During the family weekend, Quebec Chapter members had a sneak preview of the new Passport to Well-Being program that was developed by CHS-National with financial support from Baxter BioScience.

The goal of this program is to offer tools for people with a bleeding disorder to use at all stages of their lives, with information, coping skills and strategies to enable them to maximize their quality of life.

There are four separate modules in the package which cover the following topics:

“Home Care - The Road to Independence”, which was presented during the family weekend, included a presentation on the risks and benefits of home care, different types of infusions and a hands-on infusion workshop for parents with advice from those with experience.

The second workshop, “Charting Your Course” was held during the pharmaceutical information day in May. This module details the importance of record keeping to help monitor bleeds for target joints, to monitor proper dosage and to track products. It explains how information gathered both at home and with the Canadian database on care and treatment (CHARMS) can contribute to research and the well-being of individuals.

A third module, “Destination Fitness”, deals with the benefits and risks of certain activities, developing a fitness program, and adapting physical fitness to your tastes and abilities.

The final module, “Roadmap for Managing Pain” deals with ways of recognizing, discussing, and treating pain. It also deals with the effect of living with pain for both children and adults.

There are also newsletters, information booklets and workshops on these topics along with a PASSPORT that will be stamped with a ‘VISA’ when you participate in a workshop.

This program was a collaborative effort with doctors, nurses, physios, social workers and patients all contributing ideas and texts.

In order to get involved in the program, please contact the Quebec Chapter office.
You’ve never had a tree-trimming party? You didn’t ask your company to contribute to the CHSQ activities by buying the Brimblehorn’s Christmas colouring book last year? Here’s your chance!

Not only do we count on our volunteers to continue their excellent sales jobs to individuals, but for the first time this year, we’re offering companies the chance to make a donation of these great colouring books to various organizations that give out Christmas baskets in the community.

The CHSQ will take care of all the distribution, eliminating a potential stumbling block to participation.

Your company could double the impact of its donation and kill two birds with one stone: Support the CHSQ fundraising campaign while adding some joy to the lives of children in the community.

With the arrival of summer, the Parents’ Corner offers 10 tips for travelers with hemophilia, an article that originally appeared in the summer 1999 issue of this newsletter, but which is still relevant.

IN BRIEF...

Christmas Colouring Books: Brimblehorn for Everyone!

Your company could double the impact of its donation and kill two birds with one stone: Support the CHSQ fundraising campaign while adding some joy to the lives of children in the community.

What’s more, every purchase of over 200 books will allow your company to receive visibility in the book, distributed throughout Quebec.

If you’d like to get more information, or if you know of a charitable organization in your area that could benefit from this program, please contact Michelle Sullivan, who is in charge of this fundraising program at 514-848-0666, local 226, or by e-mail: msullivan@schq.org.

M.S.
Summer is finally here, a time to slow down, relax and recharge your batteries. The past few months have been a busy time in the CHSQ while we continue to follow through with priorities for the long-term plan decided upon in November and we can all use a break.

To increase the number of active volunteers in the organization, work has begun on a document to provide a clear framework for volunteer jobs and the time they require. This implies clarifying roles and responsibilities of volunteers, chairpersons and staff, making it easier for anyone who wishes to get involved to understand exactly how much time this entails and what their responsibility as a committee member involves. For the first time ever, we offered an orientation session for new Board members.

In order to maintain and develop new programs for members, work has begun on documents which will clarify procedures to follow when organizing an activity, such as the family weekend or summer camp, so as to make it clear to new staff or volunteer members the steps needed to complete a specific project from start to finish. Many of the official documents and policies in our files are being reviewed and revised to fit the present reality of the organization. By far most important dossier we’ve had to deal with is the redistribution of budgets for blood products in Quebec recently implemented by the government. Members of the Comprehensive Care Committee, including François Laroché, Aline Ostrowski, David Page, CHS Blood Safety Coordinator, and Daniel Lapointe, former Executive Director of National, have had numerous meetings with the Minister of Health, Mr. Philippe Couillard, Anne Fortin of the Blood System Secretariat and Ms. Louise Harel, Opposition Critic for Health Matters.

Our goal is to maintain the safety and availability of coagulation products along with the expert care available at Hemophilia Treatment Centres and also to preserve the vein-to-vein tracking of these products. We have the support of all medical personnel at the Hemophilia Treatment Centres, and recently, the CHS Board of Directors passed a motion in support of our efforts.

You can help us by letting us know if any situations arise where questions are asked about your treatment or where delays in obtaining product or care occur. We’ll continue our efforts to safeguard our treatment centres and the expert hemophilia care they offer.

May you have a safe and relaxing summer. △
2004 Family Weekend
On March 19, 20 and 21, the CHSQ family weekend was held at l'Auberge Matawinie, located in St-Michel-des-Saints.

This activity, cherished by all, was a great success once again this year: 160 participants attended and were able to share information with participants and presenters on different themes during the various workshops that occurred, most of which were related to coagulation problems.

Kids were also able to show their creativity during a workshop for young journalists and we’re pleased to bring some of their work to you in this issue of L'Echo du facteur.

Saturday night was a lively occasion when the CHSQ dancers, all in great spirits, gave an extra zip to our annual activity.

Many young families attended and expressed a great deal of satisfaction with the content of this weekend. Meeting with ‘older’ families is always enriching in information and advice.

Our organization’s Annual General Meeting also took place during the weekend. About fifty people attended and found out about the work done during the year 2003. Thank you to all our participants, partners and presenters who, every year, allow this activity to take place and make it one of the highlights of the CHSQ program.

Summer Camp
Seventeen youngsters, including eight hemophiliacs and two youngsters from Hemophilia Ontario, will be attending our summer camp in St-Raymond-de-Portneuf on July 18 to 23. We’re certain that the team of counsellors and our two nurses on duty all week (Ginette Lupien and Louise Bellanger) will help make the kids’ stay a memorable one.

As for our summer exchange with the Ontario Chapter, two youth from the CHSQ will be spending their holiday in an English immersion camp, Wanakita, and will be able to make new friends while being kept safe thanks to the presence of specialized nurses. We wish all the best to these two kids and are glad they’re interested in living an adventure like this. The next issue of L’Echo du facteur will include memories in pictures....

Members’ Directory
We sent you a reply form a few weeks ago to return to us if you want to have your coordinates listed in a members’ directory that we hope to publish. For those who haven’t yet sent yours in, we’re accepting names until next July 15. You can get in touch with our office or send us the information by fax at (514) 848-9661 or send it by e-mail to info@schq.org.

We wish to remind you that the information contained in this directory will only be sent to members of the CHSQ, the objective being to make it easier to contact and communicate with people.

Family Weekend for People with Inhibitors
October 1, 2 & 3 are the dates chosen for the family weekend intended for families living with inhibitors. This activity is made possible thanks to the support of Novo Nordisk, Bayer and Baxter, and we’d like to thank them for having accepted to finance this initiative once again. (A weekend was held in Quebec in 2002.)

The Hotel Manoir des Sables, located a few miles from Magog in the heart of the Eastern Townships, will welcome us from Friday night to Sunday noon. On the program: various workshops for parents, activities for the youngsters and a day care centre for the little ones.

For families interested, you can call the office to get further information and to register; all members who have paid their dues to the CHSQ and who have a child living with inhibitors or who are themselves concerned are invited to participate.

International Hemophilia Day – April 17
To mark International Hemophilia Day which occurs every April 17, we distributed bicoloured tulips, floral emblem of the CHSQ, to the members of the National Assembly.

The Minister of Health, Phillipe Couillard, to mark the occasion, rose in the Assembly to make a statement about the implication and remarkable work of CHSQ volunteers over the 45 years of the organization’s existence. Louise Harel, the Official Opposition critic in health matters, also mentioned the importance of the work done by our volunteers and raised two questions that the CHSQ had brought to her attention: the decentralization of budgets for blood products towards hospitals and the need to index the HIV compensation program to the cost of living.

In addition to commemorating April 17, our presence at the National Assembly allowed us to bring forward issues that the CHSQ

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A WORD FROM THE COORDINATOR (cont’d)

ardently defends with the objective of preserving and improving the quality of life for its members.

CHSQ Student Scholarships in Collaboration with Bayer and Baxter

The CHSQ is happy to work with Bayer and Baxter to offer three scholarships of a value of $1000 each to three students registered at CEGEP, university or in a professional school. Two of these scholarships are supported by Bayer, and one by Baxter.

We invite anyone interested to quickly communicate with our offices in order to complete the application forms.

The deadline for applications is July 31, 2004, and recipients of the scholarships will be announced September 15, 2004.

Information Day with Partners from the Pharmaceutical Industry

Last May 22 in Montreal, around twenty participants, most of whom were new members of the CHSQ, took part in an information day on the coagulation products distributed by our partners in the pharmaceutical industry.

Everyone was greatly interested in the different presentations made by the pharmaceutical companies and asked many questions, which made for a stimulating interactive activity.

At the same time, the presentation of Charting your Course (a module from the Passport to Well-Being Program developed by CHS National) was also highly appreciated.

We wish to give a hearty thanks to all the presenters and volunteers who helped make this come about, and to our partners in the pharmaceutical industry for their financial contribution. Δ

YOUTH ECHOS

CHSQ 2004 Family Weekend at the Auberge Matawinie

by
Cassandra and Roxanne Blanchet
with the contribution of Frédérick Blanchet, Kevin Houle, Louis-Charles Martin, Samuel Paquet, Luis Rodriguez, Erica Syriani and Sandra Syriani

Your stay at the Auberge Matawinie begins at the reception area where someone is waiting to answer your many questions. There are lots of organized activities and the monitors are responsible for their animation. If at any time a problem arises, they always have an alternate plan—proof that there’s no lack of planning here. And I’m referring to the cook and his helpers in particular who work to feed their visitors at this marvellous site.

The head cook admitted that there are always some who aren’t satisfied, but they can always enjoy themselves in the pool or the wonderful whirlpool bath that we all took advantage of.

In order to relax even more, people can go to the health centre to get a massage, a facial and for many other services. In the meantime, your little ones can have fun at the Bougeotte day care centre.

According to many people, Matawinie is the ideal place to make new friends and there are activities for everyone. Everyone, young or old, has a chance to enjoy himself. Δ
FOCUS ON HEPATITIS C
2nd Canadian Conference on Hepatitis C — Vancouver 2004

by François Larochef
larochef@sympatico.ca

From March 27–30, 2004, the 2nd Canadian Conference on Hepatitis C was held in Vancouver under the theme of “New Knowledge, New Hope.” As a representative of the CHSQ, I had the chance to be one of the approximately 700 participants at this conference: health professionals, social workers as well as people infected or affected by this disease. Here are my principal observations.

There were three main streams to the conference:
Track 1: Research and medical management
Track 2: Prevention and public health
Track 3: Collective action, development and community support.

The majority of the presentations I attended were in Track 1.

Even though there weren’t any great revelations during the week, the conference still confirmed a number of items. It came as no surprise to hear the combined peg-interferon and ribavirin treatment confirmed as the best treatment at this time for chronic carriers of the hepatitis C virus (HCV), including for people co-infected with HIV.

The duration of treatment suggested is 48 weeks for people with genotypes 1, 4, 5 and 6, and 24 weeks for people infected with genotypes 2 and 3. In both cases, if the HCV viral load isn’t undetectable, or at least reduced by 2 logs (100 times), after the first 12 weeks, it is advised to stop treatment.

A few statistics were presented by Dr. Mel Krajden, from the BC Centre for Disease Control: from 15 to 25% of people infected with HCV clear the infection themselves and 75-85% become chronic carriers. Of these, 15 to 25% develop cirrhosis, and 45 to 80% get a sustained viral response (SVR) to treatment. The window period for the appearance of antibodies following infection is from 5 to 6 weeks. 99% of people infected have antibodies. The average replication for HCV is 1010 virions/day.

Concerning the prevalence and treatment of hepatitis C, Dr. Frank Anderson of the University of British Columbia made the following statement about at-risk populations: Hepatitis C is present in 70% of hemophiliacs, 80% of intravenous drug users, over 40% of the prison population, while sexual transmission, spread out over a lifetime, is only 3%.

Amongst the factors that aggravate the disease we find: the age of exposure to the virus, the fact of being a man, alcohol intake and co-infection with HIV. Conversely, the fact of being a woman, having genotype 2 or 3, being young, having a healthy weight, having lived for with the disease for a short period of time and having a low viral load constitute favourable factors for a SVR to treatment.

The fact of being a woman, having genotype 2 or 3, being young, having a healthy weight, having lived for with the disease for a short period of time and having a low viral load constitute favourable factors for a SVR to treatment.

However, the treatment does carry important side effects. These are well-known: interferon can cause flu-like symptoms (fever, headaches, muscular and joint aches, fatigue), gastro-intestinal problems (loss of appetite, nausea, vomiting, diarrhea), psychological problems (depression, suicidal tendencies, impatience), thyroid problems, blood problems with a reduction in platelets and white blood cells, skin blemishes and temporary loss of hair. Thankfully, many of these side effects lessen after the first few weeks of treatment. What’s more, since almost 50% of peg-interferon is eliminated through the kidneys, the treatment can cause kidney problems that disappear when treatment ends.

As for ribavirin, it often causes anaemia (important decrease in red blood cells), skin lesions and increased risk for heart problems (shortness of breath). It can also cause severe congenital malformations or spontaneous abortions, which is why it is counter-indicated for pregnant women. Most of the time, it isn’t prescribed to men and women who don’t agree to using a contraceptive method.

For all of these reasons, 25% of people have their dosage adjusted, according to Dr. Phil Wong from McGill University. A study also showed that administering erythropoïetine (EPO), a hormone naturally produced by the body, could help overcome problems with frequent anaemia during the first weeks of treatment.

Psychosocial aspects of therapy are not negligible, either. According to Brant Roche from the Vancouver Island Health Authority, there are six important steps in managing a treatment plan to help its success:

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CD4 viral load is equal to or greater than 350 (especially since the anti-HCV treatment can have a positive effect on the HIV) and to treat the HIV first if the CD4 count is less than 350. In the end, HCV should be treated first if it constitutes a more life-threatening problem.

Dr. Lorne Babiuk believes that we’ll have to wait at least five to ten years before an effective vaccine is created. This is because researchers are still confronted with a number of challenges, notably: hepatitis C is a chronic disease, its shape changes (many genotypes), it’s difficult to find an adequate cell host and a specific antigen that will properly block the replication of the virus, and non-human models (primates) react differently to the disease.

Co-infection with HIV aggravates the severity of HCV. According to Dr. David Wong from the University Health Network of Toronto, HIV accelerates the progression towards liver cirrhosis, and this, even more rapidly if the CD4 count is less than 200, if alcohol is taken on a regular basis and if the infection took place after the age of 25. It’s often necessary to increase doses of peg-interferon and ribavirin.

For its part, HIV treatment tends to increase ALT and AST levels, as well as the HCV viral load. On the other hand, HCV treatment tends to lower CD4 levels and red blood cells, but to reduce the HIV viral load. It also must be pointed out that unwelcome medication interactions between the interferon/ribavirin duo and numerous inverse nucleosidic transcriptase inhibitors used to treat HIV, such as AZT, d4T, ddI and ddC do occur.

Despite this, it is suggested to treat people who are co-infected, but not to undertake treatment for both infections simultaneously. Still according to Dr. Wong, it’s preferable to treat HCV first if the CD4 viral load is equal to or greater than 350. In the end, HCV should be treated first if it constitutes a more life-threatening problem.

The presentation by Dr. Eric Yoshida from Vancouver Hospital and Health Sciences Centre dealt with liver transplants. HCV infection represents almost 50% of transplant cases (with an average survival of five years). Of course, the advantage of this surgery is that one is able to count on a liver in better shape. However, the liver systematically gets reinfected with HCV after transplant along with an accelerated development of the disease (higher viral load), because of anti-rejection medication (immunosuppressants) that must be administered.

What’s more, the treatment is less effective following a transplant (20 to 25% SVR) and involves greater side effects. In the few cases of re-transplantation, the survival rate after six months is only 52%.

What does the future hold?

We have to learn more about how HCV starts the disease and how it works with the cells in order to better foretell the course of the disease and the efficiency of treatment, according to Jenny Heathcote from the Toronto Western Research Institute.

As for new treatments, she spoke about promising research being done with antifibrinotics, immune modulators, enzyme inhibitors (notably proteases) and immuno regulators. She also reminded us that to discover an effective molecule for treating HCV, there are 10,000 failures and that it takes about 10 years to get a treatment to market that is effective and safe.

As for a vaccine against HCV, Dr. Lorne Babiuk from the Vaccine and Infectious Disease Organization in Saskatoon believes that we’ll have to wait at least five to ten years before an effective vaccine is created. This is because researchers are still confronted with a number of challenges, notably: hepatitis C is a chronic disease, its shape changes (many genotypes), it’s difficult to find an adequate cell host and a specific antigen that will properly block the replication of the virus, and non-human models (primates) react differently to the disease.

To conclude, a number of ideas on nutrition reiterate the importance of eating well. According to Ken Winiski from Healing our Spirit, people with hepatitis C should eat foods containing antioxidants for the liver such as vitamins C and E, selenium, alpha-lipoic acid and cystene. These antioxidants are present in large quantities in coloured fruits and vegetables (strawberries, blueberries, raspberries, watermelon, peppers, etc.), in proteins in meats, fish and substitutes, as well as in certain herbs or spices such as curcuma, artichokes, licorice and milk-thistle. These antioxidants don’t cure the disease, but they can slow its progression, increase the efficiency of treatment and reduce side effects.

Thanks to the CHS for having funded my participation in this event.
NURSES' CORNER

RARE COAGULATION DISORDERS
Factor XI Deficiency — Hemophilia C

by Claudine Amesse
Nurse Coordinator at the Hemophilia Centre in Ste-Justine's Hospital

To continue our series of articles on rare bleeding disorders, let’s look at factor XI deficiency, also called hemophilia C. In order to understand its consequences, let’s review the body’s different mechanisms to stop bleeding.

When a vessel is broken, it automatically contracts; this reduces the flow of blood. Platelets are the first cells to gather at the site of the broken blood vessel. Then, a chain reaction occurs involving different proteins in the blood called coagulation factors, to form a filament which is called fibrin. These filaments form a crisscross pattern around the platelets to stop the plug from being carried away in the bloodstream. A permanent clot is formed around the break in the vessel, now repaired.

When a particular protein is absent or present in insufficient quantity, the filaments are weakened and allow platelets to get away. The complete seal around the vessel takes longer to form, leading to prolonged bleeding.

Factor XI deficiency is transmitted by genes which are not situated on a chromosome which determines sex as in the case of hemophilia A or B. Males and females are affected in equal numbers in a ratio of 1 person per 100,000.

Certain groups, particularly Ashkenazi Jews, are exceptions to this rule and are affected in greater numbers, with a prevalence as high as 8% of the population.

The normal level of factor XI is around 100%. If a person inherits a defective gene from one of his parents, his level of factor XI will be slightly lowered to approximately 50%. If he receives two defective genes, that is, one from each parent, his level of factor XI will be lowered to approximately 1% of normal, or even absent altogether. When one parent carries both defective genes, all children will receive one of them. If both parents carry one defective gene, each child has a 25% chance of receiving both, a 50% of receiving one, and a 25% chance of receiving neither, thereby benefiting from two healthy genes. If one parent has two defective genes, and the other parent only one, each child has a 50% chance of inheriting two defective genes and a 50% chance of inheriting only one. Finally, if both parents have two defective genes, all the children will also have two defective genes.

For reasons not yet well understood, bleeding tendency is not always directly influenced by the level of factor XI in the blood. Two people with identical levels of factor XI can present with completely different symptoms, and sometimes the tendency to bleed can vary with time in the same person. It is therefore very difficult to predict the severity and the frequency of bleeding simply based on the percentage of factor XI in the blood.

People affected by factor XI deficiency have a greater tendency to suffer from nose bleeds, blood in the urine, and easy bruising. Prolonged bleeding is seen particularly after a serious trauma or after surgery involving mucous membranes in the mouth, genitals or urinary tract. Tooth extractions, tonsillectomies, ablations of the uterus or prostate are examples of procedures which involve a high risk of bleeding.

Generally, these people have few bleeds into muscles or joints with long-term consequences such as seen with those deficient in factor VIII or IX. The risk of spontaneous intracranial hemorrhaging is not very high, in contrast to people who suffer from some of the other rare factor deficiencies.

Because of the gynecological aspect, women experience the effects of the disease more acutely than men. Heavy menstrual flow and excessive bleeding after childbirth or abortion are symptoms which these women encounter frequently.

The options for treatment and prevention are varied, but must be selected carefully taking into account the advantages and disadvantages of each, and according to the type of bleeding to be controlled or prevented.

The first patients to be diagnosed with this disease were effectively treated with fresh frozen plasma. The main disadvantages of this treatment are the large volume of plasma required, fairly frequent allergic reactions and the danger of transmitting blood-borne viruses. This last risk can be reduced through the use of plasma which has undergone a viral inactivation process with solvent detergent. Unfortunately, this product is not currently available.

Factor XI concentrates do exist; however, they present the risk of unwanted thrombosis and must be used with great care. It is recommended to use them only in the cases of uncontrollable bleeding or surgery which represents a high risk of bleeding, and under strict medical supervision, preferably in a hemophilia treatment centre.

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DDAVP is a synthetic hormone used with patients with mild factor VIII deficiency and von Willebrand Disease for its ability to increase the levels of factor VIII and von Willebrand factor in the blood. It is also useful to treat or prevent bleeds in patients with factor XI deficiency. The process by which this occurs is not well understood; however, as the therapy is effective in many situations and has little risk of serious complications, it is used as a first-line treatment. Cyclokapron and Amicar, medications well known in the world of hemophilia for their ability to stop or slow fibrinolysis, responsible for the breakdown of clots, particularly in mucous membranes, are often used alone or in association with DDAVP. Finally, hormone therapy, or use of the birth control pill, is of great benefit in reducing menstrual bleeding and all other gynecological or obstetric associated bleeding. Factor XI deficiency differs from other types of hemophilia by its mode of transmission, its symptoms and its treatment. It is of critical importance that people with signs of bleeding and a diagnosis of factor XI deficiency be referred to a hemophilia treatment centre. An experienced multidisciplinary team can ensure the proper diagnosis and the design of an individualized treatment plan, the objective being to prevent or treat bleeds and reduce the risk of associated side effects as much as possible. Δ

Many thanks to Dr. Georges-Etienne Rivard for the medical revision of this article.

References:
10 Tips for the Traveler with Hemophilia

Planning ahead contributes to a successful trip! The following ten tips can help prepare you to meet the need for adequate medical care away from home.

#1 Ask your hemophilia nurse and doctor for names, addresses and telephone numbers of treatment centers and hemophilia organizations along your planned travel route.

#2 Before you leave on a long trip (more than one month), telephone the treatment center or a physician knowledgeable in hemophilia care in the area you plan to visit. Inform the staff of the severity of your hemophilia and the dates you expect to be there. This advance information will be helpful in the event of an emergency.

#3 Carry up-to-date written information, on a physician’s stationery or an identification card, which includes:
- diagnosis or current hemophilia condition;
- type of factor and other medications you use;
- your factor dosage for joint/muscle bleeds;
- your factor dosage for life-threatening bleeds;
- any drug allergies you have;
- any pre-treatments you receive (e.g., benadryl);
- name and phone number of the facility where you regularly receive hemophilia care.

#4 Consider wearing a Medic Alert bracelet or necklace that provides:
- your complete history;
- the type and severity of your hemophilia;
- the procedure for treating you in an emergency.

#5 If you self-infuse, carry enough factor to treat the number of bleeds you usually have at home during the same period of time. Make sure you have enough of all of your supplies, including a container for the safe disposal of used materials.

#6 If you do not self-infuse, discuss with your physician or treatment center staff the possibility of carrying your own supply of factor concentrates to be administered at an Hemophilia Treatment Centre or clinic en route.

#7 If you do not want to carry enough clotting factor to last for your entire trip, make sure your

specific medication is available at the medical facilities in the area you will be visiting.

Even if you plan to send factor ahead to your destination, always take a supply with you.

#8 Because heat destroys clotting factor, always keep it cool. A picnic cooler with ice works well, and may home care companies and clinics offer "Travel kits" for carrying factor. Check with your treatment center to see if they receive travel kits from pharmaceutical companies before your trip.

#9 Find out ahead of time if your insurance coverage applies in other provinces, states or countries. If not, the cost and availability of getting product at your destination may help you decide to carry clotting factor.

#10 When traveling by air, bus or train, keep your factor and infusion supplies with you in a carryon bag. NEVER put factor in «checked» luggage.

References:
Hemophilia Headlines, Winter 1995

To those, I would like to add an 11th tip...

#11 If possible always infuse before traveling... whether by air, bus, train or your own car. It’s better if your mind is at ease in case of an emergency.

Happy Summer time! Δ

A MOMENT TO REFLECT

To a journalist who asked Isaac Asimov what he would do if he learned that he had only six months to live he replied: “I’d write faster.”
The workshop on hemophilia through the ages elicited many testimonies and interesting discussions among participants.

Matawinie, its the ideal place to slide on inner tubes; just ask Sandra Syrani.

The traditional Saturday night dance.

François Laroche, Past-president, presenting the award for Volunteer of the Year to Patricia Stewart for the quality of her work during 2003.

The young journalists workshop may have launched a few careers. Kevin, Luis, Frédéric and Samuel took their job seriously, putting Roxane Nadeau “in the hot seat”.

Two members of the Board of Directors have retired after many years of service. Donald Pouliot (on the left) and Alain Moody (on the right). François Laroche presented them with a little gift of appreciation on behalf of the CHSQ.
Here are a few people who have given many hours of their time as CHSQ volunteers, working in the background to make things happen for all of us.

**Chantal Roy**
A newcomer to the CHSQ, Chantal immediately decided to do what she could to help others and, for the past two years, has organized a Christmas party in Quebec City where parents of young children with hemophilia can meet and share experiences. She organizes everything, from the sponsorships to the date and location. Chantal has a daughter, Alexandrine, and a son Gabriel who has severe factor VIII.

**Charles Richer**
Charles Richer has been selling and delivering Christmas colouring books for many years. He faithfully offers his time and his services to distribute the colouring books that we sell as a fundraiser every winter, delivering boxes to sales points and books to buyers. Mr. Richer’s son, Benoît, had FVIII hemophilia.

**Charles Pagé**
Many of the documents you’ve received by mail over the years have passed through the hands of Charles Pagé. He can be counted on to help out whenever a mailing has to be done, spending hours filling envelopes with information to be sent to members. He offers his time to both the provincial and national offices. Charles has severe FIX hemophilia.

**Sylvie Roy**
One of the most popular workshops during the family weekend is the brainchild of Sylvie Roy – the Café Rencontre - a workshop that brings parents together to discuss living with a child who has hemophilia. For a number of years, Sylvie Roy was the one who organized the theme for the workshop, leading the workshop itself. Sylvie has also classified all the documents dealing with hemophilia in the CHSQ offices so they can be used as a reference library for members. Sylvie has a son, Francis, with severe FIX hemophilia.

**François Laroche**
François has been actively involved in the CHSQ for over ten years. He has served on the Board of Directors since 1996 and has twice served as President. François brought his training in journalism to the CHSQ and is editor-in-chief and creator of L’Écho du facteur, our quarterly newsletter doing much of the writing, page layout and editing the newsletter. This is one of the most appreciated of all our services. He is also active on the Comprehensive Care Committee, working to maintain services and treatment for all. He is a member of the International Committee, the Program Committee and the Executive Committee. He also served as interim executive director, commuting regularly from his home near Quebec City to Montreal and back. François can always be counted on to do the job he says he’ll do.

His diplomatic manner and eloquence, as well as his friendly and gentle personality, make François an exceptional model for others to follow. François has severe hemophilia A. △

**P.S.**

The publication of this newsletter has been made possible thanks to the financial contribution of these pharmaceutical companies: Novo Nordisk and Baxter

and also thanks to Wyeth and Bayer