Two years later, the courts have finally appointed an Administrator for the 1986-1990 class actions settlement which was first announced by Health Canada in March, 1998.

Approximately 64% of people with bleeding disorders who received plasma-derived clotting factors prior to 1990 were exposed to the hepatitis C virus, making chronic hepatitis C one of the leading complications of bleeding disorders. This issue of *Hemophilia Today* includes a special supplement designed to help persons living with hepatitis C, and their family members, learn more about the disease and the impact it has had on the hemophilia community. It is dedicated to all of the CHS members who have worked tirelessly during the past years to help those infected and affected by hepatitis C.

Read more about this and other news in the Special Hepatitis C Supplement included with this issue.
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s we enter the new millennium it is appropriate to look ahead to see where the CHS is going and how we might get there, if possible. So with that in mind our President, Erma Chapman, reports in this issue of Hemophilia Today, on the Strategic Planning session held January 29 and 30, 2000. There was a remarkable degree of consensus at the retreat and the results are interesting. Rather than striking off in bold, untried directions, the participants came to the conclusion that the CHS needs to affirm what it has been doing in the past. That is to say, there was agreement that while we are generally satisfied with our performance in the past, we need to enter this new century with a rededicated heart and mind and continue the work that has meant so much to our constituents: assure equal access to care for all hemophiliacs; communicate with a large percentage of our members; defend those affected by blood-borne pathogens; support research; increase the CHS’s profile in the world community.

While it is easy to say that we will contribute to our fullest in these crucial areas, it requires a new dedication in our members and Executive to make the dreams come true. For we will be successful only if we all contribute to our fullest; anything less and we risk leaving tasks undone, issues unresolved, members disappointed. So we all ought to be prepared to shoulder our responsibilities when called upon to help.

Clearly, Karttik Shah, agrees, and his Youth File column is a discussion of the approaches we might find helpful; participation with other organizations in the development and dissemination of information (here, the Canadian AIDS Society’s Skills Building Conference that in part dealt with treatment regimens for person with HIV/AIDS); the support for youth that is being offered to attend the World Congress of Hemophila in Montreal later this year. We must continue to foster good relationships with other charitable organizations so that we can share information, and we must provide support for our youth: they are the CHS’s profile in the world community.

The Blood fractionators are also doing their part to ensure new treatments are available in the new century. David Page’s interview with Astrid Reimann, Scientific Development Manager for Bayer Inc., in his column, The Blood Factor, discusses the most recent development in safer coagulation products, Kogenate FS, made with sucrose not human albumin. This promises for the first time in Canada a treatment that will be virtually free of human viruses. Your Editor urges everyone to read this column and see for themselves the promise afforded in this new technology.

In keeping with the theme, Patricia Stewart’s column, The Female Factor, deals with the recent establishment of some new clinics in Quebec that deal exclusively with women’s bleeding disorders. Thus a precedent has been set in Canada, and all provinces should join with Quebec in setting up clinics to deal with these important matters. Women’s issues have been ignored long enough, and it is time to act—it’s past time to act. We congratulate Ste-Justine’s Hospital in Montreal and l’Hôpital St-Sacrement in Quebec City for leading the way in providing care for women with bleeding disorders.

And so, as Hemophilia Today adopted a new look with our last issue, we feel that we too are holding up our part of the millenial drive. If we could only convince those responsible for holding up the hepatitis C compensation plan to speed things up a bit, perhaps we would be able to say that this new year, this new century, truly ought to be celebrated.

(Please send any comments raised by this, or any other Editorial to the Editor, Hemophilia Today, 1409B 4th Street N.W., Calgary, AB T2M 2Y8. Or fax your comments to (403) 282-3295)
Defining strategic directions for the CHS

‘Tis the season of annual meetings, and I am hoping to see many of you as I make my way to several gatherings of CHS Chapters and Regions. At the meetings where I am given an opportunity to speak, I will be sharing our new strategic vision of the CHS. For those of you who do not hear it from the horse’s mouth, I would like to update you as part of my column.

Our strategic direction is exciting and, I find, energizing and motivating. But rather than a significant new direction, the vision affirms the growth and development of CHS as an organization. The needs of our most vulnerable people – those who are undiagnosed or newly diagnosed with a bleeding disorder, those with HIV, those with HCV, those who are infected by multiple blood pathogens – are addressed and prioritized. As well, we are looking forward with anticipation to new and existing opportunities for research, for an expanded global presence, and for an improved education and awareness of bleeding disorders other than hemophilia.

At our strategic planning retreat on January 29 and 30, 2000 (yes, on Superbowl weekend!), 25 board and staff members reconsidered the CHS mission, defined our values and articulated a vision for the next three to five years. Following this examination of our heart, we identified the business, which had to occur to accomplish this vision, within the boundaries of our mission and values. Our facilitator, John Pepin, divided us into two groups to define the business. When we reassembled, we found that both groups had the same goals and objectives for the next three to five years. By starting with the shared vision, we were able to identify the strategic directions for the CHS.

The directions, which were agreed upon unanimously, were as follows:

• Assure equal access to the highest standard of comprehensive care available for people with bleeding disorders.

This direction includes our continued struggle for standards of comprehensive care throughout the country; our role as watchdog of Canada’s blood system, including preparations for crises; advocacy for the safest products; development of a program to educate physicians who work in emergency departments across this country about bleeding disorders; advocacy whenever health care reforms threaten access to care and treatment for those with bleeding disorders; and advocacy for safe and cost-free access to product and blood alternatives. As part of this direction, we also considered the need for a fellowship or residency in bleeding disorders, as part of training new physicians who will be our caregivers in the future.

• Identify and communicate with a large proportion of “our people”.

As part of the values exercise, we defined “our people” as including people with bleeding disorders, their families and their care providers (e.g., nurses, physicians). The role that the CHS has played in providing support, education and information for people with bleeding disorders and our professional care providers will continue, as will communication vehicles such as our web site and Hemophilia Today. As well, we are considering the implementation of a major education and awareness campaign for von Willebrand’s Disease, followed by the evaluation of the needs of people with vWD and implementation of programs to meet these needs.

• Defend the interests of members affected by blood-borne pathogens.

A substantial effort over the next few years will be made to develop and implement programs with regard to Hepatitis C. As well, the CHS needs to continue its role in meeting the needs of those who are co-infected with HIV. Other activities within this strategic direction included support programs for infected and affected people, education and information dissemination, and assuring that compensation efforts are concluded successfully (e.g., MPTAP indexing, HCV compensation for all).

• Support research.

We have heard from many of our members that research activities within the strategic direction were designed within a framework of both programs and research as strategic plans, rather than as a choice between research and programs. As an organization, CHS has annually contributed to research funds from the Million Dollar Club to ensure that a realistic amount of money is available for basic research projects. We will continue to do this, as well as to work with the trustees of the Million Dollar Club to augment the capital from which funds are made available each year. We are presently working with a funding source to establish our “Care Until Cure” fund for clinical research. And we would love to be able to find funding to allow our doctors, nurses, social workers and physiotherapists the time they need to concentrate on research efforts.

• Increase the presence of the CHS within the global bleeding disorders community.

The CHS is already active within the global community, with twinning projects between Tianjin, China and the Calgary clinic, as well as between Senegal and the Quebec Chapter. In addition, many of our educational print resources are used throughout the French-speaking world. The CHS is currently involved in planning with the World Federation of Hemophilia for their Congress 2000 in Montreal this summer, and we have submitted a bid to host the World Congress 2004 in Vancouver.

In conjunction with these strategic directions, it is imperative that the CHS diversify its funding base, increase the effectiveness of the Board of Directors, and work together to achieve our shared vision.

While the strategic plan is ambitious, we are a capable and resourceful group of people. My promise, as your President, is that we will commit to this direction and determine any change to that direction as a group. I look forward to working together over the next few years to achieve our goals.
The Voting Class Certificate Holders of the Hemophilia Research Million Dollar Club have elected Daniel Baribeau, Frank Bott and Lawry MacLeod as the Trustee-Administrators for the year 2000. Frank Bott was voted in as the new Chair.

Daniel Baribeau was a member of the Board of Directors of the Canadian Hemophilia Society – Quebec Chapter from 1992 to 1996 and during that period he served on the CHS National Board. In 1994 he became the President of the Chapter and served in that capacity until 1996. He presently sits on the Blood Safety Committee of the Canadian Hemophilia Society – Quebec Chapter and also on the Liaison Committee (composed of blood product recipients) which advises the Board of Directors of Héma-Québec.

Frank Bott, Chair of the Hemophilia Research Million Dollar Club, has been involved with the Canadian Hemophilia Society at all levels for over thirty years. As National President in the late ’60s and early ’70s, he focused on building a foundation for growth in the areas of fundraising, administration and constitutional reform. He has since continued his involvement, particularly with respect to finance and administration, strategic planning, program development and publications. As editor of the Toronto and Central Ontario Region (TCOR) publication, he has kept current with issues affecting persons with hemophilia and other related bleeding disorders.

Lawry MacLeod has been involved with the Canadian Hemophilia Society at both the national and chapter level since 1981. He has served as Nova Scotia Chapter President, as a member of the National and Chapter Boards of Directors, and participated on several national committees including Fundraising and Awards. As a member of the Nova Scotia Chapter Executive, he was involved in the initial promotion and purchase of several Million Dollar Club shares by the Nova Scotia chapter.

The Canadian Hemophilia Society wishes to extend its congratulations to Daniel, Frank and Lawry.

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**Risks associated with pathogen transmission**

Transmission of clinically significant pathogens in plasma derived CFC’s occurs rarely if ever thanks to a number of factors including the current purification process, combined with donor screening and advanced serological and genome detection techniques for pathogens as well as thermal, physical and chemical viral inactivation methods.

However some viruses such as parvovirus B19, which are resistant to the inactivation process, are still transmitted through CFC’s, and although relatively harmless, it serves as a reminder that we must remain vigilant in the area of pathogen transmission from plasma derived CFC’s.

The risk of blood borne transmission of nV CJD through plasma derived recombinant CFC’s is still theoretical and remains a point of concern until more information becomes available. I came away from Dr. Paul Brown’s session, however, with at least one new element in the understanding of nV CJD transmission and that is the idea that it is not the beef, that has the infection since any infection must come from a cross contamination of the beef with central nervous system (CNS) (especially spinal cord) tissue containing the infectious prion material, during the rendering process.

We also learned that there are two new ( yet unconfirmed )cases of nV CJD in France and several other cases are presently under investigation.

What seems to be consistently clear, however, is that the fractionation process for plasma derived CFC’s shows a significant 106 fold reduction in prion load between raw plasma product and final products. In essence there are very few or no prions left in CFC’s at the end of the fractionation process. Therefore the greatest adverse effect associated with the use of CFC’s ( particularly recombinant products) remains the possibility of inhibitor development.
Open Forum On Blood Safety – Hospital Issues

The NBSC held it’s 1st public forum of the millenium in Calgary on February 10th and 11th, 2000. The focus of this forum was hospital issues surrounding blood safety. After much discussion by the NBSC during the preparation of this forum it was decided to divide the numerous issues into two separate forums, setting the groundwork for the next forum in September in Halifax. Those issues not covered in the latest deliberations will be addressed in the next forum.

The CHS was invited to participate to give a consumer perspective of certain issues, especially those surrounding patient information and informed choice/informed consent. The forum began appropriately with a consumer oriented panel concerning these issues. Panel members included representatives of CHS, Hospital Information Services for Jehova’s Witnesses, the

Canadian AIDS Society, medical and nursing staff, laboratory technologists, an ethicist and Bonnie Tough who gave us a legal perspective on the issues.

A lot of discussion surrounded the notion of what informed consent/informed choice really means and the pertinence of obtaining a signed consent form. Although no consensus was reached, everyone agreed that the paperwork was secondary to the process. The focus needs to be on establishing a reliable process that guarantees quality information exchange between the patient and the physician as well as the availability of alternatives, when judged appropriate and chosen by the patient after discussion with the treating physician. Many questions were raised concerning who would be the most appropriate person to have this discussion with the patient and no consensus was reached except to agree that the most informed person would be the preferred resource to discuss transfusion/treatment alternatives with the consumer.

On day 1 of the discussions, speakers included hematologists, anesthesiasts, laboratory technologists, consumers and blood bank coordinators. Several aspects of blood safety issues at the hospital level were discussed, including: inventory management at the bloodbank and the impact of variable supply on bloodbank operations. Dr. Graham Sher presented some statistics from the CBS showing a steady increase over the last few months of donations collected as well as increased quantities of inventory sent to regional centers. Although this information is encouraging, several speakers expressed certain problems with inadequate supply and especially supply management between regional centers and different hospital bloodbanks. We also saw, in some detail, the organisation and the work process of some hospital bloodbanks. Finally Ms. Karen Lipton from AABB gave a perspective of a quality management programme in Hospitals in the USA.

Day 2 concentrated on administrative aspects of blood and blood products within the hospital, including a consumer and a legal perspective. Finally, a presentation was made about the BC provincial Blood Coordinating Office, and the integrated Hospital system in Québec.

This forum provided a chance for each link in the vein-to-vein chain of blood transfusion to exchange openly on issues pertinent to the macroscopic view of blood safety in Canada. Pathogen transmission is only a part of the picture, and has been addressed by the two operators in the system. Supply and availability of product, as well as a quality management programme in hospital bloodbanks, are important variables in the equation.

It was suggested that a comprehensive quality management programme in hospital transfusion services, beginning with effective patient information geared to informed choice, is a solution to a complex multifactorial problem. In order to achieve this we need National Canadian laboratory standards with an adequate system of accreditation for all bloodbank laboratories in Canada.

And in the area of pathogen transmission the most recent information from CDC concerning the SEN virus is that after isolating the genetic code, nine strains of the virus have been identified. More importantly, Canadian studies suggest that the effects of this virus are similar to hepatitis-A, therefore acute and not chronic in nature. However, we are still waiting for approval from the Italian research team at Diasorin Inc. before having access to the data presented by CDC.

Research involving rFVIIa (NiaStase®, NovoSeven®)

With respect to present and future research, the sky is the limit! Main areas of research for the use of rFVIIa include liver induced coagulopathy, continuous vs bolus perfusion of rFVIIa, the use of rFVIIa as an alternative therapeutic agent to platelet transfusion and last but not least, rFVIIa as a universal hemostatic agent.

Having participated in most of the public forums to date, I can say that in terms of exchange between the participants, the NBSC and those attending, this forum was definitely the most effective so far. More discussion is needed, however, in order to cover the scope of these very important issues on all levels, including, among others, the important issue of communications between the suppliers, regional centers and hospital bloodbanks.

We are looking forward to addressing these issues at the next forum in Halifax in September, 2000. A special thanks to Penny Chan, the NBSC staff member, for her excellent work in organizing these forums and to NBSC members for the opportunity to participate in this unique and very important element in the quest for an open, transparent and effective blood system in Canada.
**Q&A**

**Bayer Inc. Canadian Blood Services and Héma-Québec plan to introduce Kogenate FS (FS for “formulated with sucrose”) for the treatment of factor VIII deficiency hemophilia in Canada in the first part of 2000. In late December 1999, Hemophilia Today met Astrid Reimann, Ph.D., Scientific Development Manager for Bayer Inc. in Canada, to discuss this new recombinant clotting therapy. One of Dr. Reimann’s functions is to assure a link between patients, treating physicians, researchers and her company.**

**Hemo Today:** Bayer is soon to introduce Kogenate FS. Could you tell us what is the motivation for changing from the 1st generation Kogenate product to the 2nd generation?

**Dr. Reimann:** Our motivation is based on the patients’ perception that whenever you can get rid of a plasma-derived product in a factor concentrate, you should do so. In the first-generation Kogenate, albumin was involved in all 3 levels of the manufacturing of the factor VIII protein; that is, in the fermentation, the purification and the formulation. As the perception was that there might be a risk with albumin, we looked for ways we could at least formulate and purify recombinant factor VIII (rFVIII) without albumin. We decided to do this even though albumin and its sister product, human plasma protein solution (HPPS), have a 50-year safety record of never transmitting viruses. So in the new Kogenate FS, the plasma-derived HPPS is only used in fermentation. We have gotten rid of albumin in the purification and formulation steps.

**Hemo Today:** Could you explain the steps in the manufacturing process in a little more detail? First, the fermentation process.

**Dr. Reimann:** Recombinant factor VIII is made with baby hamster kidney (BHK) cells. We have a master cell line of BHK cells. Each time we want to make rFVIII, we load the fermentation with some of these cells and then we pamper them from little flask, to small bottles to bigger bottles until they can go into the fermenter. There, they are constantly fed a medium.

**Hemo Today:** How is the rFVIII produced in this process?

**Dr. Reimann:** DNA information for producing human factor VIII is already inserted into these cells. So whenever a BHK cell divides, the sequence, including the A-, B- and C-domains of the factor VIII molecule is reproduced. We think that reproducing the whole molecule with all its domains, as naturally as possible, gives the least chance of starting an inhibitor reaction.

**Hemo Today:** So this is where plasma-derived HPPS is still added to the cell culture?

**Dr. Reimann:** Yes, and even the HPPS is highly diluted in the cell culture. It represents less than 5% of the medium.

**Hemo Today:** The next step is purification of the factor VIII molecule. Does this involve removing it from the culture?

**Dr. Reimann:** Yes, you want to remove it and, at the same time, you want to purify it. In the previous Kogenate, nine columns were used to purify it. We have also substituted the former heat treatment with a solvent-detergent (S-D) step to remove any enveloped viruses. But as we are working with BHK cells, we do not expect any human viruses to be there in the first place. This new purification process involves six different columns which separate the factor VIII from the medium.

**Hemo Today:** We still don’t have a factor VIII which can be used for injection, because it hasn’t been stabilized. This brings us to the third step - formulation. Can you describe this?

**Dr. Reimann:** Yes, you have to surround the molecule so it doesn’t stick to glass or plastic, and get stuck in the bottle or syringe. In the former Kogenate formulation, if you look at the protein content, 95% of it was albumin and less than 5% of it factor VIII. So we tested more than 130 combinations of excipients, which are inactive substances which carry or deliver a drug, in this case, factor VIII, and we had one winner - that was sucrose.

**Hemo Today:** Simple sugar?

**Dr. Reimann:** Yes, a sugar made of glucose and fructose. We had had questions relating to diabetes. Would these sugars be harmful to diabetics? In fact, these sugars are not metabolized when they are given intravenously and they are removed by the kidneys. Also, they are present in such low quantities that they would not upset the sugar levels of diabetics.

**Hemo Today:** So the big change in Kogenate FS is the removal of the human plasma-derived product, albumin, from the formulation in the final bottle?

**Dr. Reimann:** Yes, we still have HPPS in the fermentation. It is important to note all companies’ rFVIII products also use insulin in the fermentation. Some companies use bovine insulin; however, Bayer uses pharmaceutical-grade human insulin from Eli Lilly and this is a recombinant insulin.

**Hemo Today:** Are there any bovine products in Kogenate FS?

**Dr. Reimann:** The only bovine product that is still used during the purification step is polysorbate, which is the solvent-detergent. (Editor’s note: Polysorbate 80, used in many clotting factor therapies for viral inactivation, is made from beef and pig tallow. This
product, gathered from animals in North America, where BSE has not been found, is heated at 250°C at 50 atmospheres of pressure for 30 minutes. This degree of sterilization is far greater than any to which proteins might be subjected.)

Hemo Today: Readers are probably especially interested in how it works. Does it work as well? What studies have been done to make sure Kogenate FS is equally effective to stop bleeding for on-demand treatment as well as prophylactically and in surgery?

Dr. Reimann: We conducted two studies: one with previously treated patients (PTPs) and one with previously untreated patients (PUPs), both in North America and in Europe.

First in the pharmacological studies, we had to show that the Factor VIII molecule that is in Kogenate FS is identical to the one in Kogenate. We were able to show that Kogenate and Kogenate FS are exactly the same pharmokinetically.

With the PTP studies, we found that the blood loss in surgery was very low (less than 250 ml). Clinicians were very impressed with this minimal blood loss. In addition, more than 93% of bleeding episodes stopped after 1 or 2 injections. This holds true for PTPs and PUPs.

Hemo Today: So, in terms of control of bleeding, Kogenate FS looks as good as Kogenate?

Dr. Reimann: There are no differences.

Hemo Today: In 1993 the big question surrounding the introduction of rFVIII, in general, and of Kogenate, in particular, in Canada, was that of inhibitors. There was a lot of concern that because it was a recombinant product, there could be some differences in the molecule which would spark an autoimmune reaction, or inhibitors, especially in PUPs. A big study in Canada shows that, at least with Kogenate since 1993, there has been no change in inhibitor rates when compared with plasma-derived products. Is this correct?

Dr. Reimann: Exactly. We have found that increased susceptibility to developing inhibitors is related to other factors, for example, certain ethnic origins or family history, and not to the use of plasma-derived or recombinant factor VIII.

Hemo Today: What did your PUP study show concerning inhibitors with Kogenate FS?

Dr. Reimann: Eight out of 64 PUPs have developed inhibitors to Kogenate SF. We are now looking at the individual mutations in these factor VIII patients to find out what made the difference. We check these patients for their family history, their HLA molecule, and for their personal individual mutation - in other words, the correlation between the development of inhibitors and their genetic predisposition. Everybody has his individual set of HLA molecules. They sit on immune cells and determine whether an immune response is raised against a newly introduced molecule that the body and its immune system have not seen before. This would be the case for factor VIII injected into a factor VIII deficient patient.

Hemo Today: Does this mean that the development of these inhibitors is related to a person’s genetic predisposition and not to a change in the product?

Dr. Reimann: Yes. And we see no change in the rate of inhibitors when compared to plasma-derived products or Kogenate. If there were something in the product itself that spurred inhibitor formation, we would see a higher percentage of people developing these auto-antibodies, and we would see it in people who don’t have these factors of genetic predisposition.

Hemo Today: What about with PTPs? What does the research show concerning inhibitor development since the study began in 1996?

Dr. Reimann: Here we have an even stronger indication that there is no change compared to other products. Most of the 71 PTPs were already on Kogenate. There have been no cases of inhibitor development with these patients since the study began more than 3 years ago.

Hemo Today: What did the studies reveal regarding adverse reactions to Kogenate FS?

Dr. Reimann: Out of 12,000 infusions there were 250 adverse events. This means a symptom occurred that was unexpected, but not necessarily related to the drug. In terms of adverse drug-related events, there were 24 that may have been remotely related to the infusion of Kogenate FS. None of these were serious. Nobody dropped out of the study because of these reactions. These statistics are comparable with results from previous products.

Hemo Today: Where is Kogenate FS in the licensing process?

Dr. Reimann: We are waiting for the Notice of Compliance (NOC) from Health Canada and a Biological Application License (BLA) from the US FDA and Health Canada. The application was originally submitted in September 1998. We expected it to be licensed in December 1999. That hasn’t happened yet. We expect it very soon.

Hemo Today: When can Canadian hemophiliacs expect to get Kogenate FS?

Dr. Reimann: As soon as the NOC comes in, the product goes out.

Hemo Today: Will Kogenate in its previous formulation still be available in Canada?

Dr. Reimann: Canadian Blood Services has agreed to support the introduction of Kogenate FS so there will be only one product available. Our plan is, in cooperation with CBS, to tightly control inventory so that when Kogenate FS comes in, there will be very little Kogenate in stock. This is not really a safety issue, it’s more a convenience issue. Kogenate in its former formulation will not be taken off the market. It will still be distributed in the rest of the world.

Hemo Today: Are there any other changes with this new formulation?

Dr. Reimann: The vial sizes are the same, whether they contain 250, 500 or 1000 units. All dose sizes are reconstituted with the same amount of water - 2.5 ml. This makes it easier to inject in children because the volume is smaller. It’s very concentrated. We’ve even changed the shape of the tubes to make sure you inject the last drop. So there will be very small vials and very small syringes.

Hemo Today: Here in Canada, some of us have nicknamed this new product KogeLite. Let’s look to the future. Is there a Kogenate ExtraLite on the horizon?

Dr. Reimann: The ExtraLite would correspond to a future product in which albumin’s sister, HPPS, has been eliminated from the fermentation process - the vegetarian form, if you will. That’s still a twinkle in the eye of the researchers.
MAUREEN BROWNLOW is a social worker in Halifax at the IWK Grace. Maureen and I recently spoke on the phone to discuss a project in progress- the revision of Hemophilia In Perspective. We were discussing the need to include a greater teen focus in a section of the manual. Maureen told me about a “Teen Day”, held in Halifax. What struck me about the event, was that it had focused on teens – a well deserving and sometimes overlooked age group and that it was developed and run by several interest groups including, but not limited to, teens with bleeding disorders.

By working with families and medical and support staff associated with several chronic conditions, Maureen and her peers were able to reach a larger number of teenagers, also providing them with the benefit of learning from and about each other.

Bravo Maureen and congratulations to your planning committee. Thanks for keeping me in touch with your event and for sharing this success with us. I hope your story inspires other clinic teams and families to follow this innovative Halifax example. Rumor has it, a program aimed at siblings of children with bleeding disorders is in the early development stage in Toronto. A certain social worker and TOCR staff member are known to be behind this idea. Hopefully, we can tell you all about it someday soon.

As always, we are interested in hearing from our readers about interests and article contributions. I’m available at creighton@idirect.com or call the CHS office at 1 800 668 2686 and Clare Cecchini will get me in touch with you.

Keep In Touch
Karen Creighton

HALIFAX EXPLOSION II

By Maureen Brownlow, MSW

The Halifax Teen Day at the IWK Grace – a day for young people from a number of communities throughout the Maritimes to get together, share and have fun. What did they have in common? They all had a chronic health condition, which has kept them connected to the IWK Grace.

Teens with arthritis, Inflammatory Bowel Diseases, Cystic fibrosis, Diabetes, Spina Bifida, congenital heart disease and Hemophilia have been getting together in their own groups since the early ’90’s. In ’98, young people with either C.F. or IBD had a very successful joint day. From that experience, a multi-disciplinary group of staff got together to plan a day for teens with any chronic illness. The teens themselves were involved from the beginning in planning the format of the day and suggesting topics for the sessions.

From registration at noon ‘til closing at 9pm, approximately 70 young people had a ball.

Dean

I enjoyed the “mixer” activity, especially the one called “Where do you stand?” We went to one side or other of the room, depending on our answer to a question. It was cool to see how many people had the same ideas about things as I do.

“Express and Explore” had boys and girls in separate groups to talk about what it’s like to be a guy or a girl; what are stereotypes, gender differences, and how they’d like to be treated by the opposite sex.

The third session found them in small groups devoted to youth with specific conditions. Conditions represented by smaller numbers who had some things in common, were mixed. The four people with bleeding disorders were paired with six who had kidney disease. This grouping was chosen because they all know quite a bit about their individual conditions and each group spends time together several times each year. The major difference is that the youth with kidney disease usually spend their time together in hospital, and those with Hemophilia see one another at Family Weekends and at camp as well as at Clinic. We played a game in which each person chose a question, which asked for an opinion. “If I had one wish” or “If you could marry anyone, who would it be and what are their most attractive qualities?” were two of the questions. If some were shy starting the game, it didn’t last long. The answers brought similarities between people who had just met and gave old friends a new outlook on each other.

Joseph

Teen Day was a good opportunity to meet other teens dealing with diseases. Because everyone had something “wrong”, no one was singled out. Our own conditions helped us identify with each other and created a comfortable atmosphere.

Next, the individual groups planned “Cool Creations”- ways to tell others about living with the various conditions. Our four young people with Bleeding Disorders stole the show with an Oscar winning video filmed on location in front of the hospital. Needless to say, it involved someone with severe Hemophilia on a skateboard!

A pizza supper followed for teens and staff volunteers and then the karaoke. Where were the Much Music scouts? It was a “blast”. The DJ could hardly keep up with the requests. In the beginning, songs were sung by individuals or small groups of friends. Later, all those who liked a song joined the group.

Katie

The talent at the karaoke was awesome!

As with all successful events, hours of planning were needed. Planning began in March with a large group of staff who were interested in the idea. A list of ‘Teams’ was drawn up and one or two team members volunteered to be the working group. Each team made a list of
Skills Building Conference

In November of 1999 I attended the Canadian AIDS Society annual HIV/AIDS Skills Building Conference. This conference is designed to enhance the skills of individuals serving clients with HIV/AIDS. There are a variety of tracks of knowledge enhancement to choose from during the conference. I followed the medical and psycho-social aspect of HIV/AIDS.

One of the main points of interest was treatment regimens for persons with HIV/AIDS. Anti viral therapy is often complicated for individuals with HIV/AIDS. However, when hemophilia, and in many cases HCV co-infection, is present the issue of finding the appropriate drug combination becomes even more complex. Many drug combinations can cause a significant amount of liver damage. This is an important consideration with HCV co-infection. Also, many Protease Inhibitors have been associated with increased bleeding episodes in Hemophiliacs. Protease Inhibitors (PIs) have also been associated with severe lipodistrophies. Lipodistrophy is fat redistribution within the body and is in many cases irreversible. Though, Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTIs) provide an alternative to PI therapy; NNRTIs have been associated with fatal hypersensitivity reactions. There is no single “cookie cutter” antiviral regimen appropriate for all individuals with HIV/AIDS. Before making any changes or starting a new antiviral regimen it is important to research each and every drug. You may do this by accessing the Canadian AIDS Treatment Information Exchange (CATIE) at www.catie.ca or if readers would like some information on the issues that I have presented I would be happy to provide you with a copy of the report for Hemophilia Ontario on the Canadian HIV/AIDS Research Conference of 1999. This report was compiled by me and a colleague who, like me, is a member of the Hemophilia Ontario AIDS Advisory Committee.

World Scene

On the world scene, the Canadian Hemophilia Society continues to be involved in the planning of the WPH World Congress, to be hosted in Montreal this July. We are also busy developing a high quality pre-congress youth program for the youth delegates from Canada and around the world. The program will highlight leadership development and planning for the succession of leaders. Succession planning is the key to any successful and viable hemophilia association. For it is the young people who will provide leadership and input to shape hemophilia-related programming today and in the foreseeable future.

In the developed world, improvements in treatments and the availability of quality ambulatory care has meant fewer inpatient hospital admissions. This is great news for the younger generation of hemophiliacs. Recently, with the advent of HIV and HCV, hemophiliacs have once again been faced with more frequent ambulatory and inpatient hospital visits. Therefore, managing one’s health has become increasingly complex. As well, hemophilia in itself is changing and the Canadian Hemophilia Society and its provincial and regional chapters have recognized this issue. For example, in Ontario we have seen many young hemophiliacs, who previously were only using client programs and services, later becoming involved internally and working within the organization. While the advent of blood-borne viruses created something like a crisis mode in treatment, it has brought young men with hemophilia closer together in order to form either formal or informal support networks. There is a drive among many youth in various regions of Canada to take a proactive role. In fact Marc Laprise, Pediatric Regional Service Coordinator of the Toronto and Central Ontario Regional Hemophilia Society, exclaims, “this is a really exciting time for young men with hemophilia”.

I am sensitive to the fact that Canada’s successes in involving young people may not be duplicated among other countries. Some may feel that as a result of improved treatment, young men with hemophilia have become less personally involved in their regional associations. In that respect, the organization must examine itself and understand whether the current structure invites or encourages young men with hemophilia to become active.

World Congress

If you would like to learn more about hemophilia in a global perspective I encourage you to attend the World Congress in Montreal. Even if you are unable to participate in the Pre-Congress Youth Program, the five day medical and scientific congress will be presenting many topics of interest to youth. There may still be spaces available if you are interested in attending. Your chapter may be able to help with registration. Or contact the Canadian Hemophilia Society for more details. And, as always, please do not hesitate to contact me for additional information by e-mail at karttik.shah@sympatico.ca

Halifax Explosion II continued from page B

teens and contacted a few of them to test the idea – unanimous approval. We then asked for suggestions about the program for the day. A group of teens helped develop the final agenda and the program that we sent out. Interestingly, staff had a good time working with members of other teams whose paths seldom cross. As we dealt with issues such as accessibility, particularly the level of support the person would need throughout the experience (inpatients were invited), infection risk, and special diet needs we gained a greater understanding of each other’s work. Ongoing committees were established to plan the sessions and space, solicit funding and prizes, organize the registration, plan the menu, etc.

Feedback from the participants is being used for the Teen Day being held in September 2000. Some of the suggestions were that older, transitioned teens be used as facilitators, a session be held on transitioning to adult care, that more persons with physical challenges be included, and that there be more video cameras available!

Interested in hearing more? Contact: Maureen Brownlow-(902)428-8167 or mbrownlow@iwkgrace.ns.ca
Clinics Established in Quebec for Women’s Bleeding Disorders

by Patricia Stewart

This section is related specifically to women with bleeding disorders and their families. All articles are reviewed by physicians to ensure medical accuracy. If you have any questions, comments or ideas, feel free to contact me, Patricia Stewart, at the following addresses:

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Gaining access to proper diagnosis and treatment has long been a problem for women with a bleeding disorder. The CHS is presently working on a public awareness project in order to reach not only women (and men) who may have a bleeding disorder, but the medical community at large. However, there’s no use getting this message out if women can’t get access to proper testing and treatment. “It will simply be told, once again,” it’s a woman’s thing” or “women don’t have bleeding disorders.”

The health care workers of the hemophilia community have accepted women as part of their clientele and are working to adjust their clinics to include services especially for them. An innovative program within the Hemostasis Centre at Ste-Justine’s Hospital in Montreal has been set up to deal exclusively with women and bleeding disorders.

This program, called “Women’s Hemostasis” began in the autumn of 1998, under the leadership of Dr. Georges Rivard. A team was brought together to set up the workings of this program. They met monthly for a year, discussing the needs specific to women and deciding on a working model. The team includes the following members:

Dr. George Rivard, hematologist, Dr. Michèle David, hematologist, Dr. Diane Francoeur, Obstetrician/Gynecologist, Claudine Amesse, Nurse co-ordinator, a lab technician, a pharmacist, and an anesthetist. Social workers, dentists and other services are offered through the Hemophilia Treatment Centre.

In September 1999, a protocol was established and the clinic officially opened. Women have an initial meeting with the hematologist, the gynecologist and the nurse. These meetings take place on an on-demand basis.

Adolescents have an initial meeting by themselves, and a second one with their parents, this usually being the mother. They are asked to fill in a questionnaire on their medical and family history in relation to bleeding disorders and their gynecological history. This questionnaire includes a pictogram used as a visual tool to give an idea of the amount of blood lost and pads or tampons used during their menstrual period. The team meets on a monthly basis to discuss specific files and treatment. The woman or girl is then referred to the appropriate team member and a follow-up meeting is arranged. All tests and appointments are arranged for the client on the same day.

Following the lead of Ste-Justine, the Hemophilia Centre in Quebec City at l’Hôpital St-Sacrement has just organized its first women’s clinic day which will be held April 18. The women will meet Dr. Sylvie Bazin, the obstetrician/gynecologist from St. Sacrement and, if need be, the anesthetist. The hematologist, Dr. Christine Demers will be available for consultation. Women will be asked to complete a pictogram of their menstrual blood loss before their first meeting. Tests will be arranged for the same day.

These programs are an exciting step forward in the treatment of women and bleeding disorders. For the present, the demand is limited. Referrals are the main source of the clientele as well as those already aware of their medical problem. However, we know that every time a public service ad giving the symptoms of bleeding disorders in women appears in the newspapers, there are always calls for information on bleeding disorders. When our public and medical awareness campaign is finally underway, women in Quebec will have a place to go where they will be taken seriously and receive proper health care for their bleeding disorders.

PS. I have been asked to give a presentation about CHS’s efforts regarding women and bleeding disorders at the World Federation of Hemophilia Congress, which will be held in Montreal July 16-21, 2000. I would like to include some visuals as part of my presentation. If anyone has photos of any of the CHS women’s workshops that have taken place during the past few years in Mississauga, Toronto, Montreal (especially the Stump the Experts Session!) or Mt. Tremblant I would greatly appreciate receiving a copy. I promise to return any originals.
The Frank Schnabel Award was presented to Erma Chapman of Winnipeg, recognizing sixteen years of active association with the CHS and the AIDS cause as well as her many achievements in the program area. In 1983 Erma became a member of the Manitoba Chapter and, for years, headed up Client Services, which included liaison with hospital-based medical teams, services not covered by health insurance, supplementary client home care, and a recreational and physiotherapy facility. From 1992-95 she served as President of the Manitoba Chapter. During that time she was appointed a member of the National Advisory Committee on AIDS, reporting to the Federal Minister of Health. From 1992 to 1998 she was the national Vice President responsible for programs. During these years, under her leadership, programs were developed in diverse areas such as counseling, Women and bleeding disorders, new parents, chapter grassroots initiatives, standards of comprehensive care, and relationships with health care professionals.

Dr. Irwin Walker of Hamilton was the recipient of the Dr. Cecil Harris Award. In addition to many years of dedicated service as the director of the Hamilton Hemophilia Treatment Centre, he was Chair of the Canadian Hemophilia Clinic Directors Group in the early ’90’s. Over the years he was on the CHS Medical and Scientific Advisory Committee (MSAC) for at least 15 years, four of which as chair of the committee. During his tenure in that position and through his years of service he “provided leadership in promoting hemophilia care, education and research.” He was the driving force in the establishment of the Canadian Hemophilia Registry, considered to be “a very important initiative in understanding the epidemiology of hemophilia in Canada” and the promotion of continuity of care for persons moving from one centre to another. The Registry also supports much of the hemophilia clinical research. He was also instrumental in helping to establish the CHARMS program, which is being implemented in clinics across Canada to facilitate patient notifications in the event of coagulation product recalls as well as providing a forecasting tool for coagulation product needs.

The Chapter Leadership Award was established this year to “ honour a volunteer who has provided exceptional leadership and devotion to a specific chapter for many years.” The first recipient was Normand Landry of Moncton, who has demonstrated these qualities during a period of service spanning 15 years. He and Pierre Fournier were instrumental in reviving the New Brunswick Chapter in the 1990’s. He served as chapter president for many years and worked tirelessly to restore the chapter’s financial stability through fundraising. Over the years he has also served as a mentor and leader for the other Atlantic chapters. He was a key person in the creation and maintenance of the Hemophilia Treatment Centre in Moncton. He served as a member of the HIV Inter-Provincial Task Force and was an “eloquent spokesperson” on AIDS issues at the national and provincial levels. As well as being a prime mover at the chapter level, Normand has been a member of the national board from the early ‘80’s to the late 90’s and was active on the Program and Finance and Administration committees.

Ann Harrington of Toronto was one of the recipients of the Award of Appreciation presented to Hemophilia Health Care professionals “who have demonstrated outstanding service to the care of persons with hemophilia or related bleeding disorders over and above their responsibilities as a member of the hemophilia health care team.” Described by many as the “angel of St. Michael’s Hospital”, she has been the Nurse Coordinator since the adult hemophilia care centre was established in 1983, where her clients laud her for her cheerful dedication and caring. In addition to her normal duties she has been a nurse at the children’s camp, gone on canoe trips with the “guys”, given numerous presentations at meetings and conferences around the country, has made herself available and provided advice and assistance to smaller regional hospitals, and has even participated in fundraising activities for the local organization of the CHS. Ann has always had an interest in the third world, and her international outreach includes helping the relatives (who are affected by bleeding disorders) of persons who have emigrated to Canada, getting product and advice to doctors treating such patients in countries that have less developed health systems. As well, she has served on committees at provincial and national levels. Because of her international interest, she was elected as the CHS representative to the Nurses Committee of the World Federation of Hemophilia (WFH) going on to become head of that group. She is a member of the organizing committee for the WFH Congress to be held in Montreal in July, 2000.

The other Award of Appreciation was presented to Jane Neil of Vancouver. She has had over 25 years of service as a physiotherapist at the Vancouver Hemophilia Treatment Centre and has recently retired. She participated in numerous CHS national physiotherapy meetings where she was
lauded for her “knowledge, experience and good humour”. She has provided guidance and information for the “rookie” physio therapists in the group and has reported on “Functional Outcome Following Total Knee Replacements.”

**Chapter Recognition Awards**, which are given in recognition of “demonstrated achievement over the preceding year in a specific area such as fundraising, patient services, education, regional or chapter development” were given to the Quebec Chapter for advocacy and the Toronto and Central Ontario Region (TCOR) for regional development. The Quebec Chapter, in the implementation of the new blood system in that province, has positioned itself strategically through representation on key bodies such as Héma-Québec, the Hemovigilance Committee, and the Liaison Committee of Héma-Québec. The chapter has put pressure on the Quebec government to establish a treatment centre for persons with inhibitors. It has undertaken, along with the Quebec clinic directors, a review of the four treatment centres to ensure they respond to the needs of persons with bleeding disorders.

The Toronto and Central Ontario Region has been outstanding in its volunteer efforts on behalf of young families (Families in Touch network) and of those with von Willebrand Disease. A strategic planning exercise reinforced these actions by proposing and implementing the recommendation that the board of directors be more representative of the various client groups with bleeding disorders. As well, the region developed a brochure entitled “Bleeding Disorders — We Understand”, which gave recognition to von Willebrand Disease as well as the hemophilias, and served as a useful information brochure for doctors and other professionals. The regions was recognized also, as part of these thrusts, for the development of its Now Experience Wellness program, which encourages and financially supports young persons with bleeding disorders to engage in appropriate and healthy physical activities.

I want to thank the members of the Awards Committee for their excellent work in the past year, and Clare Cecchini, who, as our staff person, provided valuable support and sound advice.

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**NOTICE**

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

Saturday, May 27th 2000 at 9:00 a.m.

at the Lombard Hotel in Winnipeg, Manitoba

1. To acknowledge the designated Directors of each Chapter;
2. To acknowledge the Elected Directors at Large for 2000-2001;
3. To receive the audited financial statements of the Canadian Hemophilia Society for the year ended December 31, 1999;
4. To appoint an auditor for the ensuing year;
5. To transact such other business as may properly come before this Annual General Meeting of the members of the Canadian Hemophilia Society.

Ron MacLeod
Secretary

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**CHS Scholarship & Bursary Program**

Applications for this year’s Scholarship and Bursary Program are now available at chapters, clinics or through the National Office. The program was initiated in 1996 in order to provide financial assistance to enable young people or mature students from the inherited bleeding disorders community to pursue post-secondary education. The program is accessible to persons with inherited bleeding disorders and their children, parents or spouses as well as members of the HIV-T community. Those who have received a CHS Scholarship or Bursary are not eligible to reapply for continued support. One scholarship, one bursary and one mature student bursary, in the amount of $4000 each, will be awarded.

**Deadline for applications is April 30, 2000.** Recipients will be notified in May.

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**Nomination packages for the 1999 Annual Awards are now available at chapters and clinics or through the National Office.**

The CHS National Awards are:

- **The Frank Schnabel Award**
- **The Honourary Life Membership Award**
- **The Dr. Cecil Harris Award**
- **The Chapter Leadership Award**
- **The Award of Appreciation (Hemophilia Clinic Health Care Providers)**
- **The Chapter Recognition Award**

April 15-22 is National Volunteer Week. Help us to recognize our dedicated volunteers by nominating one of your volunteers for a CHS National Award!!!

**Deadline for nominations is April 30, 2000.**