In the process of decentralizing the budget for blood products from Héma-Québec towards designated hospitals, the Secrétariat du système du sang is imposing a new administrative process for Quebec Hemophilia Treatment Centres, via Héma-Québec, concerning the distribution of coagulation products.

Thus, beginning April 18, 2005, the delivery of products for patients who live far from their Hemophilia Treatment Centre (HTC) will now be handled by Héma-Québec and they’ll be sent directly to the blood bank at the hospital closest to their home. For patients living more than 30 km. from the nearest hospital, Héma-Québec offers the possibility of claiming travel expenses equivalent to $0.37 per kilometre. This arrangement is to compensate those who previously were able to have products delivered directly to their home.

According to the new procedures, patients will have to give in their order to the Hemophilia Treatment Centre where they’re registered, but will pick up the products from the blood bank at the hospital nearest them. This blood bank will then enter the data on the products into SIIATH (Integrated information system for transfusion and hemovigilance activities). The hospital receiving the product will be able to match the product to the patient who picks it up. When the order is ready, a copy of the distribution form will be faxed to the HTC the same day to assure follow-up of the file.

The reasons invoked by Héma-Québec to justify this change in procedure include optimizing the transport conditions for products assuring their integrity as well as better traceability.

For any questions or comments that you may have on this subject, please communicate with Jean Lapierre, local 319, or Sylvie Thibault, local 6331, at Héma-Québec, at 514-832-5000 or toll free at 1-888-666-4362.

It’s in your interest to continue to collect your products at your HTC if at all possible. Find out about this possibility from the nurse coordinator at your HTC. Because of the extra work this new distribution system for products requires, it may be preferable to stop in at the blood bank at your local hospital.

In any case, don’t hesitate to report any problem you encounter in acquiring your blood products to the CHSQ.

The CHSQ continues to follow this situation closely and we’re counting on you to help us with this work. Δ
At the same time that the decentralization of the budgets for blood products is happening, Héma-Québec is imposing a new managerial process for the distribution of products. This will bring about a major change in routine for people living with a bleeding disorder (see cover page).

This new policy is a unilateral decision by The Quebec Ministry of Health and Social Services from its Secrétariat du système du sang. Neither the CHSQ nor the Hemophilia Treatment Centres supported this process.

Patients must give their order to the hemophilia treatment centre where they are registered, but pick up their products from the blood bank at the hospital nearest to them. The blood banks will then register the product data into SIIATH (Integrated information system on transfusion and hemovigilence activities), which adds a supplementary player to the distribution process.

What's more, products will no longer be considered as transfused once they've left the hospital, as was the case until now. From now on, for each vial that’s distributed, a file will be opened (in SIIATH) and will not be closed until the patient has furnished proof that he has administered the product. Thus, it’s easy to see that this could quickly become unmanageable when a patient submits a second or third order if, for reasons of safety or convenience, they still have products in their home from the first order.

What’s more, with this new policy, Héma-Québec can no longer assure us that an individual patient will receive products with the same lot number, as much as possible, as those that he’s already received. We know that this way of distributing product was respected by the HTCs, with the old system, in order to limit the number of product lot numbers to which a patient was exposed.

The CHSQ strongly doubts that this new policy can improve a distribution and traceability system that was considered a model on the Canadian scale, if not internationally. At best, the system will work well, but not bring about any improvements. At worst, this measure, combined with the granting of blood product budgets to designated hospitals, will bring about a progressive erosion if not simply the disappearance of the hard won services and expertise of our Hemophilia Treatment Centres. In fact, now that the hospital will be responsible for the budget for products, for their distribution and for their use, it will be tempting for a hospital to claim responsibility for their prescription, as well as for the patient’s medical follow-up.

We’ve repeated these arguments during each meeting we’ve had with the principle players in this dossier, whether it be the Minister of Health himself, the Opposition Health Critic, the Coordinator of the Secrétariat du système du sang, etc., all to no avail.

We ask you to remain vigilant and report any supply problems you may experience to the CHSQ.
Choices for the Future of the CHSQ

by Patricia Stewart

In the coming years, the CHSQ will have to invest time and energy to find new sources of funding if we want to continue to safeguard the excellent health services we enjoy, as well as offer quality services to members. Part of the reason that our income has had a major drop in the past five years are the major cutbacks to government grants while, as you all know, expenses such as administrative costs have progressively increased across the board. We need to diversify our sources of funding to assure the future of our organization.

In February 2005, CHS and chapters staff and volunteers from across Canada met for a Fundraising Summit to discuss ideas about shared fundraising. With telemarketing profits dropping, new long-term projects must be created, such as planned giving. A signature event, possibly a sports or cultural event, could be held simultaneously across the country, coordinated by the CHS-National office.

Profits would be shared according to population, with a percentage going to the National office. It was agreed that no one should lose out from new fundraising activities. While the profit-sharing details are still to be worked out, the general idea received overall acceptance and everyone agreed that we need to work together to achieve our common goals. This brings up the question – what exactly are these goals?

The five priorities of the CHSQ in order of importance are: access to expert comprehensive care, ready access to safe products, research leading to a cure, access to care for people infected through the blood system and information, education and support activities for members.

In 2005, the CHSQ Board of Directors will be holding a strategic planning session to decide priorities for the coming years. Hopefully, with new staff and new fundraising projects both provincially and nationally, as well as with the cooperation of all members in these projects, our funding will increase.

Everyone will have to pitch in and help. The question will then be, what will we want to use those funds and staff time for? Comprehensive care and advocacy, research or activities? Δ
Giant Christmas Colouring Book Campaign

Results for sales of the Christmas colouring books are similar to those in 2003 in terms of quantity, since we sold some 6000 books.

However, our campaign profile has changed. In fact, sales to corporations have steadily increased in the past two years, and the person to thank for this is Ms Michelle Sullivan, who worked on a contractual basis for the CHSQ in 2003, and negotiated some 2000 new sales during that time. However, there was a decrease in sales to day-care centres in 2004. A large portion of sales is still assured by our members who don’t hesitate to order books by the hundreds.

We’d like to thank all our customers and collaborators. We encourage all our members to follow their example and make this campaign, along with other CHSQ fundraising activities, a team effort that the organization can be proud of.

With the arrival of our new Fundraising Coordinator in 2005 and the creation of a Fundraising Committee, there’ll be a lot of action and we’ll be counting on you!

Annual Family Weekend

The CHSQ key activity, our family weekend, took place during over the March 18 to 20 weekend at the Auberge Matawinie in St-Michel-des-Saints.

One hundred and sixty people, including sixty children, participated. The children were taken care of by counsellors, allowing parents to take part in workshops. These latter covered different aspects of problems that our members experience and took the form of café-rencontres, presentations, discussions, relaxation, etc.

On the program were:
- Workshop for couples living with a child with hemophilia
- Discussions: Couples living with HIV
- Café rencontre for young hemophiliacs and their siblings
- For those 15 years and over: Meeting to initiate an activity to take place in the summer of 2005
- Passport to Well-Being: Destination Fitness
- Hepatitis C: Interactive workshop to answer participants’ questions
- Update on products and the Quebec blood system
- Emergency Room: Prepare to succeed
- Yoga workshop
- Information kiosques with pharmaceutical companies, information about summer camp and student scholarships.

It’s also during this weekend that our Annual General Meeting is held. This is when the summary of what took place in 2004 is presented and the new Board of Directors is elected.

The sun shone brightly during both days, making outdoor activities possible for young and old alike and everyone had a good time dancing to the music on Saturday night.

In light of comments from members about the various events during this activity, we can definitely say that the 2005 weekend was a great success! See you in 2006…

Student Scholarship program

For the second consecutive year, the CHSQ will be offering three scholarships for the 2005-2006 year worth $1000 each. Two of them are offered by Bayer and one by Baxter. The criteria for admissibility are:

- Be a person living with a bleeding disorder
- Be a student in a recognized establishment at the college, university or professional level
- Be a member of the CHSQ

Candidates who are interested should communicate with our office in order to receive an application form: tel.: 514 848-0666 or 1 877 870-0666; e-mail: info@schq.org

The deadline for requests is July 31, 2005. The scholarships will be awarded in September 2005 to those chosen.

Summer camp 2005

Summer camp, a great place for kids with a bleeding disorder to develop social skills and learn self-infusion, will once again be at Camp Portneuf, located in St-Raymond-de-Portneuf.

There are twenty (20) registrations for this activity this year. Amongst these 20 youngsters, eight (8) have bleeding disorders and twelve (12) are siblings.

On-site care is supervised by medical personnel specialized in hemophilia care, who are present for the entire stay. Group transportation is organized for those travelling from Montreal.

For more information about the camp itself, you can consult the website: www.camp-porneuf.com.

Renewal of your membership card

You’ll find your membership card for 2005 enclosed. Thank you for your support and for the confidence you have in the CHSQ. △
by
Serge Séguin
sseguin@schq.org

I’m very pleased to be joining the staff and the CHSQ extended family as the Fundraising Coordinator.

As the parent of a handicapped child, I got involved as a volunteer-administrator in an organization for handicapped people, working on advocacy issues and in fundraising. The experience I garnered helped me to create the foundations for the Victor-Doré and Joseph-Charbonneau schools. I also proposed the first action plan for the Fondation de l’hôpital Marie-Enfant in Montreal and I’ve worked as a consultant for a number of foundations.

Fundraising action plan

The financial objective of the 2005 campaign is $90,000. The plan is based on the following three specific objectives: $65,000 from colouring books, $15,000 from special events and $10,000 in donations. The Fundraising Committee has formed a Task Force for each objective in the 2005 campaign.

The Fundraising Committee is composed of the following people: Mylene D’Fana, Chair of the Committee and the donation campaign, Marius Foltea, André Laganière, Roxanne Nadeau and Chantal Roy, share responsibility for the colouring books and Nayla-Marie Mazloum and Isabelle Servais are responsible for special events.

Bowl-A-Thon in Montreal and Beauport

Make sure you don’t miss the first Bowl-A-Thon with proceeds going to the CHSQ that will be held in both in Montreal and Beauport on Sunday May 1.

The event will take place in Beauport at the Salle de quilles Saint Pascal in the Galeries de la Canardière from 4:00 pm to 6:30 pm. The tickets are $15 per person for 3 games (shoe rental is included) or $75 for a complete alley (5 people).

In Montreal, people will be gathering at the Salon de quilles Champion Lanes in Greenfield Park, across from the Charles Lemoine Hospital, from 3:00 pm to 6:00 pm. The tickets also cost $15 (plus $2 for shoe rental) or $90 per alley for 6 players.

If requested, people can get a charitable receipt for $10 or $50 per alley in Beauport and for $60 per alley in Montreal. For more information, contact 514-848-0666 or, toll free, 1-877-870-0666, local 24.

A bright future for Brimblehorn and his friends!

When you read this, we hope to have had a positive response for our efforts to find a partner who will help us distribute Brimblehorn’s colouring book across Quebec.

With this in mind, the colouring book has to be of interest to all in order to reach as many children, parents and families as possible from all cultures. At this point, the term “Christmas colouring book” limits this. From now on, Brimblehorn’s adventures with his friends will be universal. We can already tell you that the 2005 edition will celebrate Brimblehorn’s birthday.

The new stories about Brimblehorn and his friends are worth following... and colouring.

Donation Campaign

In the autumn of 2005, for hemophilia month, the CHSQ will be holding a donation campaign. This will be the first phase in the creation of a multi-year subscription campaign.

This will allow the CHSQ to pave the way for a fundraising structure that will help us reach financial objectives in the long term that, we believe, are needed to achieve all the objectives of our mission. As Patricia Stewart, Past-president, mentioned in the 2004 Annual Report:

"Together, we'll assure the survival and the stability of this organization (the CHSQ) that belongs to us all."  

A moment to reflect

"Nothing is worth more than today."

Goethe
FOCUS ON HEPATITIS C
Alcohol and hepatitis C: to drink or not to drink?

by Suzanne Champoux
Special Collaboration

The evolution of hepatitis C is measured by the quantity of scar tissue in the liver, meaning the fibrosis level of this organ. Over the years, in 20 to 30 percent of cases, there is the risk that cirrhosis of the liver will occur. While it’s not yet known precisely what leads to this consequence, it seems that the consumption of alcohol is one factor.

The link between alcohol and the progression of fibrosis of the liver is the subject of more than one scientific study. Even though many questions are unanswered, some data can be extrapolated from results reported over the course of the last few years.

As early as 1998, American researchers (University of Illinois, Chicago) showed that cirrhosis was as much as 2.5 times more frequent in a group of people infected for twenty years with the hepatitis C virus (HCV) and who reported a high consumption of alcohol (4 to 6 drinks per day on average for at least five years while infected with HCV) in comparison to those who drank little or no alcohol (54% to 60% compared to about 23%). As for the progression of fibrosis, it was twice as rapid since the score increased by one point every 7 years in the group that consumed the most alcohol compared to one point every 14 years in the group that drank little or no alcohol. In this study, gender, manner of infection (transfusion or IV drug use) and genotype did not seem to influence the progress of the disease.

During this time, in France, researchers wanted to know if moderate consumption would be acceptable. They evaluated the consumption of alcohol of 233 people infected with HCV who were going to have a liver biopsy. One out of four (25%) had never consumed alcohol and one quarter had stopped drinking since receiving the hepatitis C diagnosis. The others drank 19 consumptions per week on average, the men drinking more (27.5 drinks) than the women (8.5 drinks).

These French researchers found two factors associated with fibrosis: the age of the subject and the alcohol consumption level. The older the person was, the higher the risk of an elevated fibrosis level. Also, the more alcoholic drinks a person consumed during the week, the more the fibrosis level increased. Thus, subjects whose fibrosis level was at 0 drank, on average, 15 drinks per week while those whose fibrosis level was at 4, the maximum, consumed over 30 drinks.

Does this mean there’s a safe limit for drinking alcohol? This is the question that interested a group of researchers from San Francisco. Unfortunately, their results, published last year, don’t seem to support this.

They evaluated 800 people infected with HCV who had never received treatment. They definitely found a link between the number of drinks and the fibrosis level: a score of 1.42 for those who don’t drink compared to a score of 1.84 in those who have more than 8 drinks per day, a difference that may seem small but which is significant. This link is especially evident in men, compared to women. This doesn’t mean that women are protected from the link between alcohol and fibrosis. In fact, the link is even more difficult to show when there’s limited alcohol intake. And the American numbers show that, in general, women drink less.

But the American researchers remind us that among those who are teetotallers, while 60% had a fibrosis score of 0 or 1, there were still 7% whose score was 4, the maximum level. Amongst those who consumed 5 alcoholic drinks or more per day, 47% had a low fibrosis score (0 or 1) and 15% had the maximum score of 4.

The risk of having a high fibrosis is thus greater if the consumption of alcohol is higher. Unfortunately, eliminating all alcohol consumption doesn’t reduce this risk to zero, which tells these researchers that there’s no really safe level for alcohol consumption.

This brings up the notion of individual susceptibility. Who doesn’t know a 75-year-old smoker who brags that they’ve beaten all the odds because of their “good health” while his neighbour died from lung cancer before 60? Individual factors, still not yet understood, would explain why the former seems immune to cancer, while the latter couldn’t avoid it.

This phenomenon also plays a role in the evolution of liver fibrosis and the susceptibility to alcohol. With some carriers of HCV, a small to moderate consumption of alcohol could be acceptable, while in others there’s a risk it will accelerate liver disease.

It’s impossible at this point to know who the lucky consumers are. If all tests show that the liver is affected by the presence of HCV, it’s probably better to abstain than to aggravate the situation by consuming alcohol. If the fibrosis seems stable or is evolving slowly, a moderate consumption could be acceptable.

The choice should be made after discussing it with your doctor.
The absence of adequate treatment for most of the world’s 400,000 people with hemophilia makes the development of a cure compelling. The possibility of developing a cure seems tantalizingly within reach. However, there remain many challenging issues and concerns for researchers, ethicists, healthcare workers, patients and treaters.

Hemophilia is an ideal candidate for gene therapy, as it is caused by mutations in a single gene. A number of vectors have been used in an attempt to obtain therapeutic levels of factor VIII and Factor IX in animal models with some success. A number of phase-one clinical trials have been conducted, and although correction of the bleeding disorder was neither complete nor long lasting, they do offer hope for a permanent gene-therapy cure of the disease.

The experience of the five-day congress in Thailand is something that I will cherish forever. As I embark on a new challenge as President of the Quebec Chapter, the CHS prepares to host the next World Congress of Hemophilia from May 21-26, 2006 in Vancouver, Canada. I look forward to attending a congress once again.

Because I will have other duties within the Chapter, I will be passing this column over to Chantal Roy, so please feel free to send her, François or myself any comments or articles you would like to have published here.

Now I leave you with something I heard in Bangkok that comes to mind: “We can work globally, act nationally and help individually”.

by
Mylene D’Fana
mylenedfana@bellnet.ca

That afternoon there was a presentation on the exciting prospects for prenatal diagnosis. The discovery of fetal DNA in maternal plasma, along with the emerging field of fetal RNA markers in maternal blood, offers promising implications for non-invasive prenatal diagnosis of hemophilia. Also, Dr. Georges Rivard presented “Inhibitors in Hemophilia - Clinical Aspects”, a session presenting the results from the Canadian study conducted in 5 HTC where they treated patients younger than two years of age with recombinant factor VIIa that was completely free of FVIII. The study concluded that rFVIIa is effective and safe for the treatment of most bleeding episodes, except for mouth bleeds, and is helpful in delaying exposure to FVIII.

Another interesting session was optimizing factor prophylaxis for the hemophilia population. There is a general consensus amongst the experts in the field of hemophilia care that until the promise of gene therapy is realized, a programme of prophylaxis started early in life and before the onset of joint damage should be considered the optimum therapy for children with severe hemophilia. Different study results were given as examples including the Canadian Prophylaxis study. Such studies will need to be long term and should focus on specific unanswered questions. They should include outcome measurements such as quality-of-life assessment and newer imaging techniques such as MRI (magnetic resonance imaging).

“We can work globally, act nationally and help individually”. A
by Nathalie Aubin  
Nurse coordinator at the Montreal Children’s Hospital

Unfortunately, many parents and patients have experienced frustration and anxiety when they couldn’t get quick and appropriate care in the Emergency Room. During the last CHSQ family weekend I had the chance to lead a workshop whose purpose is to help parents and patients be properly prepared for an eventual visit to the ER.

In order to help people with a bleeding disorder, the CHS developed an educational resource kit which includes the Factor First card and the Guide to the ER binder. This was done in consultation with members of emergency room health care teams as well as a group of doctors, nurses, parents and patients from Hemophilia Treatment Centres (HTC).

Having worked for 11 years in the ER at the Montreal Children’s Hospital, I’ve witnessed the anxiety that some parents feel during these visits, anxiety that’s often justified considering the lack of experience health care professionals have in the treatment of patients suffering from a bleeding disorder. I remember having asked some parents how to spell von Willebrand Disease: “von Will... what?”.

When the time came to inject the coagulation product, I was relieved to have a parent instruct me or show me how to prepare the product by doing it him/herself. Unfortunately, I realize I caused some insecurity through my inexperience in this particular field. That’s why it’s important for you to be well informed about your bleeding disorder and the associated treatment so that you can instruct the ER personnel.

The Guide to the ER is a tool that will make it easier to prepare for your next trip to the emergency room. How can you be prepared? First of all, bring along some medical information like MedicAlert and your Factor First card that contain all the information necessary about your bleeding disorder. Make sure you’re well informed about your bleeding disorder. Know more than anyone else!

Don’t forget that health care professionals outside of the Hemophilia Treatment Centre have little experience in the treatment of people like you. Have a personal emergency plan ready as well as emergency babysitting. This will allow you to act efficiently and quickly.

If necessary, you can visit your local emergency room beforehand and bring along documentation about your bleeding disorder. This can be done in collaboration with the nurse from your HTC. Prepare an emergency kit (ex. backpack) containing the materials needed for an infusion, but also useful items such as books, crayons, change, etc. You may be at the ER for a few hours, depending on the nature of the problem for which you’re there.

Before leaving for the ER, make sure to follow the instructions in your Personal Emergency Plan. Let the resource person from your HTC know if necessary. After a visit to the ER, call your HTC or the hematologist on-call if you think that you’re not being taken care of properly.

To sum up, here’s some advice to make your trip to the ER a success:
• Be proactive when communicating with ER personnel.
• Be well informed about your bleeding disorder.
• Repeat your explanations if necessary.
• Be polite and courteous.
• Concentrate on the problem and not on the people.
• Use “I” instead of “you”.
• Call your HTC back if necessary.

And finally, it’s important to know that most visits to the ER go well. However, you should be well prepared for those occasions when things don’t go so well.

Show your Factor First card to this person while explaining the reason for your visit. Make sure that your bleeding disorder is clearly noted in your file. The triage nurse will ask you some questions in order to evaluate your status. If you’re sent to the waiting room, ask how long the wait will be. If you think it’s too long, don’t hesitate to let them know about your concerns and contact the resource person from your HTC if necessary.

Then the doctor will do a physical examination. Show him your Factor First card. Make sure that he’s gotten a call from your HTC and that the instructions for your treatment are followed. Don’t hesitate to call your HTC or the hematologist on-call if you think that you’re not being taken care of properly.

To sum up, here’s some advice to make your trip to the ER a success:
• Be proactive when communicating with ER personnel.
• Be well informed about your bleeding disorder.
• Repeat your explanations if necessary.
• Be polite and courteous.
• Concentrate on the problem and not on the people.
• Use “I” instead of “you”.
• Call your HTC back if necessary.

• To facilitate communication for the next eventual visit, thank the personnel when you leaving.
• To keep them informed.

And finally, it’s important to know that most visits to the ER go well. However, you should be well prepared for those occasions when things don’t go so well.

These are some of the main ideas from the Guide to the ER, however I encourage you to get a copy from your HTC or from the CHSQ.

Good luck during your next visit to the ER!

References:
The Emergency Room: PREPARE TO SUCEED – A Guide to the ER for Persons with Bleeding Disorders, Canadian Hemophilia Society, 2004
QUEBEC — TUNISIA INTERNATIONAL PARTNERSHIP
The February 2005 Assessment Visit

by François Laroche
larochef@sympatico.ca

From February 10 to 16, 2005, the Quebec Chapter made an evaluation visit to Tunisia in order to lay the foundations for a partnership with the Association tunisienne des hémophiles (ATH) under the twinning program set up by the World Federation of Hemophilia (WFH). After working with the Association sénégalaise des hémophiles (Dakar, Sénégal) over the last five years, culminating in a partnership with a Dakar treatment centre and the centre in Lille, France, the CHSQ has now turned to another African nation, this one in the Maghreb region, with a population of some 10 million inhabitants.

Aline Ostrowski, Executive Director of the CHSQ, and David Page, as Vice-president of the WFH, accompanied me on my visit. Our timetable included meetings with members of the ATH, visits to the Centre national de transfusion sanguine (responsible for blood collection, safety and donation monitoring), the Institut Pasteur (responsible for the purchase and supply of blood products) and three hospitals with hematology services located in the larger cities of Tunisia (Tunis, Sousse and Sfax).

In Tunisia, health care costs are borne by the State in whole or in part through two social security funds (equivalent to our health insurance), one public and the other private, depending on whether the patient meets certain criteria ranging from employment status to civil status, and including their physical condition and financial situation. During the visit, we made a number of observations, such as:

• The ATH has a dynamic Board of Directors made up of people with a variety of complementary skills — hematologists, people affected by hemophilia, business people, computer and communication specialists, etc.;
• Members of the medical staff, physicians in particular, seemed very competent and dedicated — in addition, recruitment and training of physicians are not a problem, although for other health professionals it can pose certain challenges;
• Hemophilia and other bleeding disorders, von Willebrand disease in particular, are underdiagnosed — About 250 members have been identified by the ATH from the lists supplied by haematology centres, and some of these appear on more than one centre’s list;
• Inhibitors also appear to be underdiagnosed — perhaps because treatment is less frequent or less aggressive;
• Access to treatment is not uniform in all regions — Factor concentrates are only available in Tunis for those who need them, and moreover, only cryoprecipitate appears on the list of products covered by the social security funds for treatment of hemophilia A;
• The Institut Pasteur is paying too much for its factor concentrates — perhaps due to the small volume it is buying and/or the absence of a real tendering process;
• Communication is a challenge — Three languages are spoken: Arabic (mother tongue); French (learned at school), and Tunisian (a mixture of the two). Moreover, an oral culture is predominant outside large cities owing to a fairly basic level of education and a high illiteracy rate in rural areas;
• Transportation is also a challenge — owing to the large distances, but also because of a lack of financial resources to provide transportation to Tunis where the large majority of services are located;
• The exact number of persons affected by HIV and HCV is not known — treatment is provided for HIV, but not for HCV; these subjects are actually fairly taboo.

A number of objectives were also identified during the trip, such as the creation of a Medical and Scientific Committee in order to foster discussion among the treatment centres and standardize care, the introduction of effective government lobbying to obtain equitable access to products, the setting up of a process to more efficiently track persons with bleeding disorders mainly outside the large cities, and eventually, the publication of an information bulletin.

These more or less long-term goals, combined with the work that needs to be done to reach them, and a timetable, will be included in a joint plan of action soon to be drafted by the CHSQ and the ATH.

I would be remiss if I did not mention the warm welcome and hospitality the Tunisians extended to us. Special thanks must go to Islem Nafti, President of the ATH, Dr. Aïcha Hafsia, the Honorary President, and Nejne Grichi, the Treasurer, for their kindness, availability and attention to our needs throughout our stay.

May this partnership be crowned with success.

Inch Allah! △
PORTRAIT
Mylene D’Fana

The newly elected President of the CHSQ is Mylene D’Fana. Born in Cuba and growing up there and in Miami, she came to Quebec in 1991. She’s the mother of three children aged 9 to 12, Kevin, Emily and David. She works alongside her husband, Dany Blanchette, in their two family businesses.

In 1997, when her third child, Kevin, was diagnosed with severe FVIII hemophilia, Mylene wanted to find out everything she could about this disorder. She immediately contacted the CHSQ to become a member and was elected to the Board of Directors in March 2001. She’s been on the Executive since 2002 as Secretary and then Vice-president. She is active in fundraising, having taken on the responsibility for the colouring book campaign when there was no acting executive director in 2002.

She also sits on the Program, International Committee and Awards Committees and has been responsible for the Parent’s Corner column in L’Écho du facteur since 1999.

Always ready to give of her time and energy (and she definitely doesn’t lack energy!), Mylene is a whirlwind of action and chatter, but gets the job done.

She is also active in her children’s activities, such as hockey and figure skating, sitting on boards and doing fundraising.

She’s served as CHSQ delegate on the CHS National Board of Directors since 2001.

Congratulations and good luck, Mylene. △

P.S.

YOUTH ECHO

The Youth Committee has decided that this summer, there’ll be no draws, that it’s time for a win. But a committee is nothing without team members. Luckily, the ball isn’t in the opponent’s court, but in ours. The pass is thrown and just needs to be caught!

You’ve got it: in trying to restart the Youth Committee, a new activity’s been planned. The announcement was made during the family weekend and we’re going to take a few lines to repeat it, hoping to interest some new people.

The activity is for hemophiliacs and their siblings and friends from about 15 to 25 years of age. We’d like to get together one evening to attend a professional sports event, just to spend some time together outside of normal meetings and get to know each other better. Please note that each participant will have to pay for his/her ticket.

While nothing’s been decided yet, those present during our meeting in Matawinie seemed to want to go to an Alouettes game in Montreal. We’ll do what we can to make this happen.

So if you’re interested, or if you have other suggestions, let us know (our coordinates are at the end of the article), and we’ll add you to the list of addresses, e-mails and phone numbers we got during the family weekend. This will help us keep everyone who’s interested up to date on the latest news about this project.

We’re hoping this evening will be a milestone! △

Martin Kulczyk
Tel. : 514 483-1471, e-mail : martinkul@sympatico.ca

David Pouliot
Tel. : 450 929-2611, e-mail : david.pouliot@umontreal.ca

CHSQ Bowl-A-Thon

In Montreal

Date: Sunday May 1, 2005
Time: from 3:00 pm to 6:00 pm
Place: Champion Lanes
2999, boul. Taschereau
Greenfield Park (South Shore)
(across from Charles -Lemoyne Hospital)
Cost: $15 (3 games)
(shoe rental: $2 )

In Beaupoart

Date: Sunday May 1, 2005
Time: from 4:00 pm to 6:30 pm
Place: Salle de Quilles Saint-Pascal
Galeries de la Canardière
2485, boul. Sainte-Anne
Beaupoeart
Cost: $15 (3 games)
(shoes included)

Contact :
Serge Séguin, Fundraising Coordinator
514-848-0666 or, toll free,
1 877 870-0666, local 24
N.B. If requested, people can get a charitable receipt for $10.
The interactive workshop on hepatitis C treatment led by Dr. Bernard Willems was of great interest.

One of the most popular workshops during the weekend was, obviously, the one for parents of a child with hemophilia.

Gabriel Coulombe managed to take a few downhill rides on an inner tube.

The children were taken care of at the Auberge Matawinie daycare, so that parents could participate in workshops and presentations during the weekend.

The weekend began with a little bus trip, a three-and-a-half-hour ride for participants from the Quebec City area. It’s all part of the fun...

The Annual General Meeting is an important event during the weekend.

What could be better than to find yourself among friends, sharing a tasty meal, as did Kevin Blanchette, Frédérick Blanchet, Kevin Houle, Luis Enrique Rodriguez, Louis-Charles Martin and David Blanchette.

The Auberge Matawinie is located in an enchanting site, ideal for winter sports.
The Canadian Liver Foundation is organizing a conference entitled:

**The Treatment of Hepatitis C**

Speaker:
Doctor Bernard Willems, M.D.
Hepatologist, CHUM Hôpital St-Luc

Hôpital St-Luc Auditorium
1112, rue Sanguinet, Montreal
(Berri-UQAM metro or Champ-de-Mars)

**Tuesday May 10, 2005**
Welcome / cold buffet 6:00 pm
Conference 7:00 pm
Admittance is free but please reserve your place by calling:
(514) 876-4171 or by e-mail:
foie@fondationcanadiennedufoie.ca

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**CHS 2005 Scholarship program**

The deadline for submitting an application to the CHS National for the 2005 Student Scholarship Program is April 30. Criteria and application forms are available on the CHS website at the following address:
www.hemophilia.ca/en/11.4.php

The following scholarships will be awarded:
- One $4000 Scholarship
- One $4000 Bursary
- One $4000 Mature Student Bursary

Also, application forms for the 2005-2006 Soozie-Courter Scholarship offering a brighter future for people with hemophilia are available at this address:

Introduced by Wyeth five years ago, this scholarship program recognizes the scholastic and personal success of young hemophiliacs all over North America.

F.L.

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**New CHSQ Board of Directors**

During the Annual General Meeting held during the family weekend in Matawinie, members of the CHSQ elected a new Board of Directors for the 2005-2006 year:

- **President:** Mylene D’Fana
- **Past-president:** Patricia Stewart
- **1st Vice-president:** François Laroche
- **2nd Vice-president:** Marius Foltea
- **Treasurer:** Jacques Roy
- **Secretary:** Razek Syriani

**Administrators:**
Mohamed Boulila
Danielle Comeau
Martin Kulczyk
André Laganière
Roxanne Nadeau
Laurent Pontbriand
David Pouliot

Congratulations to everyone and best of luck fulfilling your mandate. Δ

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**ZLB Behring**

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**Wyeth**

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**Bayer HealthCare**

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See you soon!