québec, to the 99 hospitals in the province. The MSSSQ’s initiative, which has been planned since the creation of Héma-Québec in 1998, is being closely watched by other provinces. It originates in recommendations 15 and 16 of the Krever Inquiry on the blood supply in Canada, calling on the blood service to charge hospitals for blood products, thereby encouraging more rational use. According to Krever, this would also lead to the establishment of an independent relation between the government and the national blood service, helping to reinforce the ability of the supplier to quickly introduce safety measures.

The CHSQ, however, considers this project a threat to the quality of care given to people with bleeding disorders. While it isn’t opposed to the transfer of budgets for fresh components (blood, red blood cells, platelets, plasma) from Héma-Québec to hospitals, the CHSQ is greatly concerned about the transfer to regional hospitals of budgets for clotting factor concentrates. In reality, blood banks in these outlying hospitals serve as mere drop-off points for the delivery of home care products. Physicians there have no expertise in treating bleeding disorders nor experience with these rare and valuable products, but would nevertheless become accountable for the concentrates prescribed by physicians in Quebec’s four hemophilia treatment centres. This would bring about a confusing sharing of responsibilities (prescription vs. distribution and funding) that is undesirable. What’s more, the system favoured by the MSSSQ foresees
budgets based on consumption in the previous year. If utilization surpasses this level, adjustments at the end of the year are possible only if rational utilization can be demonstrated by the distributing hospitals. In the case of clotting factor concentrates, such justification will be impossible for those hospitals which merely act as depots. In our opinion, this is not a sensible and efficient way to manage these products. After having sent ‘virtual’ bills to hospitals for their use of blood and blood products in 2003 and 2004, Héma-Québec will implement the billing system in April 2005, after harmonizing computer programs with hospitals.

The CHSQ, with the support of the directors of the hemophilia treatment centres, proposes instead the creation of an integrated hemostasis program that would unite the four existing treatment centres (which would become satellite centres), in addition to the Quebec Reference Centre for the Study of Patients with Inhibitors. The recommendations include:

- That a medical director with expertise in hemostasis and the treatment of patients with coagulation inhibitors be named as head of the program;
- That the budget for clotting factor concentrates be associated with the hospital managing the program and that the latter have the mandate to ensure the proper distribution and inventory management of products, as well as their tracing in the case of a recall.
- That the necessary financial resources be provided to the program to cover the costs for the proper management of clotting factor concentrates.
- That a special budget, distinct from each hospital budget, be affected to the program, in order to cover the costs of human and physical resources necessary for the running of the satellite centres and that this budget reflect the recent increase in clientele and services offered.

Unfortunately, following numerous meetings and discussions with the MSSSQ, the Quebec Blood System Secretariat, the directors of hemophilia clinics and provincial deputies (notably Mr. Russell Williams and the opposition critic for health, Ms. Louise Harel), this proposal was not accepted. And this, despite the fact the Minister of Health, Philippe Couillard, during a meeting in January, admitted that the CHSQ case, notably concerning the need to recognize the expertise existing in the hemophilia treatment centres and to reinforce their mandate for the prescription of products and their responsibility to ensure adequate traceability, made great sense.

The CHSQ is developing a strategy to show that its proposed solution is best for patients, does not create a precedent in this field and that the system being implemented by the MSSSQ risks encountering serious problems. Discussions are ongoing with the principle actors involved. The National Assembly committees on the study of health expenditures, being held this spring, are being closely followed.

Supported by the CHS, the CHSQ is devoted to doing everything possible to reach an adequate solution for all concerned. It has no intention of giving up.

CHS BOARD OF DIRECTORS 2004–2005

As in any group of Olympic calibre athletes, certain ones stand out for their extraordinary achievements and so it is with our people. CHS people tend to be “Olympic calibre”; that’s why I’ve always counted it a privilege to volunteer with the CHS and a special honour to chair the awards committee this past year. At the November 2003 Awards Banquet, the CHS recognized a group of dedicated volunteers, health care providers and staff who had made a significant contribution to the bleeding disorders community during the preceding year(s).

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.
- Ottawa and Eastern Ontario Chapter
  – for outstanding efforts in fundraising at the regional level.

Award of Appreciation
This award honours individuals who have demonstrated outstanding service to the care of persons with inherited bleeding disorders.
- Maureen Brownlow, RSW, Social Worker, Halifax, Nova Scotia
- Julia Sek, R.N., Past Nurse Coordinator, Hamilton, Ontario

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.
- Dr. Mohan Pai, Past Clinic Director, Hamilton, Ontario
- Dr. Robert Card, Clinic Director, Saskatoon, Saskatchewan

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 other staff members.
- Robert St-Pierre, Past CHS Hepatitis C Program 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.
- Bill Mindell, North York, Ontario

Honorary Life Membership Award
This award recognizes exceptional leadership and devotion to the CHS over many years. The award is given to an individual who has merited special recognition for continuing efforts, particularly at the CHS Board level, to further the growth and development of the mission and objectives of the CHS and the development of public recognition of the CHS and its goals at the National and Chapter level.
- Frank Bott, Etobicoke, 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 2003 by June 30th. The awards package is available on the CHS website at www.hemophilia.ca. We’re eager to read your nominations and honour a new group of volunteers this year.
HEMOPHILIA TODAY SPRING 2004

The Gala Dinner really helped to raise public awareness about the Manitoba Chapter of the Canadian Hemophilia Society and presented a positive reflection of the membership. The evening was a smashing success and we are looking forward to ensuring next year’s event is equally successful.

Manitoba Gala Evening of Culinary Inspirations

Stacey Westman, Gala Dinner Committee Chairperson, Canadian Hemophilia Society, Manitoba Chapter

Hemophilia Manitoba’s “Gala Evening of Culinary Inspirations” was held on February 21, 2004 in honour of Jim Love, Manitoba Chapter President, who passed away in September. Our energetic committee worked hard for six months to plan a dinner that was unlike any other Fundraising Dinner. What set ours apart was that we had four of Winnipeg’s top Executive Chefs each prepare one of their specialties. The evening began with samples of chocolate martinis for all our guests; the elegance continued on throughout the evening. The meal consisted of an appetizer, soup, main entrée and dessert. We also secured four wine distributor representatives who paired wine/liqueurs for each course and offered free tastings to each of our dinner guests. Once the wine was sampled, it was available for purchase by those who wished to have more.

While each course was being served the Executive Chefs took stage and were interviewed on their culinary secrets by our special guest M.C., local celebrity, and radio and TV personality, Mr. Lee Major of 99.1 Cool FM. The wine reps also took their turn on stage educating us on the particular wine they had paired with each course.

Our goal for the evening was not only that everyone have an amazing meal, but also that they feel they had just had an “Outstanding Culinary Experience.” Based on the rave feedback we received, we were more than successful in achieving our goals. We were also successful in raising over $12,000 for our chapter. We were able to achieve this by having an almost sold-out event, generous sponsors, and by having most of the food donated by local companies and distributors. The Chefs and wine reps also donated their time. A silent auction sale added to the success of the night as well.

Saskatchewan Fundraiser

As the charity of choice, Hemophilia Saskatchewan was this year’s recipient of the proceeds of the High Voltage Classic, organized annually by the engineering students at the University of Saskatchewan. Over $22,000 was raised through pledges for a marathon of street hockey games. Thanks to Sid Katzman for helping to make this possible.
The second annual Just the Guys Getaway, formerly known as the Father and Son Weekend, was held October 24-26 at Camp Ki-Way-Y near Kitchener. The cloudy skies just wouldn’t break, and the rain came on and off all weekend long, but that didn’t stop the 37 soggy participants from the Central Western Ontario Region (CWOR) and the South Western Ontario Region (SWOR) from having a great time. All of the guys had a chance to try for a bulls eye during archery, swing like Tarzan on the low ropes course, and balance across the beam that was strung high up in the trees. We built birdhouses, played board games, built shelters, carved pumpkins and even had a costume party. Fortunately, the rain stopped long enough each night for everyone to relax around the campfire. The action-packed weekend also included two education sessions. Dr. Pai, Pediatric Hematologist from the Central West Hemophilia Program, spoke about current treatment practices and gene therapy research. Julia Sek and Lori Laudenbach, our Hemophilia Nurses for the weekend, spoke about parenting practices and risk assessment of activities. Both sessions were very interactive and informative. This joint event between CWOR and SWOR was made possible through the generous support of Bayer.

Once again this spring, one hundred and eighty-five members of the Quebec Chapter attended our annual family weekend and AGM at the Centre de Plein Aire Matawinie, about two hours north-east of Montreal. One workshop dealt with hemophilia through the ages, with three hemophiliacs aged 21, 35 and 45 talking about their personal experiences with a bleeding disorder as they grew up and as treatment changed. Parents had lots of questions and were impressed by the positive attitudes of these men, despite their physical problems. Other workshops included the “Demystification of inhibitors” given by Dr. Jean St-Louis, “Dealing with fatigue from hepatitis C” given by Dr. Bernard Willems, an art therapy workshop and a session that has become a tradition: “A Coffee Klatch” where both newly diagnosed and experienced parents share information and talk about everyday living with hemophilia in the family. The Infusion workshop, part of the Passport to Well-Being Program, was a chance for parents to learn and try infusion on themselves or on one another and to question older parents about their tips and techniques. Saturday night was dance night and almost everyone was up on the dance floor. There was also a special news team with youngsters from 8 to 13 years of age who worked on a newsletter with photos and articles about the weekend. This family weekend is the one occasion when all members of the hemophilia community, both children and adults, meet and share information and also have a good time. It’s a real family gathering.

Patricia Stewart receives the Quebec Chapter Volunteer of the the Year award from François Laroche, President.

One of the weekend’s many workshops.

Saturday: Dancing the night away.

The Society’s young journalists.
In the wake of the National Inhibitor Weekend, entitled the Circle of Care Workshop, held last October at Mont-Gabriel, Quebec, Hemophilia Today thought it would be interesting to do a profile of a program that is unique in the world: The Quebec Reference Centre for the Treatment of Patients with Coagulation Inhibitors.

It is well known that the appearance of an inhibitor is a serious complication in hemophilia. It requires even more specialized treatment for a condition that already calls for specialists. Though relatively rare, an inhibitor affects about 30% of hemophilia A patients at some point in their lives. What’s more, about 10% of severe hemophilia A and about 2% of severe hemophilia B patients are chronically affected. In factor IX deficiency, however, the diagnosis of an inhibitor is more serious, at times leading even to an allergic reaction and anaphylactic shock, and is even more difficult to treat. It is estimated that of the 850 Canadians with severe hemophilia A, 80 are affected by a persistent, that is, chronic inhibitor, of whom 20 live in Quebec.

The coagulation factor inhibitor can also occur in people who don’t have a hereditary coagulation problem. This is called acquired hemophilia, an extremely rare autoimmune disease (1 case in 1 million people per year, about 7 per year in Quebec and 30 in Canada) that mainly affects the elderly. Acquired hemophilia is particularly harmful since it usually detected when the crisis is at its peak (life-threatening) in a person who knows nothing about his condition and who has never managed bleeds in the past. It is associated with a fairly high mortality rate (20%).

The creation of the program

In March of 2000, in order to offer proper care to people with inhibitors, the Quebec Health and Social Services Ministry (MSSSQ) created the Quebec Reference Centre for the Treatment of Patients with Coagulation Inhibitors in Montreal. The purpose of designating this specialized center to care for a serious, complex and expensive condition was to improve the treatment and quality of services for this clientele through the development and maintenance of state-of-the-art expertise and to optimize the use of resources.

For one of the co-directors of the program, Dr. Georges-Etienne Rivard, this meant the realization of a long-held dream. “The treatment of people with this condition had to be centralized in order to offer them proper care. At times, it annoyed me to hear some of my colleagues’ anecdotes when they asked my advice. They talked about a ‘special case’ instead of the people affected by this problem who were going through a hard time. Dr. Jean St-Louis and I had been thinking about it for a while. The meetings of the Gélineau Committee on the supply, management and distribution of blood in Quebec gave us the chance to present the idea of a single center for the treatment of this condition. The Committee even included this recommendation in its preliminary report. The MSSSQ then asked us to present a document specifically dealing with the center’s operation. Ste-Justine officially received the designation on March 23, 2000.”

The principal players

Because Ste-Justine Hospital is a pediatric centre, Dr. Rivard sees only the children. Sacré-Cœur Hospital, its affiliated centre, received joint designation to treat adults under the supervision of the second co-director, Dr. Jean St-Louis. Today, adults are seen by Dr. St-Louis at Maisonneuve-Rosemont Hospital. But in reality, the treatment of patients is not done in isolation. The two doctors consult each other frequently to discuss a particular situation. What’s more, a strong working relationship exists between the two men. “We make a good team. This is the key to success when problems with inhibitors occur and require special expertise. But the linchpin of our team, without a doubt, is Sylvie Lacroix, the nurse coordinator for the program, who manages it all,” says Dr. St-Louis. Dr. Rivard feels the same. “We give a lot of credit to Sylvie for the success of this program. She’s an exceptional person as well as a great nurse. Very independent, she quickly understands what’s at stake when a situation arises. She’s very dedicated to the cause and is always available.”

Services

Let’s talk about availability. Among the services offered by the Centre, besides consultations, is a 24-hour-a-day, 7-day-a-week telephone line. If no one answers immediately, one leaves a message and is called back within ten minutes in the case of an emergency. Most of the time it is Sylvie Lacroix who takes care of this, bringing her pager with her wherever she goes. But the physicians are also involved. Dr. Rivard, along with his pager, carries both a North American and an International telephone. If you can’t reach him, it’s probably because his batteries are dead! He often does telephone consultations and answers calls from all over Quebec, Canada, and from around the world. He mentioned the case of an adult with mild hemophilia and an inhibitor referred by Dr. Man Chiu Poon from Calgary. “This was a hemophiliac who was bleeding in his tongue and his larynx. He was intubated for intensive care with the smallest tube possible to allow him to breathe. He needed a plasmapheresis treatment with immuno-absorption to remove the coagulation factor antibodies present in his blood. But, there are only three machines of this kind in Canada: one in Vancouver, one in Toronto and another at Ste-Justine. We transferred the patient from Calgary to Montreal. Not only did he survive, but he responded well to treatment and now leads a normal life. It’s at times like these that you feel great satisfaction... and we tell ourselves that transfers like this can happen anywhere in Quebec!”

This machine has saved more than one life. Dr. Rivard also told the story of the 8- or 9-month-old baby with a factor IX inhibitor suffering from a central nervous system hemorrhage who had an allergic reaction, and that of a child with FXIII inhibitors. “These people mustn’t go through Emergency. As soon as a problem arises, and if the child can get to the hospital, Sylvie, Jean or I go to meet them. Of course, this means that we have to be available at all times, because this condition often requires immediate care. Sometimes we do consultations from home and even, on one occasion, while driving!” adds Dr. Rivard, passionate about this topic.

Fortunately, such situations are exceptional. In general, in the case of a person with a congenital coagulation factor deficit, as soon as he develops an inhibitor, he is systematically referred to the Inhibitor Centre by his treatment centre. Patients with acquired hemophilia are referred by Héma-Québec, the organization responsible for the supply of blood products. “In the case of acquired hemophilia, you have to give credit to Héma-Québec, especially to its CEO, Dr. Francine...”
Focus on Inhibitors

Immune tolerance, an historical overview

Sylvie Lacroix, R.N., Georges-Etienne Rivard, M.D.,
Quebec Reference Centre for the Treatment of Patients with Inhibitors

• Is immune tolerance a new approach in the treatment of inhibitors?

No, it’s not a new approach. In 1974, Brackman and Gromsen discovered and described the phenomena of immune tolerance. All these protocols are intended to eliminate the inhibitor and, ideally, restore the normal FVIII recovery kinetics.

• Are all protocols similar?

No, there are some differences among the various protocols. The goal is always the same, but the ‘recipe’ changes. Certain protocols use a combination of immunosuppressant drugs (drugs that try to slow or lessen the system’s immune response) such as, for example, cyclophosphamide and prednisone. Others use immunomodulators (that modulate/modify the immune system) such as extracorporeal immunosorbsion. These drugs/treatments cause certain secondary effects that must be explained and discussed with each person to be treated, making sure to carefully weigh the advantages and inconveniences of each. What’s more, the addition of immunoglobulin that causes an immunomodulator effect through an anti-idotypical mechanism (antibody) has been reported.

• What are the most frequently used protocols?

There are a number of individual recipes or specific adjustments adapted to each patient’s condition, but the greatest sources of inspiration can be resumed as follows.

First of all, in the Bonn protocol (study by Brackman et al.), high doses of FVIII are used in order to induce immune tolerance (Table 1). A résumé of the results obtained with this protocol shows that in 22 patients with high response inhibitors, the average duration of treatment to obtain an inhibitor of less than one Bethesda unit is seven months with normal FVIII kinetic recovery, an average of fifteen months being required to complete the procedure.

Table 1: The Bonn protocol

| TREATMENT | TIME
|-----------|-------
| FVIII 100-150 u/kg twice a day until the inhibitor is no longer detectable and the FVIII recovery and half-life are normal; these results must be measured three times over a six- to eight-week period. | Once per day
| A 10% reduction in the FVIII dosage every two to four weeks. | Once per day
| Final tolerance evaluation: after a two- or three-day period without treatment, recovery and half-life are maintained with prophylactic or on-demand treatment. | Once per day

The Malmö protocol, initially described in 1988, consists of injecting high doses of immunoglobulin used as immunomodulators and immunosuppressors (Table 2). Up to 1996, 20 pediatric and adult patients had received this treatment. The success rate reported was 80%. The average duration of the treatment is 28 days, the rapid response being attributed to the lowering of the production of inhibitors in response to the presence of high levels of FVIII or FIX in this treatment.

Table 2: The Malmö protocol

<table>
<thead>
<tr>
<th>TREATMENT</th>
<th>TIME</th>
</tr>
</thead>
<tbody>
<tr>
<td>Extracorporeal immunoabsorption</td>
<td>Day 1 and day 2</td>
</tr>
<tr>
<td>Cyclophosphamide 12-15 mg/kg I.V.</td>
<td>Day 1 and day 2</td>
</tr>
<tr>
<td>Cyclophosphamide 2-3 mg/kg po</td>
<td>Day 3 for eight to ten days</td>
</tr>
<tr>
<td>Once a day</td>
<td></td>
</tr>
<tr>
<td>FVIII to obtain a 40 to 100% FVIII level, then FVIII administered every eight to twelve hours to maintain a FVIII level of 30 to 80%</td>
<td>Day 3 and thereafter until the inhibitor is no longer detectable</td>
</tr>
<tr>
<td>IVIG 0.4 g/kg/day</td>
<td>Days 4 – 8</td>
</tr>
<tr>
<td>FVIII 30 u/kg/day two or three days/week</td>
<td>Once the inhibitor is undetectable</td>
</tr>
</tbody>
</table>

A three-phase treatment (Table 3) has been used with eleven children (median age of two years) with severe hemophilia and high titre inhibitors. These are the results:

- the average durations of the first and second phases are six and fourteen weeks respectively; phase two is initiated when the inhibitor is undetectable (with Bethesda measurement);
- phase three is then initiated when the half-life of the FVIII is measured at more than five or six hours;
- finally, in phase three, prophylaxis is resumed.

Table 3: Three-phase treatment

<table>
<thead>
<tr>
<th>PHASE</th>
<th>TREATMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>FVIII 200 u/kg/day</td>
</tr>
<tr>
<td>2</td>
<td>FVIII 100 u/kg/day when the inhibitor level is less than one Bethesda unit</td>
</tr>
<tr>
<td>3</td>
<td>FVIII 50 u/kg in prophylaxis until the inhibitor is eliminated and the half-life of the FVIII is five to six hours</td>
</tr>
</tbody>
</table>

A protocol using low doses of concentrate was used by the Van Creveld clinic in Holland and recommended the administration of low doses of concentrate: 25 u/kg on alternate days, reduced to 10-15 u/kg three times a week when FVIII recovery measured 30%. The success rate reported using this method is 87% of the group of patients treated, but 100% in subjects with an inhibitor level under 40 Bethesda units, compared to 75% in patients with an inhibitor level over 40 Bethesda units. An average of twelve months is reported to obtain tolerance. The length of treatment is directly proportional to the maximum inhibitor level and inversely proportional to the age when the inhibitor developed.

Finally, as mentioned at the beginning of this text, treaters adjust the protocols described according to their practice and to the specific needs of their clientele. Since 1993, the North American Immune Tolerance Registry collates data from 168 hemophilia treatment centres in North America. Approximately 50% of the centres use 100-200 u/kg/day of FVIII to induce immune tolerance. In general, the duration of the treatment is shorter when higher doses of concentrate are used. The highest rates of success are found in patients with a maximum inhibitor titre of less than 50 Bethesda units.
Focus on Inhibitors

What about patients with a FIX inhibitor?

Some hemophilia patients with a FIX inhibitor are successful in obtaining immune tolerance using protocols like those mentioned above; however, experience in this field is more limited. Complications related to a nephrotic syndrome are mentioned, but allergic reactions are reported more frequently.

Anything to add?

In conclusion, one could say that for over twenty-five years immune tolerance has been recognized as a treatment to eradicate inhibitors in people with hemophilia. A lot of questions remain unanswered. Many approaches are effective; however, the perfect immune tolerance program is yet to be defined. Researchers have initiated an international research protocol in this field with this in mind. It is imperative that data from a large group of patients be collated in order to come to pertinent conclusions that may help to determine the best mode of intervention. Inhibitors are rare, but their impact is very serious with major repercussions for patients and their families.

During the inhibitor family weekend organized by the Canadian Hemophilia Society, the great generosity of these families in regards to their participation in research could be seen. Everyone present recognized its importance and demonstrated their desire to contribute to the advancement of science. This altruistic attitude is worthy of mention.

The Quebec Reference Centre

Décary, who immediately understood the necessity to act quickly in these situations,” says Dr. Rivard. “As soon as Héma-Québec receives a request, it refers the call to us and we can immediately talk to the hematologist who saw the patient. If possible, the patient is transferred to Maisonneuve-Rosemont. This means there’s no delay, no inadequate treatment and no product is wasted.”

The diagnosis of inhibitors is done on a regular basis; children are tested twice a year, while tests on older hemophiliacs are done once a year. The Inhibitor Centre then designs a treatment plan that can be followed up by the person’s own Hemophilia Treatment Centre (HTC). A check-up is done at least once a year and a report is always sent to the HTC. Along with the two doctors and the nurse coordinator, the program includes a lab technician specialized in this field and, as consultants, a physiotherapist, whose time is divided with the HTC, a social worker and a psychologist. The nurse coordinator has her own office. As for the others, the Centre shares space with the Ste-Justine HTC.

The Inhibitor Centre produces a quarterly bulletin, L’Idée fixe, that is distributed by mail to all patients and all hemophilia treatment centres in Quebec and Canada. Sylvie Lacroix is responsible for gathering the information and experiences of interest that appear in this periodical. For more details about this publication, you can communicate with the Quebec Reference Centre for the Treatment of Patients with Inhibitors at 514-345-2360 or by e-mail at sylvie_lacroix@ssss.gouv.qc.ca.

Treatment

Treatment for hemophilia with inhibitors can be very demanding. “Products available to treat this condition are substitutes for FVIII: FEIBA, porcine FVIII and recombinant FVIIa. In the case of rFVIIa, this is an effective product, but expensive, and must be used with care since it carries the risk of thrombosis,” according to Dr. Rivard. On the other hand, in certain cases, if the inhibitor titer (the proportion it occupies in the blood calculated in Bethesda units) isn’t too high, it can be annihilated with immune tolerance techniques. “Massive doses of FVIII are given to the child in order to accustom his immune system to it. The antibodies are overwhelmed and can no longer neutralize the coagulation factor. The chances of this technique working are better if the inhibitor has been present for less than one year and if the titer is lowered to between 5 and 10 Bethesda units at the start of treatment,” adds Dr. St-Louis.

“The main difficulty with immune tolerance resides in venous access,” adds Sylvie. “This treatment calls for injections at least three times a week and, often, every day. More often than not, a central line has to be installed, a PICC-line (Peripheric Intravenous Central Catheter) and this, despite the possibility of infection. I’m always impressed, however, by the attitude of the children and their parents, their perseverance, their strength. The treatment of hemophilia with inhibitors requires frequent trips to the hospital and a very particular treatment regimen for parents. We ask for a great deal of involvement because the treatment necessitates so much time and good adhesion.”

“As for acquired hemophilia,” according to Dr. St-Louis, “when patients with this condition consult us, they’re often very ill, to the point that their lives are in danger. But, at the same time, it seems that it’s easier to eliminate their inhibitor. Immune tolerance treatment is very effective for people dealing with acquired hemophilia. Massive doses of cortisone or cyclophosphamide are administered to patients and most of the time they manage to get rid of their inhibitor.”

Predisposition

There’s still a lot of work to do to identify what causes a coagulation factor inhibitor. “As far as acquired hemophilia is concerned, it’s just about impossible to foresee the occurrence of an inhibitor. We have to concentrate our research in order to find out how bleeding occurs in these patients. What we know is that they bleed differently from classic hemophiliacs,” says Dr. St-Louis. For Dr. Rivard, the factors that seem to influence the appearance of an inhibitor in a hemophilic are race, the severity of the factor, other hereditary parameters, the time when replacement factor is introduced, breast-feeding, vaccination, and more. “We have to get a better understanding of the molecular genetics of people with inhibitors in order to better foresee the prevalence of this condition,” he adds.

Future perspectives

What challenges does the future offer? Dr. St-Louis feels that we have to be able to better identify patients who are at greater risk of developing an inhibitor in order to prevent its appearance. Treatment and techniques will also improve with time, according to him. This opinion is shared by Dr. Rivard, for whom the prevention of this condition is essential. “We have to know more about the biological environment of this condition to better counteract it. One of the indications we have is the time when replacement factor is introduced. Perhaps treating with rFVIIa during the first years so as to delay exposure to FVIII, or treating with a product containing a large quantity of von Willebrand factor are possible roads to a solution, but this remains to be seen. But the limited number of cases complicates research in this field. In order to study 100 people, almost all the people affected in North America have to be included!” he concludes.

As for Sylvie, her dream is for every patient she treats to have a computer equipped with a webcam, and a laptop for her. “That way, I could get a good idea of their condition in real-time on my computer and I would be able to act more rapidly and more efficiently in relation to the symptoms that I see on the screen.” Reality or fiction? The message is out there, only time will tell if there’s an answer…

Thanks to Sylvie Lacroix and to Drs. Georges-Etienne Rivard and Jean St-Louis for their availability and their medical review of this article.
THE CULLEN FAMILY AT THE CIRCLE OF CARE WORKSHOP

We were so excited when we heard we were accepted to go to Montreal. The trip was to be a real adventure as my husband and boys had never flown. Grandma was all lined up to look after the baby.

Our son Randy has hemophilia A with an inhibitor so a weekend completely focused on inhibitors was wonderful. We went to Montreal a day early so we could meet with Dr. Rivard and his team at the Sainte-Justine Hospital.

Stacy and I were very surprised and pleased to hear Randy didn’t need a port for us to start immune tolerance. Dr. Rivard said Randy would be a good candidate for immune tolerance. We were excited; now we had something to hope for in the area of Randy’s medical treatment.

During the weekend, we learned so much about how inhibitor treatment (immune tolerance) works – past, present and future. We also learned how inhibitors develop. There were nurses and physiotherapists speaking on treatment. It was wonderful! Randy enjoyed the Tai Chi and his brother Gene made friends. Stacy and I really appreciated the fact that there is support from other families going through similar problems.

We are now well into home infusion doing the immune tolerance program. We still have a way to go as far as how and when to do blood tests for inhibitors. Communication is getting much better. The Montreal weekend was a real boost in getting us started. We are very grateful for having had the privilege to be chosen to attend.

Kim and Stacy Cullen
Regina, Saskatchewan

My name is Josh McCormack. I am 12 years old and I live in Carlisle, Ontario. I have hemophilia B and an inhibitor. Having hemophilia is a lot of work, and it can be very painful. On the other hand, there are some benefits, such as the chance to spend a wonderful weekend at Mount-Gabriel where the CHS organized a weekend for families with inhibitors. I had already attended one three years earlier and I was excited about seeing my friends again.

We drove from Carlisle to Quebec. On Friday, I had an appointment with Dr. Rivard and his team at the inhibitor centre, and I think he felt I was doing pretty well. In the evening we met all the families who were participating. It was great to see my friends, Tony and John. It was like we had never been apart.

The organizers planned a complete day of activities for us while our parents were busy learning more about inhibitors. I really liked the Saturday evening dance. I noticed that even if many of the kids had hemophilia and an inhibitor, it didn’t stop them from having a good time… even at the risk of hurting their knees. We were all happy and able to have fun.

I consider myself lucky that my family and I were invited to participate in this family weekend. I realized that I wasn’t alone with my inhibitor. Others have to face the same pain and the same challenges. I think knowing that helps a lot.

Josh’s testimonial first appeared in L’idée fixe, le journal des inhibiteurs, published by the Quebec Reference Centre for the Treatment of Patients with Inhibitors, now also available in English. Those wishing to subscribe may do so by calling Sylvie Lacroix at 514-345-2360 or by writing to her at sylvie_lacroix@ssss.gouv.qc.ca.

As always, keep in touch and be safe.
New booklet on symptoms of hepatitis C

Faye Katzman

In March 2004, the Canadian Hemophilia Society, with funding from Health Canada, published a new educational resource entitled Hepatitis C: Common Disabling Symptoms and Treatment Side Effects. Jeff Rice, Coordinator of Regional Resources and Hepatitis C Programs with the CHS, coordinated the project. Both HTML and PDF versions are available on the CHS website at www.hemophilia.ca.

In plain language, this bilingual pamphlet addresses the range of symptoms that someone infected with HCV might experience. The booklet also describes the continuum of side-effects—from mild to severe—that someone on hepatitis C medication could encounter. It is intended not only for people infected and their families, but also for health care providers, employers and insurers.

The 16-page booklet is divided into ten sections. The first seven deal with liver function, a description of hepatitis, the natural history of infection, common symptoms, other organs affected by HCV, cirrhosis and end-state liver disease, and common side effects of hepatitis C treatment. The final sections of the booklet outline financial options, tips on finding helpful health information, and community and government contacts.

The booklet provides information on common symptoms of HCV, including depression, and lack of energy. Some people find that they can’t focus, their memory is unreliable, and they have difficulty seeing a task through from beginning to end. The CHS hopes that the booklet will be a useful tool when applying for sickness benefits.

People who are on HCV medication may experience a range of side effects. Some people may experience milder symptoms, while others may become totally—even if temporarily—disabled. Some people on treatment may have to stop working. Knowing what to expect in terms of symptoms may help people to cope better.

The booklet also aims to help people be better informed so they can explore their financial options, both public and private, including Human Resources Development Canada (HRDC), employment insurance (EI), Canada Pension Plan (CPP) and Quebec Pension Plan (QPP), disability pensions and provincial-territorial social assistance.

Employee benefit packages, union disability plans and private insurance benefits might also be available to some people who are HCV positive. The booklet gives tips on how to apply for benefits and describes various plans which may help pay for the cost of treatment.

To request a copy of this booklet or to have more information on other hepatitis C initiatives, call Jeff Rice at 1-800-668-2686 or write to him at jrice@hemophilia.ca.

New treatments on the horizon

Suzanne Champoux

There is no perfect treatment for hepatitis C; thus research is ongoing. While there’s no revolution on the horizon, interesting molecules are being studied in humans.

The first molecule that could be marketed is on which modulates the immune system, thymosine, by the SiClone company (Zadaxin®). Two Phase III studies including a total of 1000 participants are ongoing in the United States. Subjects randomly receive a combination peginterferon plus thymosine or peginterferon plus a placebo for one year. Results should be available at the end of 2005.

Viramidine®, manufactured by Valeant Pharmaceuticals, has recently started phase II studies. The goal here is to replace ribavirin. This requires what is called a prodrug, a molecule that has to be transformed in the body to become an active drug. Viramidine® is a ribavirin prodrug that offers the advantage of being specifically transformed by the liver cells which should diminish the normal toxicity of ribavirin on blood cells. The two phase
States. The molecule is offered to 40 patients who already failed the first peginterferon and ribavirin treatment.

The Human Genome Sciences firm has used a technology that it developed, albumin fusion, a blood protein that has a 20-day lifespan, in order to increase the activity time of interferon. Studies show that the half-life of Albuferon® is 145 hours, that is, 6 days, compared to 40 to 80 hours for peginterferon. (The half-life is the time it takes for the concentration of the drug in the blood to be halved).

Vertex, on the other hand, is looking to develop a drug that will inhibit an enzyme in the body that the virus needs to multiply cells. Merimepodib® (VX-497) is an inosine monophosphate dehydrogenase inhibitor (IMPDH). Behind this intimidating name lies a mechanism similar to that of ribavirin; thus it works in synergy with the latter. First results in phase two studies in the United States on 85 subjects show that after 24 weeks of treatment, the addition of Merimepodib® has increased the response to treatment from 33% (peginterferon + ribavirin + placebo) to 86% (peginterferon + ribavirin + Merimepodib®). It remains to be seen if the virus reappears or not after treatment is stopped. Vertex hopes to be able to start a phase III study in 2004.

Researchers have shown an interest in adding epoetin alfa, a molecule similar to EPO used illegally in the cycling world, to treat anemia associated with ribavirin. The study carried out with 186 patients who developed anemia under treatment with the association of interferon and ribavirin showed that EPO allowed these patients to get higher doses of ribavirin while maintaining a good level of red blood cells.

For those who have heard about research with amantadine, an antiviral with a certain efficacy against the flu, an American study carried out on 171 patients reported no difference between those who received amantadine with interferon and ribavirin and those who received a placebo.

To keep up to date, the HIV and Hepatitis website at this address: www.hivandhepatitis.com/index.html is your best choice. In the hepatitis C-section, under 'New stories', there is a wealth of choice.

A drug doesn’t arrive by chance on the pharmacy’s shelves. It is subject to a severe selection process. 5000 different molecules in pre-clinical trials are tested (on cell cultures or on animals) in order to get 5 that will be tested on humans. Of these 5 molecules, only one will go through the three clinical trial phases (phase I, II and III) and be approved for marketing. A drug that has already been sold may be removed from the shelves because of a serious secondary effect, unknown until then, which has made its administration too risky.

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This article was originally published in the winter issue of L’Echo du facteur, newsletter of the Quebec Chapter of the CHS.
As people with bleeding disorders try to establish a range of strategies to deal with acute and/or chronic pain, they may be reluctant to consider pain medication due to concerns about side effects, the potential of addiction, possible negative interactions with other medications or previous experiences with using pain medication that “didn’t work”. The information that Dr. Peter Leung presents in this article, the third in Hemophilia Today’s series on pain management, addresses these topics, and will add to people’s ability to communicate with their physicians with confidence.

Maureen Brownlow, Co-chair, CHS Pain Management Working Group
Addiction is not the same as tolerance. When people use opioid pain medication, their bodies become accustomed to the dose. One may need to increase the amount to get the desired effect. Changing to a different medication can sometimes avoid the increase. Poorly treated pain is detrimental to patients. Poor pain management produces abnormal pain behaviour and may even cause patients to seek out street drugs because they are afraid of not being able to manage severe pain.

What are adjuvant medications? Why are they useful?
Adjuvant analgesics are a diverse group of drugs used to enhance pain control in specific circumstances. They do sometimes reduce pain levels by themselves but often are best used in combination with pain killers.

What adjuvant medications can be used?

Anti-depressants
Amtriptillyne (Elavil®)
Nortrytilline (Aventyl®)
Fluoxetine (Prozac®)

Anti-convulsants
Carbamazepine (Tegretol®)
Phenytoin (Dilantin®)
Valproic Acid (Depakote®)
Clonazepam (Rivotril®)
Gabapentin (Neurontin®)
Pregabalin

The rational use of pain medications can be based on the World Health Organization Analgesic Ladder.

What are the common side effects of all opioids?
– Nausea and vomiting
– Sleepiness
– Constipation
– Itchiness
– Tolerance
– Respiratory Depression

What are the other concerns related to opioids?
– Addiction
– Abuse
– Diversion (used by others or sold)

Are opioids addictive?
There are no guarantees in medicine. Physicians take all possible precautions and still there will be patients who will use more than needed. On the other hand, who is to say how much is needed except the patient himself? As long as the amount used is for pain, then the chance of addiction is quite low. Short-term use for surgery or acute bleeds is very unlikely to lead to addiction.

Pain levels change. What adjustments can be made for good days and bad days?
While slow-release forms are ideal for managing day-to-day pain levels, most doctors will allow a certain amount of shorter-acting breakthrough medications for bad days and for acute bleeds. If the breakthrough medications are being used too frequently, the doctor will re-assess the situation, look for a cause and adjust the medication.

Does marijuana work for pain?
Marijuana is probably better to reduce nausea, improve appetite and promote sleeping. Its use must be individualized. For most patients it is not the magic drug. Legal access to marijuana is difficult.

Are there things to remember when traveling?
When the patient is traveling, the doctor can provide a specific letter detailing the medications and the amount needed. He/she may even set out a suggested plan of medication for mild and severe bleeds. This will help the doctor in another city manage the pain according to what the patient usually needs, and avoid too much or too little medication. It will also provide evidence at borders that a person is authorized to carry these medications.

Always keep the medication in the original bottle so that there is no doubt as to the kind of medication being carried. Do not mix different pills (blue, yellow, big, small, round, cylindrical…) into one bottle. This can cause confusion and mistakes.

Why are some doctors reluctant to give stronger pain medicine?
There are many different answers to this question. Some doctors do not have much experience treating pain. Others are concerned about the professional consequences. Unfortunately, one of the barriers to effective pain management is that the governing body of doctors still frowns on the prescription of strong pain medicine, especially opioids.

There is also a lot of discussion as to whether doctors can ethically refuse to prescribe effective opioid medication for pain. If this happens, ask the doctor for a referral to a pain clinic. Or try to find another doctor who works well with the patient to manage his pain. Good pain management does not always mean a lot of medicine.

In conclusion, it is important to remember that there are many useful medications for controlling pain. In all cases, the type of analgesic and the route of administration must be tailored to the individual patient. What’s more, the underlying health problem must be managed by knowledgeable health care workers.
rAHF-PFM: Baxter’s third-generation recombinant factor VIII under review by Health Canada

In the spring 2002 issue of Hemophilia Today, this column reported on a new, third-generation, recombinant factor VIII called rAHF-PFM, in development by Baxter Bioscience since 1997. It received regulatory approval from the Food and Drug Administration (FDA) in the U.S. in July 2003, and from the European Medicinal Evaluation Agency (EMEA), responsible for the European Union in early 2004. The therapy is currently being marketed by Baxter in those jurisdictions under the name of Advate®. The company has submitted the drug for approval by Health Canada and the review is underway.

Baxter Bioscience has plans to phase out its current recombinant factor VIII product, Recombinate®. The exact schedule of the phase-out, however, has not been announced. It will depend on the timing of the new drug’s approval, production and planning at Baxter, and ongoing discussions with the Canadian Blood Services and Héma-Québec.

In May, Hemophilia Today interviewed Bruce Ewenstein, M.D., Ph.D., Global Medical Director for Hemophilia Therapy for Baxter Bioscience. Dr. Ewenstein worked for 17 years as a director of an adult and pediatric hemophilia centre in Boston until joining Baxter two years ago.

Hemophilia Today: Baxter already has a recombinant factor VIII—Recombinate—on the market. What led to the development of this new therapy?

Dr. Ewenstein: We started with the premise that Recombinate was a great drug. It has been around almost 15 years and has an excellent safety and efficacy record. One potential drawback, however, is the presence of human and animal proteins. I have been involved in the hemophilia community for many years in the U.S. where safety has been a major issue, and there have been recommendations to develop new products like rAHF-PFM that are free of these human and animal components. This is something people have been asking for.

Hemophilia Today: What are the similarities and differences between Recombinate and rAHF-PFM?

Dr. Ewenstein: The coding sequence for the factor VIII gene is identical for both Recombinate and rAHF-PFM. We also started with the same cell line, which is a Chinese hamster ovary (CHO) cell line, and selected a clone for its ability to grow in a protein-free environment. So from the development standpoint, this is one of the chief differences with Recombinate. Another big difference is that sugars, rather than albumin, are added in the final formulation. The last big difference is the addition of a solvent detergent viral inactivation step.

Hemophilia Today: The monograph also mentions the presence of mouse antibody.

Dr. Ewenstein: The monoclonal antibody is the same well-characterized antibody that is used in the purification of Recombinate with the one difference that it is derived from hybridoma cells that have also been adapted to a ‘vegan diet’.

Hemophilia Today: Is it fair to say there are trace amounts of mouse immunoglobulin and CHO protein?

Dr. Ewenstein: Yes, there are trace amounts that can be detected, virtually the same amounts that are present in Recombinate, but those have never been shown to be harmful in terms of allergic reactions.

Hemophilia Today: You mentioned the addition of a solvent detergent viral inactivation step. If this product does not have the potential to transmit human and animal viruses, why is there a viral inactivation step?

Dr. Ewenstein: The answer is based, in part, on regulatory considerations. In Europe there are EMEA recommendations to have a dedicated viral inactivation step against the major classes of virus in all such products. You could call it a ‘belt-and-suspenders’ approach. But from a theoretical point of view, it is not easy to imagine how a pathogen could get into the process; nevertheless, this step provides another level of security.
**Hemophilia Today:** Is there any evidence that Recombinate, the current Baxter product in Canada, has transmitted human or animal pathogens?

**Dr. Ewenstein:** No, we do not have any evidence of transmission so this is all theoretical. But I don’t think you have to wait for the next emerging pathogen to cause harm before taking preventive action. Our feeling is that viruses are constantly emerging or being discovered; they are created from other viruses. So the best approach, not knowing what nature has in store, is to do whatever you can to isolate your system from what may happen out there.

**Hemophilia Today:** Recombinate contains albumin in both the cell culture and in the final formulation as a stabilizer. Is there any evidence that albumin has resulted in pathogen transmission?

**Dr. Ewenstein:** Albumin has an excellent safety record over the past 50 years and Recombinate has proven to be an effective and safe product. But there are new kinds of pathogens, such as prions responsible for variant Creutzfeldt-Jakob Disease (vCJD), that have emerged. While these prions are eliminated to a certain extent in the preparation of albumin, there is no way to test for them in a large-scale way. At the same time, it is important to emphasize that there has been no evidence of transmission of vCJD through factor concentrates, either plasma-derived or recombinant. There is evidence now, however, that it can be transmitted through blood. So the best approach is to remove the risk to the extent technology is able.

**Hemophilia Today:** What have clinical trials revealed about the efficacy of rAHF-PFM?

**Dr. Ewenstein:** A direct comparison with Recombinate was made through pharmacokinetic studies and demonstrated that it is biologically equivalent. After the pre-clinical studies in animals, human clinical trials began at the end of 2000. In the pivotal study, rAHF-PFM was studied in 108 patients over the age of 10 who had had at least 150 prior exposure days to factor VIII, and demonstrated the same level of efficacy that we saw with Recombinate. One or two infusions were needed to treat a bleed in the vast majority (94%) of cases. We also looked at the breakthrough bleed rate in these older patients on prophylaxis; the average number was 4 events per year among patients who were reasonably adherent to the protocol.

Finally, there is an ongoing pediatric study in children less than 6 years of age who have had some exposure to factor VIII (at least 50 infusions). Again, the efficacy has proven to be excellent, essentially the same as in the pivotal study of older patients.

**Hemophilia Today:** Let’s look at the safety side. What have clinical trials revealed about adverse reactions, in particular, inhibitors?

**Dr. Ewenstein:** The good news is that in the entire clinical program, in all studies to date, there have been no high-titer inhibitors. We did see one low-titer inhibitor that showed up through laboratory testing, not because of lack of efficacy. By the time we re-tested, it had disappeared. So that makes one low-titer, non-persistent inhibitor in over 200 patients. There have been no reports of inhibitors through pharmacovigilance in the first 9 months post-launch.

**Hemophilia Today:** What about other reactions to the therapy?

**Dr. Ewenstein:** During the clinical trials, when reactions are rigorously reported, we have had no serious adverse events that were judged to be related to rAHF-PFM. Among the non-serious events, reactions are divided into “mild”, “moderate” and “severe”. Several were considered by their physicians as severe, including one high fever, which was not related to rAHF-PFM.

Since marketing, we have had a very positive experience. When compared with Recombinate for the same time after introduction, we have seen about half the number of adverse reactions reported with twice the number of units distributed. We have had ten adverse events reported in the first 9 months post-launch and most of these were mild. There was a single serious adverse event, a severe allergic reaction in a patient who appears to react to all FVIII products. It’s been a very reassuring introduction.

**Hemophilia Today:** What is the current situation with Health Canada?

**Dr. Ewenstein:** We are still in active conversations with Health Canada to provide them with the latest information on our clinical trials and would hope for a positive decision by the end of this year.
Bayer devotes research energies to a ‘new, improved’ factor VIII

David Page, CHS Blood Safety Coordinator

Following news that a scientific presentation by Bayer Biological Products (BP) was recognized as the second-best abstract presented at the recent Society for Thrombosis and Hemostasis meeting in Germany, Hemophilia Today interviewed three Bayer scientists familiar with this research into the development of a longer-lasting recombinant factor VIII molecule. They are: Michael Fournel, Senior Vice President, Research and Development; Dr. Peter Radtke, Director of Global Clinical Strategy; and Dr. Peter Larson, Senior Staff Scientist.

Many readers will know that Bayer already has a second-generation recombinant factor VIII product on the market in Canada. Kogenate FS®, which uses no animal or human proteins as stabilizers in the final formulation, was approved for use in Canada in 2001. Bayer is also in the process of launching a needleless reconstitution device—called BIO-SET—which will reduce the number of reconstitution steps for Kogenate and involve only one ‘sharp’, the needle that goes into the vein.

Hemophilia Today; however, was especially interested in the research to develop a ‘new, improved’ factor VIII molecule. Michael Fournel explains Bayer’s decision to forego development of a ‘third-generation’ factor VIII (See rAHF-PFM: Baxter’s third-generation recombinant factor VIII under review by Health Canada on page 19).

“We made a decision to market a second-generation product because of what we thought were safety concerns with the albumin present in the stabilizer. We felt that eliminating this significant amount of human protein in the final container would achieve a significant benefit. Our decision to skip the third-generation product was made in consultation with the hemophilia community, scientists and opinion leaders. They told us it made more sense to invest our research dollars in something that would offer a substantial benefit to the patient rather than the incremental difference between second- and third-generation products.”

Peter Radtke described the work for which Bayer and collaborators from the Scripps Research Institute in La Jolla, California received the award. “The work is part of a larger project here at Bayer to look at different ways to improve the factor VIII molecule itself, and ways to improve features such as ease of administration. The particular work that was recognized was for a factor VIII molecule that, once activated, stays activated for a longer period than normal factor VIII. So the molecule we’re designing has a higher stability once activated. A genetically engineered molecular bridge holds vital parts of the activated factor VIII together. This factor VIII doesn’t fall apart as quickly so it can participate in clot formation for a longer time. A person wouldn’t need as much factor VIII.”

Other strategies under investigation include looking to increase the half-life of the non-activated factor VIII and, by making modifications at the surface of the molecule, to prevent it from being cleared as quickly as the wild-type molecule. This would be done by identifying residues which are involved in the binding to a clearance receptor so that the binding is interrupted. Michael Fournel describes another approach to modify the molecule by changing certain amino acids which would influence the pharmacokinetics or the half-life once in circulation. “We’re trying to modify the structure of factor VIII by mutating certain amino-acid residues and replacing them with other amino acids which achieve our goals—true genetic engineering.”

He went on to explain the motivation behind the research. “Our goal is to reduce the frequency of administration to avoid breakthrough bleeding with prophylaxis therapy. We’d like to take three-times-a-week prophylaxis and be able to cut it down to once a week. That’s the order of magnitude. Ideally, we’d like to do even better than that.”

While those who dream of the day when gene therapy might reduce the frequency of treatments to once a year or less may find this unimpressive, Peter Larson says that the benefits would be critical. “We received a really strong message from pediatricians of the real need to lower the number of infusions required to achieve effective prophylaxis. There are many benefits to this: better adherence to treatment protocols which are so difficult for younger children, and reduction in the use of central venous access devices with their attendant risks of infection and thrombosis.”

The specter of increased antigenicity—the development of inhibitors—is always raised when molecules are being modified from their natural form. “We’re paying close attention to the problem of antigenicity,” says Peter Radtke. “We’re building the bridges that stabilize factor VIII between the sub-domains in the molecules in places where the antibodies are not able to see them. There should be no increased risk of inhibitors.”

Another area of research, according to Michael Fournel, is to look at different non-vascular routes for administration of factor VIII. “Getting the drug into circulation would be via an implant or an absorption mechanism rather than infusion into a vein.”

Hemophilia Today asked the obvious question: How long will it take before some of this research is translated into marketed products?

“Going for the home run,” says Michael Fournel, “is a challenging task. It takes a long time to get there. The normal time line for drug development can be as long as eight years. Some of the approaches we have underway are building on the existing molecule and could come sooner than that.”

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Peter Larson adds, “We’re committed to working on these developments that would really change the quality of life for people with hemophilia.”
or the past three years, a genetic study led by Dr. David Lillicrap, hematologist at Queen's University in Kingston, Ontario, has been carried out to identify all mutations responsible for severe hemophilia A and B in Canada. It has made it possible for the majority of severe factor VIII or IX hemophiliacs to know the exact mutation responsible for their condition.

All female members of these families have free access to a molecular diagnosis, allowing them to establish with certitude whether or not they are carriers of hemophilia. The molecular tests used in this study are sophisticated and expensive; most of these tests are not available elsewhere in Canada.

For 50% of severe factor VIII hemophiliacs, it is relatively easy to identify their mutation in a regular molecular biology laboratory. In these cases, a part of the gene responsible for the factor VIII deficiency (intron 22) is reversed. It’s as if a nose were upside-down on a face. It’s easy to understand that this organ can’t work. It’s what’s referred to as the intron 22 inversion or the flip.

In order to find out if a woman is a carrier in these families, one simply looks for the flip on a blood sample. It’s a test that’s fairly simple, and only requires a few weeks delay. For the other half of the severe Factor VIII deficiencies, and all factor IX deficiencies, the identification technique for the mutation can be very complex. This technique sometimes requires many months of work, despite state-of-the-art equipment and a highly qualified team of professionals.

In order to identify the mutation in a potential carrier, it first has to be identified in the hemophiliac. Ideally, all blood specimens from the family should be sent at the same time. The technicians can look for the corresponding mutation in the other members of the family. Of course, all results are kept on file. People who may be carriers and who haven’t been tested should take advantage of this study by communicating with the treatment centre of their choice.

The nurse, using the family tree collated at the time of diagnosis of the first hemophiliac in the family, will verify that the person is actually at risk of being a carrier.

Is it so important to know your status as a carrier? The first reason is that diagnosis as a carrier of severe hemophilia implies a 25% possibility of having a child patient having to go through the inconvenience of a late abortion. Thus it’s imperative to advise hemophilia treatment centre personnel as soon as the pregnancy is confirmed, usually around the 5th or 6th week. This allows the molecular biology laboratory staff to gather the material needed to identify the specific gene for this family during chorionic villus biopsy (taking cell samples from the placenta through the vaginal passage). This is planned by the genetic and gynecology-obstetrics team at the 11th week of pregnancy. Results are available at around the 13th week.

To meet this objective, the patient’s carrier status must be known at the start of pregnancy, as well as the specific mutation. Otherwise, while it is possible to accelerate the process by requesting a priority for genetic analysis, it will be a challenge to have the results in time for the 11th week of pregnancy.

Amniocentesis (punction of amniotic liquid through the abdomen) between the 14th and 16th week of gestation is the second alternative. It takes four weeks after the test to get the results, which would imply an abortion at the 18th to 20th week of pregnancy. All these delays can be avoided with an investigation carried out at the hemophilia centre before pregnancy.

The second reason why it’s important for carriers to know their status is the possibility that they are symptomatic carriers. Since carriers have only one gene that functions properly compared to two in non-carrier women, they can have a low level of factor VIII or IX. Some may present with coagulation problems like mild hemophilia. In women, these symptoms are: heavy menstrual bleeding, frequent bruising, and important bleeding following surgery or serious injury. All these inconveniences can be controlled or prevented by establishing a diagnostic and individual treatment plan at a hemophilia centre.

I suggest that all hemophiliacs and those related to a hemophiliac contact all the females in the family likely to be carriers (cousins, aunts, granddaughters of hemophiliacs) to share the contents of this article with them. If they don’t know their status, I encourage you to convince them to contact your hemophilia centre. Thus you can avoid many problems and allow them to make an enlightened decision in a timely manner.
Close to 100 health care providers gathered in Amman, Jordan to take in the orthopedic and physical therapy presentations by Dr. Jerome Wiedel and physiotherapist Kathy Mulder.

By Candace Terpstra

TCOR is now part of something much larger than itself. We are part of a global plan to improve the quality of life for people with hemophilia around the world and, in particular, for approximately 500 people with hemophilia in the country of Jordan. By working together with the Jordanian Hemophilia Society to educate people with hemophilia, their families and medical personnel while strengthening the membership and building the capacity of the organization for fund-raising and lobbying, we can improve care and treatment for all people with inherited bleeding disorders.

Our most recent visit to Jordan took place in September 2003. The highlight was a three-day medical conference which attracted over 80 participants from all three levels of care within the country: the royal military hospital, the university (private) hospital and the public hospital.

Dr. Bernadette Garvey, Co-Director of St. Michael’s Hospital Hemophilia Program, addressed the basics in her excellent presentation on clinical care and treatment of hemophilia which included the diagnosis of Hemophilia A and B, and its treatment using blood components such as plasma, cryoprecipitate and concentrates, as well as desmopressin and anti-fibrinolytic agents. Also included was a review of the complications of hemophilia and a discussion of inhibitors and their management. Last but not least was a description of the comprehensive care model of treatment which we use here in Canada.

David Page, World Federation of Hemophilia (WFH) Vice-President, National Member Organizations, addressed issues of the safety and supply of blood products.

The second session focused on orthopedic problems, with a presentation on the management of orthopedic problems by Dr. Jerome Wiedel, orthopedic surgeon and Co-chair of the WFH Musculoskeletal Committee, Mountain States Regional Hemophilia and Thrombosis Centre, Colorado. This was followed by a very thorough review of the benefits of physiotherapy in the management of hemophilia by Kathy Mulder, physiotherapist from the Winnipeg Health Sciences Centre and the second Co-chair of the WFH Musculo-skeletal Committee. In a country like Jordan where treatment is not always available, physiotherapy takes on a new meaning in the form of identifying a bleed, using RICE (Rest, Ice, Compression and Elevation). I remember thinking it was like going back to basics – basics we could use right here in Canada.

On Saturday and Sunday, orthopedic workshops were conducted at each of two hospitals with excellent results and over 50 people in attendance at each. Dr. Wiedel and Kathy Mulder participated in workshops with doctors and physiotherapists in a very practical way. Jordanian Hemophilia Society members volunteered their joints to be examined by both the surgeon and the physiotherapist. Physiotherapists were taught how to identify bleeds, as well as when and how to begin movement after a bleed. Dr. Wiedel then spoke about the physiology of the joint, explaining hemorrhahs and various kinds of surgical corrections.
The patients’ meeting was held on Saturday afternoon with over 75 members assembled to hear short presentations by the Jordanian Hemophilia Society President, Arafat Awajan, Dr. Dhowari, Dr. Wiedel, Kathy Mulder, David Page and me. Members enjoyed the opportunity to address their questions directly to the experts, a trait hemophilia society members have in common the world over.

In addition to the three days of the conference, there were several other important meetings. Dr. Garvey met with key physicians providing hemophilia care at each of the three levels of care within the country. Meetings were held with government officials to promote the WFH Global Alliance for Progress (GAP) program, which has recently received Jordanian Ministry of Health approval. This WFH program will bring resources to bear, not the least of which is the Ministry approval required to establish a medical centre twinning. David Page had an opportunity to tour the National Blood Bank, meet the Director, and discuss various aspects of blood safety.

In summary, this first year has been a huge success. The Jordanian Hemophilia Society has been highly successful in educating its members through meetings and the patients’ conference, newsletters, a one-hour television show, and the first Arabic brochure on hemophilia in the Middle East region. The first Hemophilia Conference was very well received and attended by medical professionals from all three levels of care. And this was all made possible through the Twinning Program and the collaboration of the WFH volunteers and staff with the financial assistance from the WFH, the CHS, TCOR and the JHS. In the words of Jordanian Hemophilia Society President, Arafat Awajan, “Twinning provides the foundation upon which everything is built.”