

haemophilia.ie

Magazine of the Irish Haemophilia Society



December 2009

Announcing AGM & Conference 2010

Venue: Royal Marine Hotel, Dun Laoghaire, Co. Dublin.
Dates: 5th to 7th March, 2010



We wish to announce that our Annual General Meeting and Conference will take place next year from 5th to 7th March in the Royal Marine Hotel, Dun Laoghaire, Co. Dublin.

Below you will find a taste of the adult programme which we are in the process of planning:

AGM 2010 Adults Preliminary Programme

Saturday 6th March

10am - 1pm	Annual General Meeting
1pm - 2pm	Lunch
2pm - 3pm	Haemophilia in Russia
3pm - 3.30pm	Haemophilia - Collaboration towards excellence
3.30pm - 4pm	Coffee Break
4pm - 5pm	Prophylaxis V's On Demand
5pm - 5.30pm	Support services of the I.H.S.

Sunday 7th March

10am - 11am or 10am - 11am	Women with bleeding disorders
11am - 11.30am	Dental Care
11.30am - 12.30pm	I.H.S. Youth Programme
	The work of the National Haemophilia Council

Along with our adults programme we will, as usual, have a creche for children up to 6 years of age, and a Kidlink programme for children from 7 years upwards. Alison is already working on an exciting and interesting programme for the weekend.

The Royal Marine Hotel is very accessible in that it is on the dart line from Dublin City Centre, and only a couple of minutes walk from Dun Laoghaire Dart Station. The hotel also has a leisure centre and swimming pool, a spa and very nice conference facilities.

In the meantime members please keep checking our website for further updates on the programmes.

Looking forward to seeing you all in 2010!

Booking forms and AGM packs will be sent out in the post to members in early January 2010. You will also be able to book to attend this event online on www.haemophilia.ie in early January.

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October Members' Conference: *An adults' perspective*

A very enjoyable Members' Weekend was held in the Castletroy Park Hotel in Limerick from the 16th to the 18th of October. We met up with some old friends and made new friends. The younger members attending the weekend had a very enjoyable weekend. The facilities provided by the Society and excellent staff kept them entertained for the duration of the weekend, while their parents attended a very informative and entertaining programme.

The speakers were excellent, and it was clear they were trying to help people to manage and cope with everyday problems. Anne Duffy gave an excellent presentation on "Pain Management". Mr. Owen Hegarty, a psychotherapist, provided a most light entertaining session on Saturday morning about "Balancing your Life". However, putting his advice into practice might not be as easy as it seems. On Saturday afternoon we heard Mr. Patrick Stagg from The Citizens Information Centre, who gave an account of "Benefits and Entitlements", which was very interesting. This session was very well attended despite having to compete with the Munster Rugby match from Thomond Park (visible from hotel). This member left towards the end of the session to get the final moments of the game, missing the debate which I believe was engaging and enlightening. Throughout the weekend the I.H.S. staff and the volunteers were very focused on the job in hand, which meant our time at the lectures was most relaxing. My compliments to all involved.



Anne Duffy during her presentation on "Pain Management"



Members: Anthony O'Connor, Lorraine O'Connor & Joan Buckley Keniry



Members: Mary-Clare O'Sullivan, Hilary O'Sullivan, Sheila O'Shea and Kevin Birkett chatting over coffee

Dinner was scheduled for 8pm on Saturday evening. As we made our own way to the McCarthy Suite, we walked into what I might describe like a candle holder festival as each table was decorated with a 3 foot high candle holder. The menu on the night was of a very high standard and was enjoyed by all.

Afterwards a family quiz took place, which got very competitive at times! There was a lot of "phone a friend" so guys change the rules for next year. However, an enjoyable night was had by all.

On Sunday morning I was amazed to see the late revellers up bright and early, and ready for action. The Tai Chi and Art Workshops were terrific, followed by a splendid lunch at 1pm before departing home.



Family "Art Workshop" on Sunday morning

One member was missing this year, who I really wanted to speak to. Unfortunately, Mr. Brian O'Mahony was unable to attend the weekend. A lot of people were disappointed that they couldn't congratulate him personally about Kerry's great All Ireland win. However, in his absence the I.H.S. staff team really ensured that the whole weekend was a great success.

Robin Buckley

October Members' Conference: *Young adults' programme:*



The Youth Group getting ready for the high ropes

Naturally enough, some of the group were feeling fairly peckish on returning to the hostel. This was soon cured after a little creativity involving a microwave, some Mars bars, a lot of sugar and a banana. The result of which tasted amazingly good, despite its decidedly dodgy appearance.

You can imagine, sleep was a pretty scarce commodity that night, and so the longer than anticipated bus ride to Killaloe gave us some welcome time to fully wake up on Saturday morning. We got straight into the action on arrival at the University of Limerick Activity Centre, and spent the first half of the day kayaking on Lough Derg. Although the water was totally freezing, we had brilliant craic jumping (and being pushed) off the raft in the middle of the lake before heading back to dry land for some lunch.

At the October Members' Weekend, this year's Young Adult programme was based at the University of Limerick Activity Centre in Killaloe Co. Clare. The group, numbering fourteen in all, including the youth group, the leaders and our four visitors Sam, Sharon, Claire, and Neil from the U.K., set out after dinner on Friday night for the Jamaica Inn Hostel in Sixmilebridge where we were to stay for the weekend.

Having all just settled in with a good game of "Catchphrase", Alison hit on the idea of going on a midnight walk to find a spooky haunted ruin of a local castle. In true I.H.S. adventure weekend style, we trooped off, armed with flashlights and plenty of enthusiasm. Though the expedition was largely unsuccessful, we managed to scare the life out of most of the passing motorists, and as such, it turned out to be a very entertaining experience.



Don't let this picture fool you - the weekend was action packed!

Next we headed for the high ropes course. Having survived potential hypothermia after our early morning swim, we obviously thought a little climbing would be a piece of cake. In hindsight, those “Cliffhanger” jokes definitely sounded a lot funnier with your two feet on the ground! Nearly everyone gave it a go, which was great, and it was a good feeling to have reached the top.

We finished up with some team building games, which were pretty hilarious, and later got to try our hands at archery before it was time to hit the road. Back at the hostel, we cooked a surprisingly edible dinner of ‘D.I.Y.’ Spaghetti Bolognese - it was arranged that the girls would cook and the lads would wash up, so all in all, it worked out fine.



Looking good - The Youth Group get ready to hit the water in their matching wetsuits!



Picture Perfect - Hazel Byrne shows off some of the art from the art workshop

On Sunday morning, the time came to pack up and leave again to get back to the hotel. At this stage we were all completely exhausted after the two days, so we really enjoyed the chance to relax a little during the Art and Tai Chi Workshops with the main group, before it was time again to say goodbye.

Overall, it was a brilliant weekend for all concerned, and I think everyone is looking forward to next year already.

Shauna Keniry

October Members' Conference: *Kidlink programme:*

I was really looking forward to the Members' Weekend in Limerick this year, especially the Unigolf, swimming and seeing all my friends. It's not too far from Cork, where I live, to Limerick, so it didn't take too long. We went in my Dad's car, but when we got near the hotel he got lost so we were driving around in circles for ages trying to find it.

The hotel looked nice and my room was lovely, but as usual my Mum, Dad and sister got the best beds. I got the camp bed. After we unpacked I had dinner which was very nice. After dinner I played with my friends.

Breakfast the next morning was fabulous. I had orange juice, toast, croissants and pain au chocolat. Chocolate for breakfast, YUMMY! After breakfast we went swimming. The pool was smallish, but the depth was just right for me. We had a great time, the leaders also joined in the fun. Then it was time for lunch. Lunch was terrible. The chips tasted awful and the burgers, don't ask me about them.

In the afternoon we went to Unigolf. There were four people in each group. It was just like real golf only played indoors in a big red building with specially made clubs. We had proper scorecards and golf balls. I really enjoyed it especially as I won. After Unigolf we went back to the hotel and did circle time. During circle time we played games and talked about what we liked and didn't like about the weekend.



Yippee we're off to Unigolf



That's me in the blue sweatshirt



Our fantastic Kidlink volunteers: Mark, Aoife, Catriona, Barbara & Owen



Can we take him home? The Kidlink group think they have found the new I.H.S. mascot!

On Saturday evening everyone went to a big meal together. I had roast beef for dinner; it's one of my favourites. After dinner there was a table quiz. Our team was called "Team Actimel" and we won. The prize was a big box of chocolates which we shared with the other tables. After the quiz I played with my friends and stayed up half the night.

On Sunday I did Art and Tai Chi. It was an unusual art class. Firstly the teacher read us a story to inspire us, and at the end of the lesson she tidied up after us. I did two pictures. The first was of a boat and the second was of Anfield. After Art we did Tai Chi. I had never done Tai Chi before so it was a new experience. It took a long time, but in the end it was worth it because I enjoyed it.

By then it was lunchtime. After I had eaten I said goodbye to my friends. I felt happy after the long weekend. I was disappointed to see my friends leave but all in all I enjoyed my weekend. I'm really looking forward to next year.

Conor Birkett

October Members' Conference: *Creche programme:*



The smiles say it all!

All this is run in a child friendly, fully supervised environment.

This year the October Member's weekend in Limerick's Castletroy Park Hotel was a huge success. Having had all our old familiar faces, we also had a number of new faces in the crèche which is fantastic. We are already looking forward to meeting you all again in March.

In the meantime here's wishing you all a very Happy Christmas and a Happy and Healthy 2010.

Deirdre Ryan

My name is Deirdre Owens. Having had a brother with severe haemophilia, and now a son, my family and myself, have been involved with the Irish Haemophilia Society, for a number of years.

Six years ago myself and my colleagues Carmel and Claire volunteered our services to run a crèche for the I.H.S. tots at the AGM. For those of you that are unfamiliar with the service we offer, our main aim is to facilitate parents and children throughout the weekends that are organised annually by the Society.

The crèche is open to all our members under six years of age. Our two day programme is fun filled with both indoor and outdoor activities – weather permitting of course! Indoors the children interact freely playing games, dressing up, reading stories, watching dvd's, and a big favourite is the arts and crafts table.



Boys rule!

Service of Light

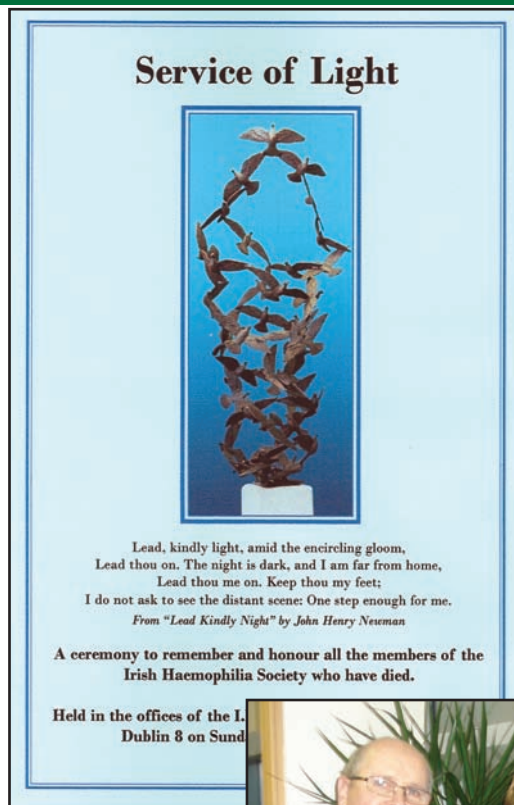
A “Service of Light” took place in the offices of the Irish Haemophilia Society on Sunday November 29th. The service, which was prepared by Fr. Paddy, was conducted by his colleague Fr. Bernard, in the absence of Fr. Paddy due to illness. The ceremony focused on remembering those who have died and the light and joy they brought to our lives.

During the service, the Memorial Book, which contains the names of all members of the Society who have passed away, was blessed, and candles were lit and placed around the memorial sculpture in their honour. Joe Rabbette played guitar and his daughter Noreen sang three beautiful hymns. Over thirty members attended the service, including founder member Mary Buckley.

After the service light refreshments were served. This time also allowed people to reflect privately at the memorial sculpture, and re connect with members whom they had not seen for some time.

For those who were unable to attend the service, please be assured that your loved ones name was honoured during the service.

The Memorial Book is held in the I.H.S. office. If you would like a passage or message to your loved one to be placed in this book, please contact Debbie Greene in the Society.



“Service of Light” pamphlet

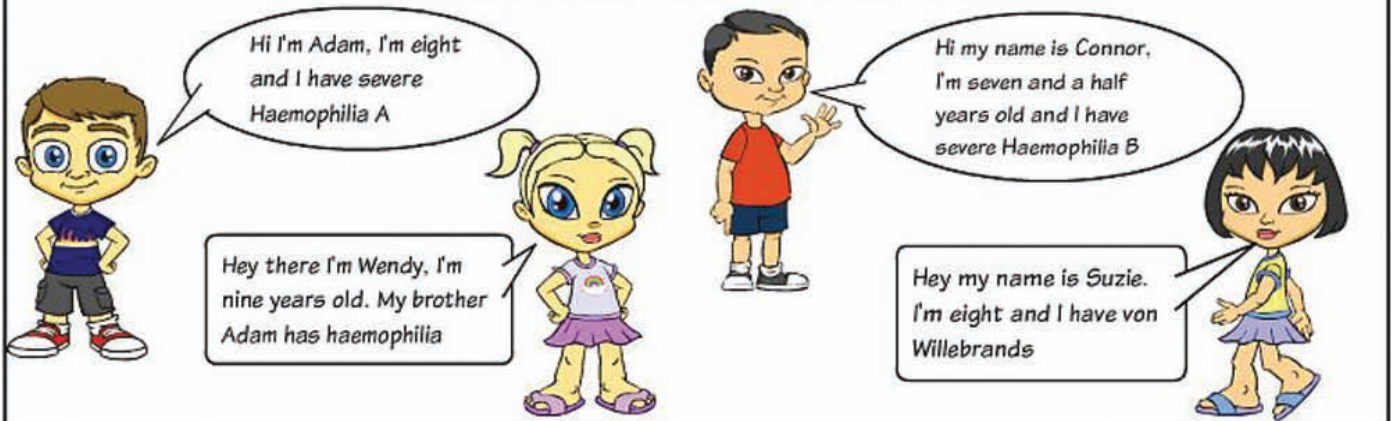
Joe, Marion & Noreen Rabbette



Memorial Sculpture



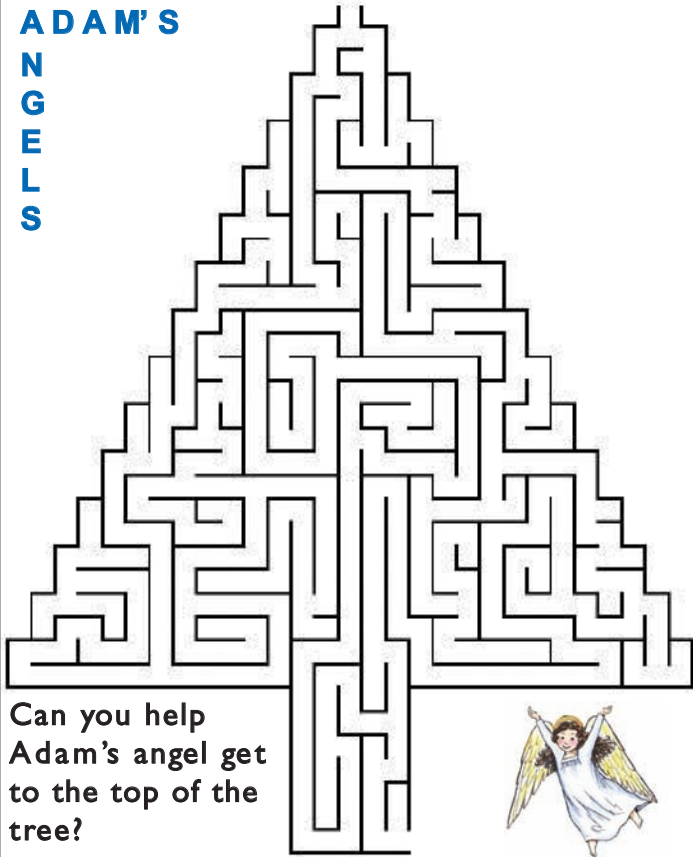
MEET THE KIDLINK CLUB MEMBERS



KIDLINK CLUB MEMBER WENDY TALKS ABOUT HAVING A BROTHER WITH HAEMOPHILIA



ADAM'S ANGELS



Can you help Adam's angel get to the top of the tree?

SUZIE'S SPOT THE DIFFERENCE

Can you spot the six differences in Suzie's pictures below?



Spot the difference: (1) The dog, (2) the bow on the Christmas Tree, (3) The third stocking on the mantelpiece, (4) The star on the Christmas Tree, (5) The pink present is missing at the front, (6) The tree is different in the middle picture

CONNOR'S CHRISTMAS CRACKERS



How does a snowman travel to work?
On his icycle!

What do you get if you cross an apple with a Christmas Tree?
A pineapple!

What do snowmen eat for breakfast?
Snowflakes!

What do you call a donkey with three legs and one eye?
A winky wonky donkey!

Why can't you tell a joke while ice skating?
The ice might crack up!

HAPPY CHRISTMAS EVERYONE



www.toondoo.com

A Message from our CEO



This is the last issue of our magazine for the year 2009, a busy and productive year. Despite the doom and gloom enveloping the economy, we have had a year where the attendance at our conferences has been very high, where we have added a Parents' Conference to the already existing Annual Conference and Members' Conference, and where we have organised a successful Relatives Day. A number of peer support groups for members with Hepatitis C and HIV have also been implemented. The input of the staff and the board into the organisation and running of the events has been crucial. However, I want to acknowledge that it would not have been possible to run our conferences and events smoothly, successfully and with the full participation of all groups of members if it was not for the dedication of our volunteers. We have volunteers who organise the crèche, who volunteer for the kidlink programme, the youth and young adult programme and who help to make sure that we are able to offer an enjoyable and integrated experience to all categories of members. We also had volunteers who, during the year, fundraised for us by running in the Women's Mini Marathon, Dublin City Marathon, Climbing the Highest Mountains in Ireland, and organising a Shaveathon. We also had an unexpected fundraising event such as the recent Threshing Event in Castledermot, organised by Rita Horan and her colleagues.

This event, which was organised in memory of the late David Sixsmith, was a huge success and we are very grateful to the Castledermot Vintage & Threshing Club for organising this event and for thinking of the Irish Haemophilia Society when deciding on the charity to benefit from this most enjoyable and worthy event.

A large number of regional visits took place during the course of the year. These included visits to; Cork, Waterford, Killarney, Limerick, Galway, Sligo, Letterkenny, Cavan, Carlow and Thurles. The attendance at the regional visits varied and we will routinely review the venues for such meetings to ensure that we are delivering the optimum service to members. It is important to note, however, that these visits give members an opportunity not only to gain information about the Society's programmes and activities, but a real opportunity to raise issues of concern in relation to treatment and care.

If you have an issue of concern in relation to treatment or care, please contact us in writing. In this way we can raise the issue with the appropriate comprehensive care team and seek a timely and satisfactory response. A number of issues have been raised during the year and there is a satisfactory mechanism in place between the Society and the haemophilia care teams at the three comprehensive treatment centres. The issue you raise need not necessarily be relating to one of the three comprehensive centres in St. James's, Crumlin or Cork University Hospital. You should feel free to raise an issue in relation to treatment or care at any hospital throughout the country and we will look into this in conjunction with the teams at the haemophilia treatment centres. Ideally, you should let us know about your concern in writing as this makes it easier for us to raise this in a structured manner with the treatment centres. A small number of such concerns were communicated to us by members in

2009 and these were dealt with satisfactorily by our liaison with the treatment centres.

Belarus

The Society had a haemophilia organisation twinning programme with the haemophilia organisation in Belarus in 1999. At that time, the focus of the programme was visits from children with haemophilia from Belarus to Ireland for one month's respite from the effects of the radiation following the Chernobyl disaster. At that time, we were also concerned about the level of organisation of the Belarusian Haemophilia Society and we did our best to assist them. The World Federation of Hemophilia have been taking a greater interest in Belarus in the course of the last couple of years and Belarus is now officially designated as a target programme for the Global Alliance for Progress (GAP) Programme. This programme, which is supported financially by the Irish Haemophilia Society, seeks to improve all aspects of haemophilia treatment and care in a country over a four year period. This includes; improving access to comprehensive care, access to factor replacement therapy, better diagnosis, establishment of a National Registry and improving the organisation of the Haemophilia Society.

As part of the latter objective, Anne Duffy and I visited Belarus as part of a WFH delegation in early November. Anne conducted a psychosocial workshop with the Board and key volunteers. On the following two days Yuri Zhuylov from Russia and I, conducted a workshop with the Board. We outlined the key elements in organisation of a national system of care and sought to assist them to define their strategic objectives for the next three years. This was a very successful process and resulted in the board defining clear and achievable objectives in relation to the level of haemophilia treatment, the introduction of a National Registry, increasing information to all

Safety & Supply

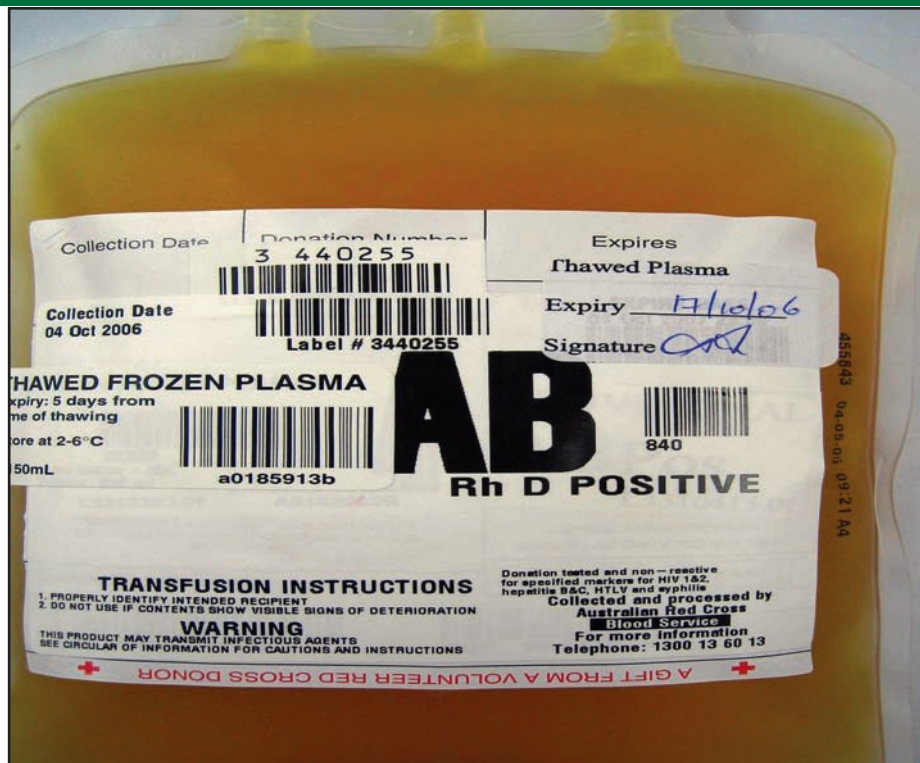
people with haemophilia and increasing the capacity of the organisation in the regions outside the capital, Minsk. The Haemophilia Society in Belarus is in much better shape than it was several years ago. They have a committed group of enthusiastic volunteers. We had eight volunteers with us for the entire two day workshop. Their commitment and enthusiasm were obvious. Crucially, they also have on the board a number of key volunteers from the regions outside Minsk. The targets they have set for the next three years are achievable. Progress has already been made. Treatment has improved in the two hospitals in Minsk and the amount of Factor available has greatly improved over the course of the last four years. From 2005 to 2009, the quantity of factor concentrates for treatment of haemophilia in Belarus have quadrupled.

The patient organisation is working closely with the doctors in the treatment centres and they recognise the need to organise more forcefully in the regions. They also recognise the need to produce and distribute a regular newsletter and other information and educational materials. I was glad to see an enormous improvement in the level of organisation and commitment and we will certainly give them any assistance we can in the future.

Finally, you will see two notices enclosed that we have received from the National Centre for Hereditary Coagulation Disorders at St. James's Hospital, and from Our Lady's Children's Hospital Crumlin which clearly outlines their recommendations in relation to Swine Flu Vaccinations, which I would ask you all to read.

Wishing you all a Happy & Healthy Christmas and New Year.

Brian O'Mahony



The issue of deferral of blood donors as a "discrimination" issue has been the subject of protests and legal challenges in a number of countries in the past several years. Many National Haemophilia Societies, including the I.H.S. take a strong and active interest in maintaining the safety of the blood supply. To this end, we support any donor deferral measure which serves to reduce the potential burden of infectivity in the blood supply. Deferring people as blood donors - including those who have lived in the UK for certain periods of time, blood recipients and men who have had sex with men (MSM) is discrimination, but it is necessary to do so and totally justified to maximize the safety of the blood supply. No person has a right to give blood but all people should have a right to receive safe blood or blood products. The issue which has been raised in public and in legal challenges on several occasions is the ban on MSM donors.

The Canadian Hemophilia Society have always been active in working to optimise the safety of their blood supply. Currently they are involved in a case in Canada, as a notice (or interested) party. This case revolves around an MSM donor who lied on the donor questionnaire and whose actions led to the recall and destruction of a lot of blood products. This man, Kyle Freeman, is being sued by Canadian Blood Services and he in turn, is counter suing them on the grounds of breach of his rights. The case is of fundamental importance as a successful legal challenge to donor deferral measures could undermine the safety and integrity of the blood supply and cause chaos in the area of blood donation.

Mr. David Page, CEO of the Canadian Hemophilia Society (C.H.S.) will be giving evidence in the case on behalf of C.H.S. On the following page you will find an article that David has authored for our magazine.

Brian O'Mahony

Blood safety case in final weeks in Ottawa

By David Page

OTTAWA – November 23, 2009

The civil case of Freeman vs. Canadian Blood Services (C.B.S.) and Health Canada began in Superior Court on September 28 and will last until mid December. The Canadian Hemophilia Society (C.H.S.) has been granted intervener status so as to represent recipients of blood and blood products.

The case originated in 2002. Kyle Freeman had donated blood on 18 occasions between 1990 and 2002; however, after the last occasion in June 2002, he informed the Canadian Blood Services in an anonymous e-mail that he had lied when responding to the questionnaire, specifically with regard to the question. Male donors: Have you had sex with a man, even one time, since 1977? C.B.S. discovered his identity and sued Freeman in civil court for negligent misrepresentation and damages. Freeman countersued C.B.S. and Health Canada on grounds that the question violated his constitutional rights.

Court testimony established that Freeman lied to four questions on the blood donor questionnaire, including one related to his sexual history of having had sex with other men (MSM). According to Health Canada regulations, men who have had sex with other men, even once, since 1977 are permanently deferred from giving blood because of the increased risk of transmitting blood-borne pathogens, notably HIV and hepatitis B. Had Freeman replied honestly to these questions, he would have been ineligible to give blood.

The judge in the case will have to answer three basic questions:



- Does the Canadian Charter of Rights and Freedoms apply to blood donation and the blood donor screening process?

- If it does apply, do the donor screening questions related to men who have had sex with men violate charter provisions on equality?

- If the questions do violate this section of the charter, can this be reasonably justified, for reasons of public health?

The C.H.S. is arguing that, whether or not the Charter of Rights and Freedoms applies in this case, the MSM question is justified under the Charter. Final legal arguments will be made the first week of January 2010. A judgment is expected later in 2010.

The key messages the C.H.S. is communicating publicly during the trial are:

- The C.H.S. is intervening in this case to protect the rights of all people who rely on the safety of the blood supply system in Canada.

- C.H.S.'s interest in blood safety comes from its experience of Canada's tainted blood tragedy and the devastation this tragedy caused its members. The C.H.S. is committed to ensuring a safe and secure blood supply for all Canadians so that such a tragedy never happens again.

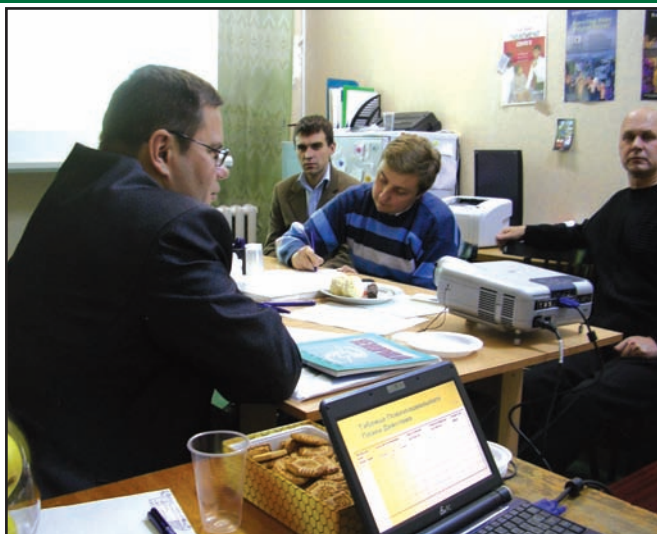
- The C.H.S. supports the position of Canadian Blood Services and Health Canada in maintaining the current MSM donor deferral criteria.

- The C.H.S. believes public health science and the precautionary principle should determine donor deferral criteria. These indicate that any relaxation in the MSM donor deferral criteria would make the blood system less safe.

- People only use blood when they need it, and when they have no option. They are completely dependent on the stewards of the blood system to ensure that blood is as safe as possible.

- No matter how small a risk may be, it is a risk that is borne 100% by the recipient of the blood and 0% by the donor.

Psychosocial Training in Belarus



Board Members of the Belarusian Association of Haemophilia Patients

I was pleased when Catherine Hudon, Program Manager for WFH invited me to return to Belarus to give a full day Psychosocial Training to the board of the Belarusian Association of Haemophilia Patients. The task of preparing for a full day of training was daunting. However, I was encouraged by the thought that I was returning to be with the inspiring people I had met in Minsk last March. That meeting had touched my heart, the thought that I was returning to visit friends calmed my anxiety and even helped me think beyond the box, and allowed my creativity guide me. I arrived in Minsk late on Thursday afternoon. When I emerged through Customs it was great to see my name on a card held by Alex with a warm welcoming smile.

On Friday morning we arrived early at the headquarters of the Belarusian Association of Hemophilia Patients. Liudmila Golitsyne, one of the board members, was very busy doing last minute preparations in the office for the meeting. Language was not a barrier, as we greeted each other. It was lovely to meet all of the board members. Some were parents of children with haemophilia and others were adults with haemophilia, including three men who had travelled from the regions outside of Minsk for the weekend training. The morning presentations titled

‘Psychosocial Issues through the Life Stages’ gave an explanation of what psychosocial support means, the normal developmental stages and psychosocial needs and objectives of each stage for a child with haemophilia. The afternoon sessions were more practical. ‘Managing Your Pain’ was based on the WFH Monograph on Pain Management.

‘Psychosocial Issues and Hepatitis C’ was adapted from the ‘Living with Hepatitis C’ booklet produced by the Consultative Council on Hepatitis C. These two sessions in particular were well received and generated good discussion including treatment for Hepatitis C.

For light relief in between these two sessions, I experimented with the use of puppets as a way of teaching young children about haemophilia. ‘Lucky Duck’ is a bright yellow duck with haemophilia. His friend ‘Treatment Turtle’ is a ninja turtle who helps Lucky Duck deal with haemophilia. The dialogue with the puppets gave positive reinforcement to these messages:-

- To use RICE (Rest Ice Compression Elevation) to manage bleeds especially in the absence of adequate factor supply;
 - The importance of education, keeping up with lessons while at home during bleeding episodes;
 - The need to care for teeth and gums through twice daily brushing.
- Catherine Hudon thought this was a good example of teaching children.

The last session was the most important: ‘Psychosocial Action Plan’. There was discussion amongst the board members to decide on the actions which needed to be taken, when these needed to happen, now, soon or later, what resources were

available and needed, and who will carry out each of these tasks.

Brian O’Mahony & Yuri Zhuylov, President of the Russian Haemophilia Society arrived on Friday. Over the next two days they would provide intensive training for the board members on Advocacy Skills. This was a huge learning curve for me which I thoroughly enjoyed. Brian presented on ‘Action Planning’ and the need as an organisation to set realistic goals and the manageable steps necessary in order to reach these goals. This was done in an informal way which allowed for animated interaction to take place between everyone. As an observer of this process, it was interesting to notice the body language, facial expressions and tone of voice of the speakers. Later, when I heard the translation, I could match up some of my felt experience to the words. I was very impressed with how the board members engaged in this process of Action Planning, despite it being a new concept for them. In order to do this they had to see beyond the present obstacles and not let themselves get bogged down in discussion. Yuri Zhuylov is both a gentle person and a great speaker. The board respected his input because of his many years experience of dealing with a similar bureaucratic system in Russia. To me it was like observing a great teacher in action. I could see the rapt attention of his audience, like they were hanging onto his every word!

It was time to go, and I left with a heavy heart. I had felt that the 3 days were a very intensive experience. I had gained greater insight into the daily reality of these people and the obstacles to haemophilia care which they experience. I was impressed by their resilience, determination, and their optimism in the face of their particular situation. I left inspired and uplifted by my visit to Minsk.

Anne Duffy

Grants & scholarships

We would like to thank everyone who sent in applications for the grants and scholarships this year. We were delighted with the response we received. A total of 20 applications were received. This year we put together a score sheet and I have to say the sub group from the board had a very difficult job indeed deciding on the recipients. I am now pleased to announce winners and recipients as follows:

MAUREEN DOWNEY MEMORIAL GRANT

Daryl Butler	€4,000
Irene Clarke	€2,000
Fergus Friel	€1,000
Michael Higgins	€1,000
Colm O'Sullivan	€1,000
Lorcan Friel	€1,000

MARGARET KING EDUCATIONAL SCHOLARSHIP

Christina OSullivan	€2,000
Dermot Friel	€1,500
Richard Butler	€1,000
Deryn Ryan	€1,000
Liz McDonald	€500

Many congratulations to all of you especially to Daryl and Christina. For those of you who were unsuccessful we would like to encourage you to re apply next year, and we will be putting tips and criteria for applying for our grants on the website in the Spring. Below you, will find a letter we received from Irene Clarke who was the recipient of the second award in this years Maureen Downey Memorial Grant.

Debbie Greene

A Big Thank You

"I can not thank the Irish Haemophilia Society enough for selecting me as the recipient of the second award in the Maureen Downey Memorial Grant for this year. I know it will help me greatly as art supplies and materials are very expensive. This year I started my 'Undergraduate Course' in 'Fine Art and Education' at Aberystwyth University, Wales. It is a three year course and I know it will be hard work, but I am prepared for that. I am settling in very well and have made plenty of new friends. I miss home, but I know how lucky I am to be doing this course. The path of studying has not been easy for me as I had to battle my way through school with dyslexia and I will not let it defeat me. Art is my passion and I know that I will succeed in the end. The help and support I have received from the Society in the past will always stay with me. This money will be put to good use as I have to buy art materials most weeks. It will also ease the pressure on my parents who are fully behind me in my studies. Wales is a lovely place, but it is so far from home and I am making the most of this opportunity by joining different Societies, which will broaden my experiences while I'm here. Thank you from the Irish cailín in Wales who will always remember your kindness".



Irene Clarke November 2009

Noticeboard

Santa and Nama



As I sit down to write, there are floods in the West. We are all coughing with swine flu, and pains in our chest.

Poor Santa is worried, he will get no thanks. The Elf's income levy, is all gone to the banks.

Public service workers are striking, as Christmas comes near. And at the picket line are Rudolph, and all the Reindeer.

Half the people went north, to buy presents to deliver. Now they cannot get home, as the bridge is in the river.

The budget has come, and pay will be cut. Half the shops are struggling, the others are shut.

We can deal with these problems, in a way that's quite funny. We just give them to NAMA, with all of our money.

HEALTH AMENDMENT ACT (HAA) CARD



Health Amendment Act Cards are awarded to men, women and children who were infected with Hepatitis C through administration within the State of contaminated blood and blood products.

The HSE have begun sending out letters and laminated sheets depicting the HAA card and its entitlements to every hospital in Ireland beginning with the eight designated hospitals targeting admissions, accounts, patient registration points and A&E departments in an effort to raise awareness. Each hospital will also be supplied with information guides and leaflets.

If you are having any difficulties, it is very important that we are made aware of this. Please contact Anne Duffy in the office on 01 6579927.

“Seasons Greetings” to all our members from the board and staff of the I.H.S.



Our office will close on Wednesday 23rd December 2009 and will re-open on Monday 4th January 2010. In case of an emergency please contact Anne Duffy on 087 2320255

Fundraising

Castledermot Threshing & Vintage Working Day



Rita Horan from the Castledermot Vintage Club presenting Kevin Birkett with a cheque for €24,000!

At a Gala Presentation Night held in Castledermot, Co. Kildare in November the Irish Haemophilia Society was presented with a cheque for €24,000. The generous donation was the proceeds of a fundraising event organised by the Castledermot Vintage Club in memory of I.H.S. member David Sixsmith, together with a contribution from David's father, Norman.

Among those who attended the hugely enjoyable evening were I.H.S. members Kevin Birkett, Ger O'Reilly, and Pat and Carmel Downey. Speaking after the presentation Kevin outlined the history of the Society and acknowledged the importance of fundraising to help maintain our ongoing campaigns and programmes. He thanked the people of Castledermot for their generosity and presented Rita Horan, PRO of the Castledermot Vintage Club, with a plaque to commemorate their efforts on behalf of the Society.



Kevin Birkett presenting Rita Horan with a framed scroll acknowledging this fantastic fundraising event

Rita had very fond memories of David who owned the only steam engine at the vintage club's first 'Threshing and Vintage Working Day,' which was held in 2007. It was a far cry from this year's working day, which was held in September and was attended by 5,000 people and no fewer than 24 steam engines.

The enormously enjoyable family day featured traditional threshing, vintage farm machinery, tractors, trucks, cars and motorcycles. There was something for all tastes and interests with traditional crafts such as hand weaving, the making of copper tools, crafts demonstration by the ICA, a blacksmith making horse shoes, the dismantling and reassembly of a Ferguson tractor in under 19 minutes, and lots more, such as dancing, music, plant and flower stalls, cake sales, book and bric-a-brac sales. The children were entertained with a funfair, pony rides, pet farm, competitions to win a goldfish, face painting, sponge-throwing, a clown and more.

Dublin City Marathon



Ger O'Reilly, who attended the event on behalf of the I.H.S., was bowled over by the day. "I wasn't sure what to expect. The size of the event really took me by surprise." Meeting visitors to the working day and chatting about the work of the Society, Ger got a good idea of the esteem in which David was held. "I quickly got a sense of how highly David was regarded and respected by all that I talked to. People had travelled from all corners of the country in his memory. They felt they needed to be a part of it [the working day]."

The Castledermot Vintage Club has raised €74,000 for charity since its foundation in 2007. Its next 'Threshing and Vintage Working Day' will be on Sunday 26th September 2010. If you enjoy the sights and sounds of yesteryear it's an event you can't miss.

The Irish Haemophilia Society would like to offer its condolences to David's wife Marlene and to all the Sixsmith family.



Noel Wynne getting ready to run the Dublin City Marathon

Hi my name is Noel Wynne. I became a member of the Society back in 2006 when my youngest son Callum was diagnosed with severe haemophilia. Over the last few years we have attended many of the weekends away and found them a great way of meeting people and also gaining new knowledge about haemophilia. It was at the AGM in March 2009 that I set myself the challenge of running the Dublin City Marathon as a fundraiser for the Society. I started training that following month. I had never run before so it started out slowly, and over the summer months this progressed. In September I ran the half marathon in the Phoenix Park as part of my training, and it was not too bad. I managed to complete it in 1 hour and 46 minutes. It was then that I found the courage to actually register for the Dublin City Marathon, so that was it no going back now. The night before the marathon the nerves set in and very little sleep was got. I arrived in town and my family all came into support me which was great. Nine o'clock came, and we were off. The first 13 miles went great then it started getting a bit more difficult. At 18 miles I wanted to give up, but got through that. I got to 21 miles and had another 5 to go so I felt the end was near. Then for the last 3 miles I decided to step up the pace as I wanted to finish within the 4 hour mark. I was delighted to cross the finishing line at 3 hours 57 minutes and 12 seconds. As I crossed the finishing line I felt a great sense of achievement, but was glad to be finished. Now the pain was setting in and I could feel aches all over my body which stayed with me for a few days. Now I have forgotten about all the pain and I am starting to think about what the next challenge will be!

Calendar of Events for 2010

DATES FOR YOUR DIARY FOR 2010!

FEBRUARY **REGIONAL VISITS**

Dates:
Monday 8th to Friday 12th February

Venues:
To be confirmed

MARCH **AGM & CONFERENCE**

Dates:
5th to 7th March, 2010

Venue:
The Royal Marine Hotel,
Dun Laoghaire,
Co Dublin.



The Annual General Meeting and Conference next year will take place in the Royal Marine Hotel in Dun Laoghaire, Co. Dublin. On page 2 you will find the preliminary adults programme. Letters and booking forms will be posted out to all members in early January. Keep checking our website for further updates!

APRIL **PARENTS WEEKEND**

Dates:
23rd to 25th April, 2010

Venue:
The Castleknock Hotel & Country Club,
Castleknock,
Dublin 15.



Following on from the success of our first ever Parents' Weekend this year we are pleased to announce that we have already started planning our second conference. Attendance at this weekend is open to all parents of a child with a bleeding disorder. We are confident that this weekend will be a success again, and it is hoped that along with attending the various lectures, it will be an opportunity for parents to meet other parents to discuss common concerns.

MAY **WEEKEND WORKSHOP** **CONFERENCE** **for**

Members Living with Hepatitis C & HIV

Dates:
21st & 22nd May, 2010

Venue:
Dublin - venue to be confirmed

JUNE **LADIES MINI MARATHON**

Date:
Monday 7th June, 2010



OCTOBER **MEMBERS WEEKEND**

Dates:
15th to 17th October, 2010

Venue:
To be confirmed



Although we do not have a venue confirmed yet we have set the dates and are already working on another exciting and interesting programme for our October weekend. Further information will be available in the New Year.

SEPTEMBER **RELATIVES DAY**

Dates:
Friday 10th September, 2010 - Cork
Saturday 11th September, 2010 - Dublin



We are pleased to announce that a Relatives' Information Day will take place next year in Dublin and Cork. This Information Day will give relatives an opportunity to gain a better understanding of haemophilia. The meeting will be an ideal introduction for grandparents, uncles, aunts and any other relatives for whom haemophilia is a new experience. This will be an opportunity to get answers to all those unasked questions. Please encourage your relatives to come along.

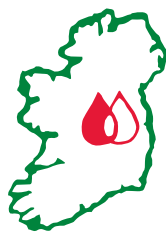
NOVEMBER **HEPATITIS C / HIV** **CONFERENCE**

Dates:
13th & 14th November, 2010

Venue:
Cork - venue to be confirmed

NOVEMBER **REGIONAL VISITS**

Dates & Venues
To be confirmed



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