The XXX International Congress of the World Federation of Hemophilia (WFH) took place in Paris from July 8 to 12, 2012. Almost 5,400 delegates (a record attendance) coming from over 130 countries (another record) met in the City of Lights for these five days.

This large, biennial scientific meeting of a community interested in or affected by bleeding disorders - doctors, other health care professionals, pharmaceutical industry representatives, patients, parents, etc. - was also an opportunity for discussions that were greatly appreciated by all participants.

Here are a few impressions from CHSQ delegates to this congress.

- F.L.

... 

The World Congress of Hemophilia took place in Paris last July 8 to 12. This event, which takes place every two years, is organized by our friends at the World Federation of Hemophilia (WFH). This was my first world hemophilia congress and I must admit that I was very impressed by the size and professionalism of this congress. Approximately 5,400 people participated in this event, a record number.

During the opening ceremonies, organizers highlighted the 50th anniversary of the World Federation of Hemophilia. As a Canadian, I was proud to hear that its founder was Mr. Frank Schnabel, a Montreal hemophiliac, and that the head office of the WFH is located in Montreal. Over the past fifty years, there have been many advances in care for hemophiliacs.

Here in Canada, we are very privileged because we have access to the best of treatment and the latest in technological advances. Sometimes it’s easy to think that all hemophiliacs around the world can get the same care we do, but that’s far from being the case. We saw a video dealing with some hemophiliacs living in Africa that was very touching. I was deeply moved and I must admit that, since then, I appreciate the fact that I was born in Canada more than ever.

The goal of the Closing the Gap fundraising campaign is to help other people living with bleeding disorders obtain care similar to ours. During congress, delegates raised almost $40,000 and Mr. Jan Willem André de la Porte generously offered $80,000 for a grand total of $120,000.

Initially, I had hoped to attend this congress to have access to all kinds of information specifically about rare bleeding disorders since, as you surely know, I regularly write a column entitled Rare bleeding disorders’ corner in L’Echo du facteur. I wasn’t disappointed as I got to attend many interesting presentations where I was able to learn and understand many things that will be very helpful when writing my next articles. I found the sessions where doctors presented posters resuming their research very informative. We got to talk directly with the specialists. The pharmaceutical company kiosks were also interesting to visit to get information about new drugs.

Throughout this congress, I could sense that the world of hemophilia was in full swing; talk was about new treatments, new prolonged action drugs and even gene therapy. The coming years will be very exciting, since scientific advances will likely be numerous.

Many volunteers, as well as CHS employees, worked very hard to get the 2016 world hemophilia congress. Montreal and Miami were the finalists. Unfortunately, following a vote, Miami won the right to this event. Perhaps another time!

And what can I say about Paris, this magnificent city whose rich historical heritage is priceless? Everything was perfect, be it the presentations, the cultural events, the choice of the venue or the services offered by various participants. The French were even pleasantly courteous with us; the Quebec accent may have helped there!!!

I must congratulate the people from the World Federation of Hemophilia on the success of this congress. I also want to thank the Canadian Hemophilia Society - Quebec Chapter for giving me the opportunity to attend this event.

- Sébastien Bédard

cont’d on page 3 : Paris 2012 >
On September 22, the CHSQ held a strategic planning exercise to carry out an organizational diagnosis and identify its goals for the next three years. We maintained our vision and mission as you know them, but we adjusted and reduced our axis of intervention from seven to five items:

1- Ensure accessibility to optimal care and medical services for all people living with a bleeding disorder.
2- Support research.
3- Defend the interests of people affected through ongoing vigilance.
4- Ensure the support and education of members and health care professionals in order to raise awareness for our cause amongst them and the general public.
5- Develop partnerships with the national and international community to share our mutual expertise and improve care offered to people with a bleeding disorder at the international level.

We also slightly modified our organigram. We redefined Geneviève Beauregard’s position, which formerly was Program Coordinator. The staff position she’ll now occupy is Programs and Operations Manager. We created another complementary position to Geneviève’s, this being Manager of Public Relations and Development; we are presently recruiting for this position.

The position of executive director, as such, has been abolished. The two employees will report directly to the CHSQ Board of Directors. The part-time administrative assistant position, working under the manager of programs and operations, was retained. These changes to the internal structure of the CHSQ took place in the wake of the non-renewal of the contract with former Executive Director, Charles Vanasse, and in order to function more efficiently as an organization.

Our objectives for 2013-2015 will include: increase our visibility, increase our membership, place more emphasis on advocacy, increase our autonomous financing, increase the number of members actively involved and better prepare our future leaders.

The environment of non-profit organizations in which the CHSQ evolves is in constant change. These changes and these new orientations are needed in order to progress towards the realization of our mission and, in particular, in order to better serve our clientele, meaning you the members.
O nce again, the World Federation of Hemophilia Congress was highly successful in bringing together experts from various medical fields, pharmaceutical companies and, last but not least, patients. From what I understand, it’s very rare for these three groups, so different from each other, to work hand-in-hand like we do. One could say that the world hemophilia community includes many friendly and intelligent people.

I’ve never left a congress with such optimism. As early as January of this year, we knew there were real breakthroughs in view of a cure for hemophilia B taking place in England by Doctor Edward Tududdenham and his team. He presented new statistics: after six months, the six patients treated with his innovative gene therapy have maintained a factor IX level between 1 and 6%, making them moderate hemophiliacs, while beforehand, all had severe levels (< 1%) of this deficiency. While we’re not really talking about a total cure, you must admit that the progress is huge. While there are still many details to iron out with this therapy, I feel that the word ‘cure’ is definitely no longer science-fiction. Hallway discussions (and there are a lot of these, as you can imagine), also made me realize that a similar discovery to ‘cure’ hemophilia A won’t be too long in coming...

Another source of celebration – treatment for hepatitis C continues to improve. Soon we’ll see a therapy without the infamous interferon, responsible for so many side effects. Everyone like me, who is able to wait for a new treatment that’s less difficult to absorb, still has to wait for this product to be accessible.

As far as international cooperation goes, the WFH is working to introduce a new business model with pharmaceutical companies. As we know, the products we use to treat hemophilia are only accessible in wealthier countries. In lowering the price of their products, would large pharmaceuticals around the world see an increase in their sales by having access to new countries and thus actually see no profit loss? This suggestion is a win-win situation for all. After all, Treatment for all is the slogan of the WFH.

These are the three things that impressed me the most, but I have a little book filled with notes from the congress. Don’t hesitate to ask me to tell you more about it the next time you see me!

- David Poulion

M ore than 5,400 delegates from the bleeding disorder community attended the XXX International Congress of the World Federation of Hemophilia (WFH). From July 8th to July 12th, hemophilia patients, family members, national member organizations, health care professionals and members of the pharmaceutical industry came together for the five-day biennial congress in Paris, France, also known as the “City of Lights”.

The opening ceremonies took a different direction this year compared to previous congresses. With the start of the WFH 50th anniversary festivities, we got to see highlights of the progress made over the past 50 years in hemophilia communities around the world. The premiere of a special film featuring our former twins from Senegal entitled The Winning Coalition showed the full impact of the WFH and the work done through winning programs.

Also, a new fundraising campaign was launched called Close the Gap. As estimated by the WFH, 6.9 million people are living with a bleeding disorder. Of these, 75 percent remain undiagnosed and receive inadequate or no care at all. The campaign goal is to close the gap in care between those who have access to care and those who do not. The objective is to raise $5 million dollars between 2012 and 2014. One of the campaign co-chairs announced a special challenge gift of half a million dollars.

For every dollar given to the campaign he will donate two dollars to the WFH. The delegates present took the challenge seriously and by the end of the week more than $50,000 had been raised.

Pre-congress workshops for professional development and the final congress program included something for each of the health care professional fields. Presentations on nursing, psychosocial work, dentistry, orthopedics, laboratory sciences, women & bleeding disorders, clinical research and gene therapy were part of the schedule during this busy week.

The congress program included plenary and concurrent sessions that covered both medical and multidisciplinary topics.

The medical program presented by leading experts in hemophilia research included sessions on new approaches to the management of hepatitis C, personalized prophylaxis, WHF research initiatives, rare bleeding disorders, prevention and prediction of inhibitor development, developing models of hemophilia care, gene therapy for severe hemophilia B and the use of long-acting products versus gene therapy transfer.

The multidisciplinary program covered topics on psychosocial models in hemophilia: preparing future generations, aging with hemophilia, the economics of hemophilia care around the world, women with inherited bleeding disorders, questions and answers on sexual health, and family perspectives, issues and support.

Lobbying has become a habit of mine while at congress. During the WFH annual general meeting, the national member organizations got to choose which city would host the Congresses in 2016 and 2018. While Montreal lost the bid to Miami for Congress 2016 by only a 4-vote difference, Glasgow, Scotland won over Guadalajara, Mexico for Congress 2018.

Once again the congress surpassed my expectations and I was proud to be part of the Quebec delegation. Looking forward to the next WFH World Congress in 2014 from May 11-15 in Melbourne, Australia for another global encounter between the members of the bleeding disorders community. Don’t forget to save the date!!! §

- Mylene D’Fana
Fahey, Patricia Stewart and Isabelle Hardy — who attended a training session on the Saturday following the conference. The goal is to inform the general public, as well as health professionals, about bleeding disorders and their effect on women. You’ll surely have an opportunity to meet them during one of our next activities.

You can find more information on this first conference by reading the national newsletter Hemophilia Today, Vol. 47 no. 2.

Summer Camp for children living with inhibitors

A long-awaited activity took place this summer from July 26 to 29, 2012, at the Centre de villégiature Jouvence near Orford - four days of outdoor activities for youngsters living with inhibitors and their siblings. It was great to see their smiles and the complicity amongst them.

For these few days, the youngsters enjoyed a variety of activities, such as designing a t-shirt with the camp logo, canoeing, storytelling of legends on the water, kayaking, swimming and a great night of movies, not to forget campfires and our famous LIPDUB, a lip-sync video to a popular song. It was simply magic! For the very first time, these youngsters were together, without their parents, in a safe environment.

The camp team was incredible and included two nurses, Claude Meilleur, Nurse-coordinator at the Quebec Inhibitors Centre from the CHU Sainte-Justine and Hélène Néron, Nurse-coordinator from the Centre de l’hémophilie de l’Est du Québec at the CHA Hôpital de l’Enfant-Jésus. They were responsible for safety as well as offering the kids a teaching workshop to increase their knowledge.

We also had two excellent animators, Gazou and Picotine, who did a great job ensuring that we all had a good time while being careful. And I can’t leave out the precious help offered by Kevin Blanchette, a young hemophiliac who’s very involved in our community, who lent a hand during camp. Kevin quickly became everyone’s big brother and took his role to heart.

I’d like to thank the whole team from the first Camp for children living with inhibitors for your great work and ‘until next year’.

CHSQ Summer Camp

A successful 41st Edition! This year, pirates was the theme to amuse the kids at summer camp. From August 5 to 10, our 28 youngsters got to share, have fun and, of course, learn more about their condition at Camp.
Trois-Saumons. I think the most popular activity for everyone was filming the LIPDUB. Two nurses accompanied us during our stay and ensured care and camp safety. Claudine Amesse, nurse-coordinator from CHU Sainte-Justine, and Ginette Lupien, a retired nurse still involved with us, in particular by helping us keep this camp working.

This year there were five certified employees from Camp Trois-Saumons, an assistant counselor, Kevin Blanchette, and our new camp director, Emily Blanchette, a big sister who's involved and who, in past years, attended camp as an assistant. Everyone did an incredible job amusing our youngsters on an enchanting and safe site.

Thanks to all of you and I invite all youngsters to come and experience a fun-filled and safe camp experience next year.

**Upcoming Activities**

**Student bursaries**

Every year, in collaboration with the pharmaceutical companies, three scholarships of up to $2000 each are offered in two categories: academic scholarships and encouragement scholarships.

There's still time to submit your application. Do you have a bleeding disorder? Are you studying at the collegial or university level or at a professional institution, or are you an adult who would like to undertake a professional course? There's still time. You have until midnight October 31 to submit your application.

You can obtain the form on the website or by contacting the office at 514 848-0666, local 21 or, toll-free, at 1 877 870-0666.

**Women in Red Weekend**

On October 12 to 14, a weekend for women dealing with bleeding disorders will be held at the Manoir du lac William in Saint-Ferdinand.

On the program:
- a medical workshop with none other than Dr. Rochelle Winikoff, hematologist responsible for the Hémostase au féminin program at CHU Sainte-Justine
- a workshop presenting the new CODErouge program
- A workshop on managing stress
- Discussions as well as relaxation... all in good company.

You can read the highlights of this promising activity in the next issue of L'Écho du facteur.
The coming years may prove to be rich in news about hemophilia in general and I believe that people living with a rare bleeding disorder may benefit from this. Over the past few months, I was witness to some advances concerning the disease that I have, which is severe factor XIII deficiency, sub-type A. I thought this would be a good time to talk to you about it.

Since the mid 1990s, nothing new has been offered to people suffering from a deficiency in factor XIII. In Canada, no factor XIII concentrates had been officially approved by Health Canada. The only concentrate available was a plasma-derived factor XIII called Fibrogammin P™ marketed by CSL Behring, which could be ordered through the special access program (SAP). Last June 19, Health Canada approved a new factor XIII concentrate in Canada marketed by Novo Nordisk called Tretten™ (this product will be known as Novo Thirteen™ elsewhere in the world). This product is only used for people suffering from factor XIII deficiency, sub-type A and not those suffering from sub-type B. The fact that this product is recombinant, meaning it is made without any human or animal ingredients, makes it totally safe in terms of viral transmission.

The approval of Tretten is based on the results of a phase 3 clinical trial, Mentor™ 1 (Blood 2012; 119: 5111–7). Another trial, Mentor™ 4 (Poster presented at the World Federation Congress in Hemophilia on July 8–12, 2012, produced by Novo Nordisk), was also published dealing exclusively with the use of Tretten in children under 6 years of age, but data from this study was not used for approval of the product in Canada. Tretten will be available in a 2500 IU format as a lyophilized powder reconstituted in a solvent for infusion. The dosage recommended by the manufacturer is 35 IU/Kg every four weeks as prophylactic treatment. The method of preparing the product is very simple: one simply uses an adapter supplied in the box in order to mix the solvent with the powder. This medication is stored in the fridge between 2 and 8ºC.

One interesting fact is that the half-life of Tretten seems to vary depending on age. In children under 6 in the Mentor 4 trial, the half-life was evaluated at approximately 15 days, while in adults in the Mentor 1 trial, the half-life was evaluated at approximately 11.5 days.

Every time a new product appears in the world of hemophilia, patients and doctors must consider the risk of developing inhibitors. In the case of factor XIII, the development of inhibitors can have serious consequences that include intracranial bleeds that could cause death. For us, the patients, the choice of changing medication isn't easy, especially when we've been using a product that is effective, safe and without side effects for many years. I hope this information can help clarify the choices that you may be considering in the coming months.

In 2011, CSL Behring received approval in the United States for a cousin of Fibrogammin P, a plasma derived factor XIII concentrate called Corifact™. The advantage of this product in comparison to our Canadian version is that it comes with the Mix2Vial™ reconstitution procedure, greatly facilitating preparation of the product. Corifact is available in 1000 and 1600 IU formats and can be kept up to six months at room temperature (maximum 25ºC), which would facilitate travel. This product could be an interesting alternative to Fibrogammin P.

Factor XIII deficiency is very likely poorly diagnosed across the world and this is, in large part, due to difficulty in precise dosing.

In the 1990s, new spectrophotometric techniques arrived, allowing for the quantification of factor XIII but, over time, it was found that these techniques were not really precise. These inaccuracies could engender erroneous diagnosis, bad choice of treatment and sometimes even lead tragically to
A MOMENT TO REFLECT

“They start small, but become stronger and deeper over time, and once their course is set, it’s impossible to turn back. So it is with rivers, time and friends.”

Ancient Sanskrit poem

bleeds such as intracranial bleeding.

It was observed that the standard Berichrom™ test using NADH (nicotinamide adenine dinucleotide hydrogen) without iodoacetamide showed a low sensitivity for factor XIII levels inferior to 15% and that results obtained were often overestimated. Drs. É. Ajzner and L. Muszbek, from Hungary, highlighted this problem and proposed solutions in an article published in 2001 entitled Kinetic spectrophotometric factor XIII activity assays: the subtraction of plasma blank is not omissible (J Thromb Haemost. 2004; 2 : 2075-7).

Dr. Georges-Étienne Rivard introduced this new manner of dosing factor XIII at CHU Sainte-Justine in the summer of 2011. The Berichrom test, using NADPH (nicotinamide adenine dinucleotide phosphate hydrogen) has been used since then. The limit of this sensitivity test is 0.6%. To date, it seems that the levels of factor XIII measured with the help of this new test are lower than anticipated.

In my case, following results obtained with this new procedure, my prophylactic treatment went from 1000 units every 4 weeks to 1000 units every 3 weeks.

Moreover, Dr. Rivard proposes calculating doses with the help of this new method for both factor XIII sub-types A and B for all Quebec patients suffering from a deficit in factor XIII. If you’re interested, speak to your hematologist.

***

Other very interesting studies are presently underway concerning the role of factor XIII in cardiology, orthopedics, pregnancy and other fields of application.

As I mentioned in the introduction, the coming years will be very exciting, since scientific advances in hemostasis risk being numerous. Bye for now.

§

TO MAKE YOUR CHILD'S WISH COME TRUE...

As a person with a bleeding disorder who requires frequent treatment with the infusion of blood products, your child is probably eligible to have a wish come true through either the Children’s Wish Foundation or Make-a-Wish Canada.

Criteria differ a bit from one organization to another, but they both have the same objective: to grant a wish or dream that’s important to your child.

For more details as to admissibility criteria for each of these organizations, we invite you to consult the following links:

• for the Children’s Wish Foundation: www.childrenswish.ca/en-ca/wishes
• for Make-a-Wish Canada: www.makeawish.ca/wish_stories

The CHSQ would be happy to hear about your children’s wishes that are granted...

- F.L.
HEMOPHILIA TREATMENT CENTRES’ CORNER

The Hémostase au féminin program: A multidisciplinary approach to serve women!

by

Catherine Thibault
Pivot Clinic Nurse
Hémostase au féminin program
Hemostasis Centre
CHU Sainte-Justine
catherine.thibault.hsj@ssss.gouv.qc.ca

Since the launch last May of the CODErouge program, For women who bleed too much, bleeding problems that women experience have come to light, which will likely result in an increase in the number of women diagnosed and better care for those who are affected. But how exactly is care for women with a bleeding disorder integrated into hemophilia treatment centres? In my role as the pivot nurse for the Hémostase au féminin program at the CHU Sainte-Justine, allow me to explain this.

The targeted clientele are adolescents and women with bleeding symptoms that are deemed excessive. Each year, approximately 200 consultations and follow-ups are done! We can see these women for nosebleeds (epistaxis), gum bleeds (gingivorrhagia), easy bruising, etc. However, the principle reasons for these consultations are basically dysfunctional menstrual cycles and post-partum hemorrhaging. Patients who have already been diagnosed with a bleeding disorder can also profit from an annual follow-up.

Besides annual follow-ups, it’s highly recommended that these patients consult us to plan any intervention that could cause bleeding: surgery, tooth extraction, piercing or tattoos, as well as to be followed during pregnancy and to plan childbirth.

The success of the expertise at the women’s hemostasis centre is due to the recognition of multidisciplinary work.

Patients can obtain a consultation at the female hemostasis clinic with a referral from their doctors or by self-referral when a member of their family has an inherited bleeding disorder.

The success of the expertise at the women’s hemostasis centre is due to the recognition of multidisciplinary work. The pioneers of this program, Drs. Georges-Étienne Rivard, Michèle David and Rochelle Winikoff (hematologists) as well as Dr. Diane Francoeur (gynecologist), have largely contributed to building the vision of the program. Over the years, they have integrated numerous other key participants: pivot nurses, gyno-obstetricians, anesthetists, pediatricians, family doctors, lab technicians, psychologists, specialists in internal gynecology and obstetrics medicine (MIGO), the high-risk pregnancy clinic (GARE), etc.

Every Tuesday morning, professionals from these fields are invited to meet to discuss complex cases, to decide birthing plans, or simply to make a presentation in the form of a journal club. These meetings are beneficial for the ongoing training of participating professionals, and also encourage continuity in the care of the patients concerned.

The mission of the Canadian Hemophilia Society is to improve the quality of health and the quality of life of all patients living with a bleeding disorder. With this vision, professionals involved can reach this objective by proposing alternative solutions to the problem of menorrhagia. In fact, many means are offered to counteract the dysfunction of a menstrual cycle and are chosen in relation to the health, interests and preferences of the patient: oral contraceptives, Mirena intra-uterine device (IUD), cyklokapron, etc.). A meeting with the hematologist and the gynecologist is arranged to choose the best choice adapted to each person. Psychosocial support is also assured by the team, when needed.

It is therefore a winning choice to consult your multidisciplinary team, in order to benefit from the personalized treatment that’s best for you!

The opinions expressed in various columns are those of the authors and do not necessarily represent the viewpoint of the CHSQ.
To let us know your comments or to give your opinion on any related topics, send your text to the following address:
L’Écho du facteur, CHSQ, 2120 Sherbrooke Street East, Suite 1102, Montreal (Quebec) H2K 1C3
telephone: 514-848-0666 or toll-free: 1-877-870-0666
fax: 514-904-2253
or by e-mail to the following address: info@schq.org
Web site: www.hemophilia.ca
I'm pleased to write to you on my behalf and that of Hélène Néron, nurse coordinator at the Hôpital de l'Enfant-Jésus in Quebec City, to tell you about the first CHSQ summer camp for inhibitor patients held July 26 to 29, 2012.

Arriving
Once we finally got to the Centre de villégiature Jouvence, after a one-hour ride with music and lively discussions amongst the boys and girls, we were led straight to the dining room. The buffet was perfect and the food, which was well prepared, tempted even the most difficult palates... Meals were plentiful, original and varied (duck, moose...) and everyone was satisfied throughout our stay.

Because the chalet was a bit far, we were allowed the use of a golf cart, which pleased a lot of kids. Leisurely walks along paths leading to the main chalet weren't so enticing.

Rooms were assigned in a joyous atmosphere. Once we attained our objective, meaning everyone was in bed, whispered discussions continued, but weren't too disturbing... It was perfect!

From morning to night, Picotine and Gazou accompanied us with a variety of activities such as painting T-shirts, soapstone sculpture, aerial walking, swimming and splashing around, roasting marshmallows and mystery games around the campfire... and, you'll never guess... Yes they did it! A lipdub! And I must say, Hélène, Geneviève and I met some real actors... but maybe their parents already know this!

Leaving
Finally! The youngsters enjoyed their stay so much that they want to prolong it to a full week next year. However, the present context of our hospitals makes this very difficult to do.

I'll leave you with a few comments that some of the youngsters sent me so that you can hear about their feelings and reactions to this first weekend:

Marc-Antoine:
“I liked everything, the nurses, the counselors were really nice and funny and they were always there for us. The only problem: the stay was too short and I didn’t have enough time to do everything I wanted to do.”

Marc-Antoine and his sister Audrey-Anne:
“It was great to spend time with our hemophilia friends. And Marc-Antoine added: because they’re very special to me…”
Hello everyone!

After a fairly busy summer, it’s great to be back with you! It’s great to have holidays and take a well-deserved rest, but it seems that all good things come to an end!

Before jumping into my topic, I’d like to share a very important moment in our lives. Our big boy, Dylan, who’s nine, does his own infusions now! The more he grows, the more he realizes that he has to miss out on some activities because I can’t always accompany him and be there in case of needs related to hemophilia. We talked about it and he mentioned that he’d be ready to learn self-infusion. Two days later, he tried it for the first time and was successful! Bravo Dylan, it’s a big step towards autonomy!!!

***

If you have or have had school-age kids, you know that school is a fertile ground for bullying. This problem has always existed, but recently, it seems that this topic is raised more and more often in the media and in the population in general. Children can be very cruel towards their peers and it’s even easier when the latter have a handicap (whether or not it’s visible).

Kids are bullied for everything and nothing: one wears glasses, another doesn’t have the latest style in clothes... However, I’d like to talk specifically about the bullying our young hemophiliacs can experience.

During the last school year, our son was discouraged with the idea of having, once again, to go to school on crutches. He had a mild ankle bleed, and we didn’t want him walking on it so crutches were needed... He’d never had any reaction in the past to using crutches, so we wondered what was different this time. He finally admitted that since he didn’t have any injury that could be seen, like a broken leg, they laughed at him and his crutches. Some youngsters told him he just wanted attention and was pretending to be injured. He spent his days trying to explain about hemophilia and that using crutches would help prevent making the bleed worse to kids who were completely insensitive to his situation.

Bullying a child who has a medical condition or handicap often includes actions that exclude the child, treating him with scorn, making him uncomfortable with his handicap, teasing or making cruel remarks about the condition.

As parents, what can we do to stop this behaviour? What should we say to encourage our youngsters not to become victims? I don’t have any magic solutions to offer, but I did some research on the subject.

Amongst other things, it says it’s important to encourage our children to denounce any bullying they experience and assure them of our support if this occurs.

It’s preferable to encourage the child to assert himself in these situations and to inform an adult about what has happened. When our child tells us that he’s been bullied, we shouldn’t be afraid to look for a solution so as to help him in this situation.

When our child tells us that he’s been bullied, we shouldn’t be afraid to look for a solution so as to help him in this situation.

On this note, I wish you a great, trouble-free school year, and remind you not to hesitate to share your ideas about future topics with me at echodufacteur@schq.org.
FUNDRAISING

We hope to see many of you there. (See the advertisement below.)

New Blood Campaign
Every year, many organizations solicit you in the hope of receiving a donation that will help the cause they support. We ask you to think about making the CHSQ a recipient of your donation.

The CHSQ is a registered charitable organization: thus we are able to issue a charitable receipt for any donation given.

You’ll soon receive the form for the 2012 New blood campaign. Your donation just makes good sense!

Dance for Life
Are you ready? Make sure you reserve this date on your calendar: November 10, 2012 (that’s the 10/11/12). The 6th edition of Dance for Life will soon be here. A colourful and entertaining show that will make you want to move.

by
Geneviève Beauregard
Programs and Operations Manager

Dansez pour la vie
6th edition
November 10th 2012
A magnificent colourful show
More than 40 artists presenting in all styles
Art Show and Silent Auction
$75 VIP Package includes: Valet parking, a picture with a professional dancer, wine, beer and other appetizers as well as additional surprise benefits
Regular Tickets $25

www.dansezpourlavie.ca

info@schq.org 514 848-0666
The Solofuse™ reconstitution device by Pfizer now available in Canada

Last May, Pfizer Canada put a new product on the Canadian market, Solofuse™, the first reconstitution device that includes a pre-filled syringe containing the diluent and factor VIII recombinant (Xyntha®).

Once the freeze-dried product is reconstituted with the diluent (4 ml of 0.9% sodium chloride solution), Xyntha can be administered by intravenous infusion using the Solofuse syringe, eliminating the step of transferring the reconstituted solution, the whole process being done with one single syringe.

Developed without albumin, Xyntha Solofuse is offered in vials of 1000, 2000 and 3000 international units that can be combined. “Patients often ask us about the reconstitution devices that exist, since they want to be able to choose the one that best corresponds to their lifestyle, says Elizabeth Paradis, Nurse Coordinator with the hemophilia program at Horizon Santé-Nord, in Sudbury. Xyntha Solofuse offers patients another choice.” - F.L.

Wanted: Community Presenters for CTAC

The Canadian Treatment Access Council (CTAC) is looking for people living with HIV, or co-infected with viral hepatitis (B or C) in order to train them and support their participation as community presenters for CTAC. This project is part of the Tools for Action workshops so that they, in turn, can train other presenters to offer workshops from one end of Canada to the other.

People living in rural areas are highly encouraged to apply.

For more information, contact Gilbert Mallais, Capacity Reinforcement Coordinator: 416 410-1369, local 234 toll-free: 1-877-237-2822 or Gilbert@ctac.ca. - F.L.

Passing of John Plater

I was still in France in the days following the congress in Paris when I learned the sad news of the death of John Plater. I was profoundly upset by this announcement.

John was a tireless and devoted activist who had a huge impact on so many of the issues and struggles of the CHS and Hemophilia Ontario. Those fortunate to have spent time with him will remember his booming voice and laugh, his generosity and his outstanding people skills. He was easy to talk to and every exchange was rewarding. He was also a top-notch legal counsellor.

Another of my hemophiliac brothers is no longer with us, but his legacy will be felt for many years to come. He will be sorely missed... §

- F.L.

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