

haemophilia.ie

Magazine of the Irish Haemophilia Society

Edition: June 2012

*Representing people in Ireland with
Haemophilia and related
bleeding disorders.*



The Society at a Glance

Parents
Conference 2012
Attendance

128 ←

↑ Followers on
Facebook

243

↑ Registered
Volunteers

34

2012 Mini
Marathon
Participants

22 ←

↑ Website Hits
(Apr - May)

3,231

WHAT'S INSIDE:

- * An update on the Twinning Programme between the I.H.S. and Vietnam.
- * Information and advice on Self Infusion.
- * Mini Marathon Report.



Are you what we're looking for?

44 year old organisation seeks men with bleeding disorders aged 18 to 35 to attend an overnight meeting on bleeding disorders.

Don't worry we won't bore you with lectures. We'll have workshops on everything from sport to sex.

Who knows what the future holds? Nobody!

Who'll always be there to hold your hand? Nobody!

It's time to get informed about your bleeding disorder.



HIS I.H.S.

Date: 8th & 9th September 2012

Venue: The Clarion Hotel Liffey Valley, Co. Dublin

PRELIMINARY PROGRAMME

Saturday September 8th

11.00am - 12.00pm	Registration
12.00pm - 1.00pm	Lunch
1.00pm - 3.00pm	Fitness & Health
3.00pm - 3.30pm	Coffee Break
3.30pm - 5.00pm	Relationships & Sex
7.00pm	Dinner & Entertainment

Sunday September 9th

10.30am - 11.30am	Benefits
11.30am - 1.00pm	Open Forum
1.00pm - 2.00pm	Lunch

*If you only go to one event this year -
make it HIS I.H.S.!!*

CONTENTS

- 4** CEO's Report.
- 6** Twinning Partnership; An Update.
- 10** I.H.S. News.
- 11** Dates for your Diary.
- 12** Cubs Club.
- 13** Kidlink Page.
- 15** A Marathon Journey, well a mini one! Read all about the 2012 Flora Women's Mini Marathon.
- 16** Information on the 2012 Grants & Scholarships offered by the I.H.S. and the application process involved.
- 19** Parents Conference Report.
- 22** In The Spotlight - Self Infusion.

A Note from the Editor



*Debbie Greene,
Administrator*

Hello Everyone,

It's been a busy couple of months since our last magazine in particular with our Parent's Conference and a visit from our Twinning Partners from Vietnam. I hope you enjoy reading this edition of the magazine, and if at any stage you would like to see a particular topic covered in our magazine give me a call on 01 6579900.

On pages 4 and 5 our CEO Brian O'Mahony updates members on the availability of the new Hepatitis C treatments.

The following pages you will find various articles in relation to our twinning visit to Vietnam back in March, and our twinning partners visit to Ireland in May which I hope you will find of interest. Our twinning partnership has started, is growing and it is hoped that we can help the Vietnamese Society build and grow as a patient organisation. Their community is committed, active and enthusiastic and I have no doubt that in time they will achieve better care in their country.

Our very own Nina Storey took the plunge again this year and did the Mini Marathon, read all about it on page 15.

On pages 16 & 17 you will find all the information you need in relation to applying for our Grants and Scholarships. The opening date for applications is 1st July 2012, so why not think about applying this year, it's hugely beneficial.

If you are interested in reading all about our 4th Parent's Conference, go to page 19 where you will find an article written by member Orlagh McGleenan along with plenty of photos from the conference.

And finally, please contact the office on 01 6579900 if you have any questions, queries, or would like to talk to somebody in confidence.

**Debbie Greene
Administrator**

CEO'S Report

Hepatitis C Treatment

The new treatments for Hepatitis C genotype 1 – Telaprevir and Boceprevir - have been licenced for use since late last year. These treatments taken with Pegylated Interferon and Ribavirin offer a probable cure rate of close to 80% compared to 40% for the previous combination treatment of Pegylated Interferon and Ribavirin alone. The course of treatment will be very difficult for members with significant side effects but the results look very promising and the Society have been taking every measure to ensure that our members with Genotype 1 Hepatitis C are aware of these treatments and can avail of them. The process of getting access to the treatments has been slow and frustrating. The therapies underwent Health Technology Assessments which demonstrated that both were cost effective. This was completed in January and our expectation was that treatment would commence in February. This did not occur and the therapies were not approved for reimbursement. Consequently, we sought an urgent meeting with the Minister for Health in April and met Minister Reilly on World Haemophilia Day - April 17th. I made a strong case to him for immediate approval for these therapies and explained their vital importance for our members. The Minister approved the therapies during our meeting. Despite this, at the time of writing in early June treatment has not yet commenced. Delays within the system including staffing issues and which budget the drugs will be reimbursed from, have been delaying factors.



Brian O'Mahony,
CEO

We continue to work constantly with the Hepatologists, St. James's Hospital and the HSE via Dr. Barry White to resolve these issues without further

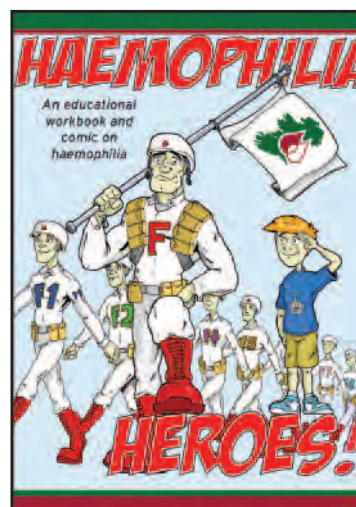
delay. We have now received a categorical assurance from the CEO of St. James's Hospital that treatment will commence in June. If this does not occur, we will once again be contacting the Minister for Health on an urgent basis. It is not appropriate that a decision, once made at the highest level, should take so long to translate into action on the ground.



Meeting Minister for Health, Dr. James Reilly TD on World Haemophilia Day, April 17th 2012.

Haemophilia Heroes

Our latest publication is a first - an Action Comic and Workbook for boys with haemophilia. This publication, which was designed entirely in house, includes games, puzzles and an action hero. We hope that all the boys with haemophilia like this new departure and we will be following up with a similar publication for siblings later this year - watch this space.



The latest IHS publication, *Haemophilia Heroes* can be downloaded from the IHS website www.haemophilia.ie

Twinning with Vietnam

Following on from our successful twinning visit to Vietnam in March a delegation from our twinning partner, the Vietnam Society for Congenital Bleeding Disorders (VSCBD) visited the Society in May. The delegation comprised of Dr. Nguyen Thi Mai and Ms. Ngo Thuy Hanh.

Dr. Mai is a Haematologist at the National Institute for Haematology and Blood Transfusion in Hanoi and she is also the secretary of the VSCBD and a stalwart and constant worker for the organisation. Ms. Hanh is a volunteer with the VSCBD and a carrier who has 2 sons with mild Haemophilia.



Dr. Mai and Ms. Hanh gave a very interesting presentation at the Parents Conference on haemophilia in Vietnam.

Dr. Mai and Ms Hanh joined the staff, volunteers and members in attending the Parents Conference in Athlone. It was a very beneficial occasion for all concerned. Dr. Mai and Ms. Hanh had the opportunity to see first hand the type of programmes and events we organise and meet many of the members. In turn, the members had an opportunity to meet and chat with them. Dr. Mai delivered an excellent lecture on haemophilia in Vietnam to the parents and separately to the children. This was very well received and gave the members an opportunity to hear first hand the reality of living with haemophilia in a country where adequate treatment remains a long term goal and treatment with prophylaxis or recombinant products are not realistic possibilities at this time.

During the visit, the Society staff worked closely with Dr. Mai and Ms. Hanh on areas where they wish to improve the capacity of the VSCBD. This included publications and website (although it must be said that the VSCBD has an excellent website to which they contributed daily blogs during their visit). It also included event organisation, budgets and accounts, organisation of childrens programmes and volunteer recruitment. A detailed session looked at governance and the functioning of the board and the optimisation of the board / staff working relationship. Progress was made on identification of future objectives to assist VSCBD in improving their governance structure and functions.

Dr. Mai and Ms. Hanh also had an opportunity to visit the Comprehensive Haemophilia Treatment Centres at NCHCD and Our Ladys, Crumlin. They met with the team at NCHCD and had a broad and pleasant discussion. Dr. Mai also participated in clinics at both centres. They had an opportunity to visit two families at their homes and observe

home treatment which is not available for people with Haemophilia in Vietnam due to shortage of factor concentrates.



Dr. Mai and Ms. Hanh with staff from the National Centre for Hereditary Coagulation Disorders.

Socially, the visit was also very busy. Their inexhaustible curiosity had them taking photographs of birds, parks, houses, gardens and anything that moved or stood still. We had a very pleasant reception in the office for them attended by board, staff and volunteers and an Irish evening at my home where they sampled Irish stew, bacon and cabbage, smoked salmon, bread and butter pudding and other typical dishes washed down with baileys and Irish coffee. They visited Christchurch, St. Patricks Cathedral and the Jameson Distillery (which they really enjoyed). They enjoyed an evening of Irish traditional music with the staff although, thankfully, they were spared the evening of karaoke which the staff wanted to organise. (You would have to hear the staff singing to fully appreciate how fortunate they were that this did not occur).

The visit went exceptionally well. I know that all of the staff team really enjoyed having them as our guests (see page 9 for comments from the IHS staff on the Twinning Visit) and when they departed, it was as if family members were leaving. We look forward very much to our continuing collaboration and work with them and hope to welcome them to Ireland again in the future.

Brian O'Mahony,
CEO

Twinning Partnership; An Update

As most of you will already know by now the Irish Haemophilia Society started a twinning programme with Vietnam in late 2011. Here you will find articles on a twinning visit made by the Irish Haemophilia Society to our twinning partners in Vietnam back in March 2012, followed by a visit from the Vietnamese Society to our organisation in May 2012.

Twinning Visit to Vietnam

When I was asked to go to Vietnam for the twinning visit – I obviously jumped at the opportunity. I thought about how my presence could help the team in Vietnam. What I didn't realise was the powerful impact this trip would have on me and how the warmth and hospitality of the Vietnamese people would add so much to my experience. More importantly, I learned how resilient the Vietnamese people are and how in the face of such difficult circumstances the doctors in each centre do an excellent job. For my first time in South East Asia I was not disappointed. Everything about Vietnam seems like a culture shock. The traffic is to sum up – crazy! The streets are crowded and loud, the food is amazing and healthy – although I could leave the pig uterus and testicles but maybe I am being fussy?? The people, from hotel staff to shop assistants, patients to doctors are friendly and warm.



Workshops were a vital part of our visit to Vietnam

The visit was filled with workshops on various topics such as Volunteer Recruitment, Fundraising, Advocacy and so on. We met people with haemophilia and their families, we visited the hospitals and treatment centres and then we finished with a visit to Ho Chi Minh City to open a Southern Club of the Haemophilia Society. The hospital and laboratories in Hanoi are newly built and very impressive. There are a lot of patients visiting the centre – on any day there may be 30 Out-patients and 20 In-patients with haemophilia.

As they have no treatment at home, they must go to hospital, but due to the large and long size of Vietnam,

this trip to hospital can be quite a trek. When we visited the wards in the adult and children's hospitals, Dr Mai explained each case and whether the patients had haemophilia VIII / IX and what type of bleeds they had been admitted for and how long they have spent in hospital. The adults smiled and nodded and the children were clearly extremely excited about the small gifts we gave them.

Nowadays, in Ireland the kids arrive at our weekends, more often than not, physically able to do anything that their peers without haemophilia can do. Today in Vietnam the reality is in stark contrast with Ireland. Children and adults alike have serious mobility problems, pseudo tumours seem commonplace and long stays in hospital are par for the course. Although the experience in the centre is a very sad and difficult one to accept, it drills home the importance of our trip to try and help the Vietnamese Society to improve the quality of life for their patients.

From the moment we arrived in Hanoi and Ho Chi Minh alike we were extremely well taken care of by all of the staff and families we encountered at both hospitals. In Hanoi, I definitely felt like I had experienced the real Vietnam. Ho Chi Minh looked more cosmopolitan, but the reality in the hospitals seemed much more grim, the wards were extremely overcrowded which was surprising, given on first glance the city seems richer than Hanoi. The talks all went very well, despite the language barrier, but it is difficult at first to see where you can make improvements due to the lack of factor concentrates and facilities.

The positives are that the people working in the centres are passionate about what they do and they genuinely want to see the patients have a better quality of life. Also at the talks there were some excellent voices for the future in people who have haemophilia and their family members.

I don't think in all that I have written I have given the trip a justified summary. It was a hard reality but one that I am very grateful to have been given the opportunity to be involved in and I hope that over the course of the Twinning Programme the Vietnamese Society can benefit greatly from the progress they will inevitably make.

Fiona Brennan

Twinning Visit to Ireland

When the twinning visit to Ireland was confirmed everyone was looking forward to meeting our guests after hearing all about our trip to Vietnam earlier in the year. We put together a full schedule for the visit which included training, home visits, our guest attending our Parents Conference, a visit to the National Centre in St. James's, a visit to the Paediatric Centre in Crumlin and some sightseeing and social activity.

Dr. Mai, (Consultant Haematologist) and her colleague Ms. Hanh (a volunteer for the organisation) arrived on Thursday 10th May, and after a day of rest joined us as delegates and guests at the Parents Conference in Athlone. They were introduced to members at registration on Friday evening and seemed to enjoy mingling with everyone over the course of the weekend. They attended all the lectures and workshops. On Sunday morning Dr. Mai gave an excellent presentation on haemophilia care in Vietnam; it was very informative and gave a real insight into the lack of treatment available to patients there and clearly struck a cord with our members. In Vietnam children under the age of 6 years receive free treatment, but children over the age of 6 years and adults must pay between 5% and 20% for their treatment, based on their income, so this is a struggle for a lot of people. Members listened with great interest, many questions were asked during this session and suggestions were also made. Following this Dr. Mai and Ms. Hanh gave a talk to the Kidlink/Youth Group on care in Vietnam. They also gave an excellent demonstration picking up M & M's with chopsticks! Later they mentioned how much they had enjoyed the conference, meeting people and how they had learned a lot.



Dr. Mai and Ms. Hanh with the leaders and members of the Kidlink and Youth Groups at the Parents Conference 2012.

On Monday our visitors were brought on a tour of the National Centre which was organized by Nurse Manager Anne Grogan. The centre were very hospitable and they made them feel very welcome. They were shown around the centre, the laboratory, the physiotherapy department, and hepatology. Following lunch the ladies were brought to the Paediatric Centre in Crumlin. Dr. Mai was invited to join Dr.

Beatrice Nolan for a haemophilia clinic and Ms. Hanh was brought to visit St. Michael's ward.



Dr. Mai and Ms. Hanh took part in training with the IHS Staff

On Tuesday Dr. Mai and Ms. Hanh had a full day of training in the office. We had put together a training schedule for them, all the staff in the office were involved in some aspect of the training. We started with a general twinning meeting which was followed by training on the Irish model of care covered by Brian and Declan, publications and the website covered by Nuala and myself, and conferences and event organisation covered by Fiona, Nuala and Nina. These sessions were both productive and encouraging. The work Dr. Mai does is remarkable and during these training sessions we discussed how important it is to start with small meetings and to realise that it has taken the Irish Haemophilia Society a long time to get to where we are now.



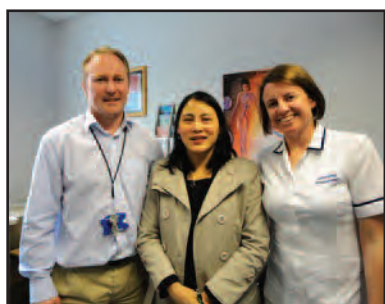
Dr. Mai and Ms. Hanh with several members of the IHS board.

In the evening a twinning reception was organized in the office. It was a lovely evening and great to see staff, members, some of the board, some volunteers, a representative from the H.S.E. and a representative from a pharmaceutical company attend the event.

On Wednesday morning Anne and I brought Dr. Mai and Ms. Hanh on two home visits. Both families were extremely welcoming and our guests were absolutely delighted to visit them. Lots of photos were taken, and lots of conversation took place with plenty of questions. In one of the homes a mum showed our visitors the process of actually giving home treatment to their child. Our visitors were clearly immersed in the whole process.



A highlight of the Twinning visit was home visits to I.H.S. members.



Dr. Mai met with Niall Hogan, Orthopaedic Surgeon and Emma Sherlock, Physiotherapist from the NCHCD.

Following lunch Dr. Mai was invited to join Dr. Kevin Ryan for the adult haemophilia clinic in the National Centre and Nina brought Ms. Hanh to Christchurch Cathedral for some sightseeing.

Later in the evening Brian & MaryRose O'Mahony hosted an evening for our guests in their home. This was a very enjoyable evening and our guests loved the Irish stew and Irish coffees!

First thing Thursday morning Dr. Mai and Ms. Hanh were brought sightseeing to St. Patrick's Cathedral. The rest of

the day was spent in the office training. Fiona, Anne and Eoin Moriarty (board member) did some training with our guests on our Children's programmes and Anne also spoke to them about the services we offer to our members. In the afternoon Brian and I had a very good meeting with Dr. Mai and Ms. Hanh in relation to bringing the organisation forward. Lots of comparisons were made between the two countries, a new 5 year plan was discussed and Brian offered to help their Society put this together during his visit to Vietnam in October. We also spoke about the possibility of reconstructing the board and put together a 'To Do' list which included their organisation putting together a Medical Advisory Group. Later in the evening the staff brought our visitors to an Irish themed evening in the City Centre where they listened to traditional Irish music, drank a glass of Guinness and had more Irish stew!



Sampling some of the Irish Tourist Attractions with a visit to the Jameson Distillery.

Friday was the last day of training in the office which included Volunteer Training, Board Training and a discussion on Budgets and Accounts. Training officially finished at lunch time on Friday, but I reckon we could have gone on for another couple of days if time allowed us. Following lunch the ladies were brought on a tour of the Jameson Distillery which they thoroughly enjoyed and they were delighted to be chosen as tasters of the different

whiskeys. After the tour the ladies were brought shopping in the city centre and finally later in the evening were brought back to the hotel where goodbyes were said.

The ladies flew home on Saturday morning at 6am.

It was a fantastic and beneficial visit. I, for one, thoroughly enjoyed it. Dr. Mai and Ms. Hanh are lovely people, unassuming and humble. They are terrific company, and they learned a lot (as did we). It was an absolute pleasure to have them visit our organisation. The twinning visit in my opinion was very constructive, practical, encouraging and positive. It showed us all how much they care about their members and patients and how much they want to learn and improve the care in their country and we in turn will assist and support them in any way we can.

Debbie Greene

Twinning Visit: The Staff View

I was very impressed with Dr. Mai's determination to improve the quality of life for her patients. She does so much with so little. Her patients seem to make great demands on her. I hope we can help her to empower her patients to become more proactive and involved in the Haemophilia Society. Meeting these ladies helped me appreciate what I have and to challenge myself to be happy with less and share more.

Anne Duffy

The time I spent with Dr. Mai and Ms. Hanh was extremely enjoyable. On the way to the Parents Conference we talked about Ireland. Everything from its geography to the diversity of culture. I also got to hear about their families and how life with haemophilia is for them. On Tuesday I got to talk with Dr. Mai and Ms. Hanh about the model of haemophilia care in Ireland. It was a really informative session for both sides I think and it was clear to see they are doing a lot of the right things, but organising it into a well laid out plan will help them so much in moving forward. Overall I think the trip was a success with obvious bonds built between the IHS staff and the two ladies, hopefully this is a bond will help both societies to grow.

Declan Noone

I feel that Vietnam is so far behind us in haemophilia care and support; it must have been very difficult for Dr. Mai & Ms Hanh to see how much we have and how little they had to return home to in relation to haemophilia in Vietnam. Dr. Mai and Ms Hanh are two lovely, kind and committed people and I know that they will both continue to work hard to improve haemophilia care and support.

Nina Storey

Meeting Dr. Mai and Ms. Hanh has been one of the highlights of my time working with the Society. They are both passionate about improving haemophilia care in Vietnam and the services that the Haemophilia Society provides to patients. I know they got a lot from their visit to Ireland, but I learned a lot from them also. I look forward to working with them on more projects and I wish them every success in their future plans.

Nuala McAuley



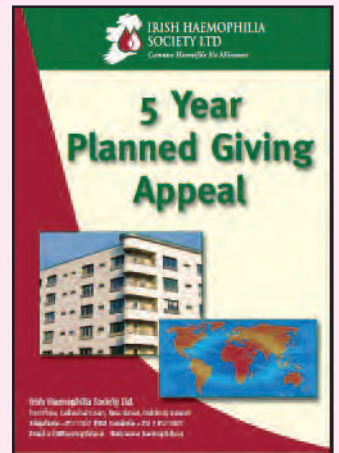
The I.H.S. staff with Dr. Mai and Ms. Hanh at a Twinning Reception held in the I.H.S. office.

Log on to www.haemophilia.ie to view photos from the IHS Twinning Visit to Vietnam and the Vietnamese Twinning Visit to Dublin.

Planned Giving

Our planned giving campaign is now underway. Please see the enclosed leaflet and information for more details.

If you require further information contact Nina or Debbie in the office on 01 657 9900.



Brian O'Mahony Award - Call for Nominations

At the Annual Conference of the I.H.S. in March 2012, it was announced that an award will be considered and presented on an annual basis to an individual who, in the opinion of the Society, has made an outstanding contribution to haemophilia care in Ireland. The Award will be made in the name of Brian O'Mahony in recognition of his 30 year contribution to the Society.

Nominations can be proposed by members or by the board of the Society and the final decision will be made by the board. Current members of the Society board may not be nominated

If you would like to nominate an individual who, in your view, has made an outstanding contribution to the Society, please send in your nomination and reasons for nominating the individual to Nuala McAuley (nuala@haemophilia.ie).

Nominations should be received by Friday, September 28th.



The Sheerin family at a recent I.H.S. AGM.

A huge thank you to everyone involved in the fundraiser.

A great night was had by all who attended.

On the 24th of April, a fundraiser was organised by members of the Society Tom and Claire Sheerin and the extended Sheerin family in Cooney's Hotel in Ballymahon, Co. Longford. The Sheerin family band who were joined by a host of special guests put together an excellent night of music, fun and enjoyment. For a Tuesday night the place was bursting at the seams and everyone seemed to be really enjoying the music. It was also great to see Tom's parents join the Sheerin Family band on stage for a few songs. And what a musical family they are. The event raised over €3,000 and the proceeds were split between the Irish Haemophilia Society and Our Lady's Children's Hospital, Crumlin. Debbie Greene and myself went along on the evening to represent the Society and I have to say it was a great evening. Congratulations Tom and Claire for putting together such a wonderful and entertaining evening and I for one am looking forward hoping that I will get to the next one whenever it is.

Declan Noone

Dates for your Diary

JULY

Date: 1st July

Event: Opening date for Grants & Scholarships Applications

SEPTEMBER

Dates: 8th & 9th September

Event: HIS IHS

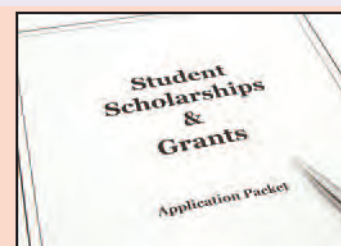
Venue: Clarion Liffey Valley



SEPTEMBER

Dates: 14th September

Event: Closing date for Grants & Scholarships Applications



OCTOBER

Dates: 12th to 14th October

Event: Members Conference

Venue: Heritage Hotel, Portlaoise

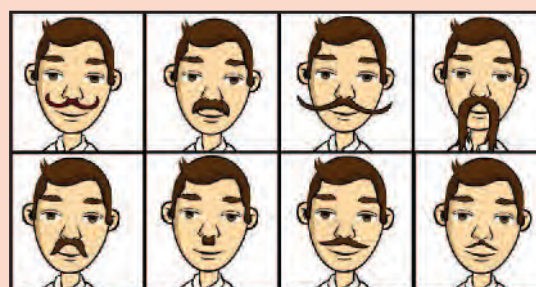


NOVEMBER

Date: 1st - 30th November

Event: Fundraiser

Venue: Everywhere

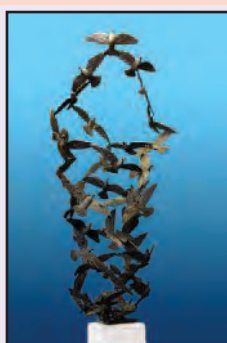


NOVEMBER

Date: 4th November

Event: Memorial Service

Venue: I.H.S. Office



Cubs Club

*Hello everyone and
welcome along to the
second edition of Cubs Club.*

Let's not waste time and get on with the learning.

Max has a
bleed in his knee.
He has taken his factor,
but now he needs to
rest, elevate his knee
and put ice on it.

Can you help Max find
his way to the couch to
rest? Don't forget to pick
up the cushion and ice
pack along the way!



Do you know what R.I.C.E. is?

R.I.C.E stands for Rest, Ice, Compression and Elevation.

Why is R.I.C.E so important?

Rest is the easy one; you just have to slow down, maybe watch a movie.

Even though it can feel really, really cold, ice really helps slow the bleeding down.

Compression means wearing a bandage wrapped around the area of the bleed, this can help stop the bleed too.

Elevation is easy too - while you are resting just keep the part of your body where you have the bleed propped up on a cushion.

These simple steps can really help slow the bleeding and help your body heal faster - so you can get back to playing with your friends as soon as you're better.



Looking after your teeth

It is important for everybody to look after your teeth for lots of different reasons...but some people may not like going to the dentist very much and other people might like to have a big, white, healthy smile!! For people with a bleeding disorder it is really important to look after your teeth because it might be more difficult if you have to get fillings or a tooth out.

THE TEETH TEST - TRUE OR FALSE

Do you think you can get all of the answers right?

When you are finished, log onto www.haemophilia.ie and see if you answered them correctly?

1. Drinking fizzy drinks is good for your teeth?
2. You do not need to brush your teeth everyday?
3. Fillings are what the dentist puts in my tooth when it has started to decay?
4. Cheese is a snack that can help keep my teeth healthy?
5. Dogs have 42 teeth?
6. We bite our food with our molars?
7. We chew our food with our incisors?
8. We should brush our teeth for 2 - 3 minutes twice a day?



Fun Dental Facts:

The toothbrush was invented over 500 years ago



An elephant gets its last set of permanent teeth at 23 years old

Elephants have only 8 working teeth because each tooth is the size of a brick



A killer whale uses sharp teeth to catch its prey but it does not chew its food - it swallows it whole

Members' Conference 2012

Preliminary Programme

Dates: 12th to 14th October

Venue: The Heritage Hotel, Portlaoise

PRELIMINARY ADULTS PROGRAMME

Friday 12th October

18.30 – 19.30 Registration

Saturday 13th October

09.30 – 10.00 Registration

10.00 – 10.30 Introduction to the Board

10.30 – 11.30 Taking responsibility for your treatment

11.30 – 12.00 Coffee Break

12.00 – 13.00 Debate / Open Forum

13.00 – 14.00 Lunch

14.00 – 17.00 Relaxation / Stress Management Mind and Body 'A Holistic Approach'

19.30 Dinner & Quiz

Sunday 14th October

10.00 – 13.00 Social Media / IT : Members Workshop

13.00 – 14.00 Lunch

CRECHE GROUP

Stories,
Movies &
Play Time.

CUBS CLUB

Movies, Art,
Drama &
Games.

KIDLINK

Games,
Team Building,
Swimming.

YOUTH GROUP

Adventure
Centre

Evaluations from the Members Conference 2011!

Excellent weekend!

Varied,
very informative.

This was our first weekend
away and we were thoroughly
impressed with the whole
programme.

Great programme,
Great weekend!

Like the fact that it
was different, but still
inclusive.

Very different -
Really interesting.

One of the best weekends ever!

Very enjoyable.

Very good theme.
About living rather than policy and treatments.

A Marathon Team Effort

The 30th Women's Mini Marathon took place this year on the 4th June. The Flora Women's Mini Marathon is the biggest all women's event of its kind in the world. Since the first race in 1983 a total of €137 million has been raised for charities all over the country, which is a great achievement.

The day itself was great fun, although it is a 10k race, the atmosphere is fantastic and you really don't feel like you have walked (me), jogged or ran that far. The many bands playing along the way help to keep everyone in high spirits. It is a great feeling to cross the finish line and receive your commemorative medal, knowing you have completed the race for yourself and helped to raise money for charity as well and for many to reflect on why they took part in the race. It is always wonderful to see the sea of different colour t-shirts with the names of so many worthy causes. The real winners at the end of the day are all the charities who benefit from this fantastic fundraiser. On that note, we would like to say a huge thank you to everyone who took part on the day to help raise funds in aid of the Irish Haemophilia Society; we really appreciate your support. Well done to Veronica Dunne, who received a donation of €50 from two generous Americans outside Buswell's Hotel.

Our first lady over the finish line was Jacqueline Reid in a time of 49 minutes, don't lose heart ladies, this is Jacqueline's 5th marathon this year.

It was great to hear our charity name being called out as we approached the finish line and to see our photo in the paper the next day.

If you think you couldn't do a 10k race, think again, this was my third year to take part in the mini marathon and trust me if I can do it anyone can. Encourage family or friends to take part with you and make a day of it. So please keep us in mind next year if you decide to participate again or for the first time.



Don't just take my word for it, some of the women who took part this year told us their favourite part about the race and the day itself.

Lynn 'this is my 8th Women's Mini Marathon, my favourite part is the bands playing along the route'

Sandra 'making it a family day, supporting each other along the way'

Amy 'crossing the finish line'

Sharon 'doing it for charity and the atmosphere with all the ladies'

Can we quote you next year?

Nina Storey



Check out more pictures from the day on www.haemophilia.ie

Grants & Scholarships



YES NO

Q.1 Are you going to college?

--	--

Q.2 Have you been accepted on a post second level educational course?

--	--

Q.3 Do you have haemophilia or a related bleeding disorder?

--	--

Q.4 Are you a family member of a person with haemophilia or related bleeding disorder?

--	--

If you answered yes to question one or two and to question three or four,

CONGRATULATIONS! You are eligible to apply for an I.H.S. Grant!

You can apply online on our website www.haemophilia.ie. You can also download the application forms from our website, complete them and post them into the office.

**Opening date for applications for Grants and Scholarships is:
1st JULY 2012**

This year as a mark of respect to our dear friend Fr. Paddy McGrath who passed away last year, the Society are delighted to announce a special award named after Fr. Paddy "The Father Paddy McGrath Award", which will be the second prize for our Educational Grant.

Educational Grant

The Jack & Maureen Downey Educational Award (€4,000) – First prize.

The Father Paddy McGrath Award (€2,000) – Second prize.

This grant is made available to a person with haemophilia or related bleeding disorder, who has been accepted on a post second level educational course.

The recipient for 2011/2012 was Patrick Browne.





Educational Scholarship

The Margaret King Educational Scholarship
(€2,000) – First prize

This grant is made available to an immediate family member of a person with haemophilia or related bleeding disorder, who has been accepted on a post second level educational course.

The recipient for 2011/2012 was Lorraine O'Connor.

**Closing date for applications for Grants and Scholarships is:
14th SEPTEMBER 2012**

When all applications are received and the closing date arrives a sub group of three board members (which can not include anyone with a family member applying for the grants) meet to consider the applications and make recommendations to the rest of the board. The successful applicants are then notified by post of their award at the end of October, and an official announcement and presentation is made to them at the following AGM.



TIPS FOR APPLYING

When applying we would encourage you to sit down and take some time to complete the application form, as the more complete and detailed your application is, the higher your chance is of success.

Some applications in the past have been poor due to some basic errors, such as:

- * Not doing a spell check
- * The Irish Haemophilia Society spelt incorrectly
- * The name of the grant/scholarship spelt incorrectly

So remember:

- * Always do a spell check
- * Answer all questions, do not leave any questions unanswered
- * Give as much information as possible attach a back up sheet if necessary
- * Make sure you apply on time

And please do fill out the application yourself!

Don't forget even if you received an award last year, you can still apply this year!

Good luck everyone!

Debbie Greene



A Wish the IHS Granted

extremely international and my classmates have varying backgrounds. LSE attracts very high profile guest speakers and there is a wealth of extra-curricular activity - both academic and non-academic. I am going to return to work in financial services this autumn upon completion of the programme.

I'd like to take the opportunity to offer a little advice for those in a similar position to myself, for what it is worth! Firstly, don't let your haemophilia prevent you from pursuing whatever it is you want to do. Whilst it may rule out certain rather dangerous activities, many many things are possible. You may need to be that bit more careful and responsible than your peers in certain situations, but see the positives in that, it is enabling you to become more responsible and acquire genuine and valuable skills. Secondly, push yourself to do your best in everything that you do. The world is a highly competitive place, never more so than now. I would strongly advise anyone who is studying to seek out extra opportunities, academic and non-academic, to push yourself and develop more knowledge and skills. If you do this then it will benefit you personally and differentiate you from many of your peers.

Given that this article has had a broad theme of appreciation, I would just like to say a quick thank you to my family. My parents have always supported me, both in my education and other activities, and have given me a tremendous platform in life. They always got involved, be it via parent associations at school or training on the sports field. They enabled me to fully participate. My grandparents are also very special to me and they kindly let me stay with them during my time at UCC. They have done a lot for me and for the haemophilia community. I'd also just like to acknowledge my paternal grandfather who recently passed away. He encouraged me to take up pitch & putt and golf which were fantastic, giving me other sports to play when I had to give up playing some others.

For those of you who were reading closely I also alluded to developments in my personal life. Last year I got married here in London to a wonderful woman, Ana Maria, who I met whilst working here during 2010.

Ana is always very supportive and didn't flinch about the haemophilia! Finally, thanks to everyone at the Society and to everyone who make the Maureen Downey Educational Grant possible. I hope I have demonstrated that the funds that are made available really do make a significant difference.

Colm O'Sullivan



My name is Colm O'Sullivan and I have haemophilia. I am currently studying for an MSc in the Philosophy of the Social Sciences at the London School of Economics and Political Science (LSE). Last year I attained a BSc Honours in Finance from University College Cork (UCC). I wrote this article to share some of my experiences throughout third level education and to thank the Society and its members for the support I have received, via the funds made available under the Maureen Downey Memorial Grant, throughout this time. This has made a real and significant difference. Having the ability to use the grants I received to offset some of the cost of studying has enabled me not to have to worry to as great an extent about financial matters and to really focus on my academic work. I primarily used the grants to help pay towards my registration and tuition fees.

To reiterate on my point in the previous paragraph, the financial assistance I had received from the Society really helped to put me in a position to go and do some extra-curricular work and this was an experience that was invaluable to me. Not only did it help me in my academic work, but it also gave me that little bit extra on my CV, which was also important.

After travelling to Italy and then Ecuador, I returned to UCC to complete my final year of my undergraduate programme. At this point I had decided that I would like to do a Masters degree at LSE. I felt I wanted to study something a little different. My time in industry showed me that you don't need to study finance to work in financial services and I had many academic questions I felt were unanswered about finance and economics. I decided to apply to study Philosophy of the Social Sciences so I could look at the structure and take a critical approach to the economics discipline. To that end I am currently taking classes such as Philosophy of Economics, Rationality & Choice, and History of Economics: From Moral Philosophy to Social Science. I am also writing a dissertation on the organisation of the economics discipline and economic methodology. I am very much enjoying this programme and find it strongly compliments my previous degree. LSE is a fantastic place to study. It is

Parents' Conference Review

The 2012 I.H.S. Parents' weekend took place in the Sheraton Hotel, Athlone on the weekend of May 11th to 13th. Myself, my husband and our three young children were in attendance. Yet again it proved to be a well-organised and extremely enjoyable weekend! A huge thank you to the Irish Haemophilia Society!

After a long journey from Belfast to Athlone (where we took the wrong decision to go via Mullingar!), we arrived at the beautiful Sheraton Hotel in Athlone. I was delighted to discover that it was part of a shopping centre complex, not that I would be able to avail of this wonderful facility given that our three kids are all under the age of five! After checking in we enjoyed some delicious bar food and retired for the night.

After leaving our kids at the Crèche and Cub groups on Saturday morning, we attended the first talk on developments in Factor VIII and IX. It seems the trials for a long acting factor IX are going extremely well and, in the not-too-distant future, this is a very real possibility for Haemophilia B patients. Fantastic news!



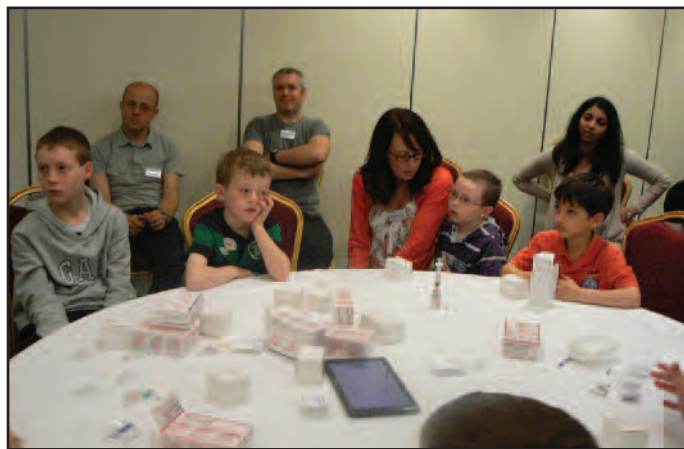
Dr. Beatrice Nolan spoke at the conference on Clinical Trials and the Effects of the Economy on Haemophilia Services.

Dr. Nolan went on to explain the technicalities of how scientists are able to attach antibodies onto the Factor VIII molecule. This is the reason why factor VIII remains in the body for longer. The clinical trials have now reached a point where they are looking for children to participate as soon as this summer! After some discussion Brian O'Mahony explained how with a longer half life, a single dose will keep you above the minimal level for longer. This may be good news for a more inactive child who does not require the "peaks" that come with regular prophylaxis. However, many parents voiced a concern that they may not be covered for a physical activity 3 or 4 days after treatment, when levels are beginning to drop.

This subject naturally led on to the dreaded conversation of how long ports could last and when should parents

start considering joining the 'vein train'.

The latest advice suggests they should remain in site for around five years. This came as a surprise but also as a motivation for Conall and I to get to grips with injecting James through veins. A workshop followed with practice 'arms' and needles. Myself and Conall took this opportunity to join the Kidlink programme upstairs, where Haemophilia Nurse Specialist, Mary Kavanagh taught the boys how to mix factor, draw it up and find veins. Timothy kindly volunteered to show the younger boys how to self infuse. I found this workshop extremely helpful and came out feeling very positive. For the first time the notion of sticking a needle in my son was not so unrealistic!



Mary Kavanagh, Haemophilia Nurse Specialist, led workshops on self induction for both adults and children.

The action packed morning was followed by yet another delicious Sheraton meal! Afterwards the subject turned to bullying which provided a forum for some interesting and shocking conversations. The main point we took out of this discussion was that, if a serious bullying incident ever occurred we should request a copy of the school's bullying policy and put our concerns in writing.

After a quick dip in the pool it was time to don our glad rags, or in Emily's case a pair of heels, a wand and a crown, and attend the Gala dinner. The highlight of the

evening had to be Silly Billy who was on the lookout for some 'Professional Bubble Catchers'! The joyous giggles of the kids could be heard in Mullingar! We enjoyed little Adam's break dancing, Harry's natural conjuring skills and Emily and Priya's magical mending! Silly Billy was also expertly helped by Jennifer and Brandon!



After a day full of activities the children were treated to a magic show on Saturday night by Silly Billy the Magician.

The next morning brought a very humbling experience when Dr. Mai outlined the situation of people with haemophilia in Vietnam. We couldn't help but feel very privileged after watching the moving slide show. Some of the images will haunt me forever. Dr. Mai is doing truly amazing work with an extremely small budget and few resources. Brian remarked on the dedication and utmost care with which the medical staff treated their patients, often visiting homes, not only for treatment, but also for diagnosis purposes. The situation is worsened in Vietnam because patients have to pay 20 percent of the cost of the treatment and 5 percent if extremely poor.

The Mother's circle was the most valuable experience of the whole weekend for me. The open forum was in no way intimidating and I felt at ease to discuss worries and concerns. The Vietnamese mum chatted about Vietnam, mainly about the stigma attached to Haemophilia there.

It was reminiscent of the 1940s, 50s and 60s in Ireland, when the condition was often not talked about and left undisclosed. It saddened me to hear of fathers leaving their families after their son was diagnosed. The prospects of getting married are not good for carrier females, not only because of the stigma attached to the condition, but also because of the cost associated with the illness. As Brian said that morning, a family he met in Vietnam were forced to sell some of their furniture because their son had a bleed.



The highlight for many who attended the Parents Conference was the Mothers and Fathers Workshops.

The weekend wound up with a scrumptious lunch. After profiting from one last plunge in the pool, we bid our farewell to Athlone and another fantastic weekend. Poor James was reluctant to go and even shed a few tears when strapping on his seatbelt. We will be back in October, Factor Turtle!

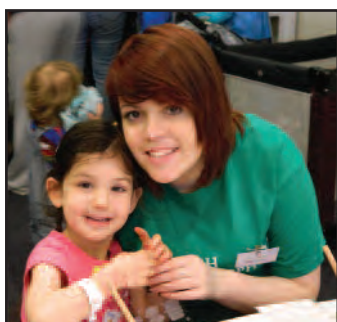
Thank you again!

Orlagh McGleenan

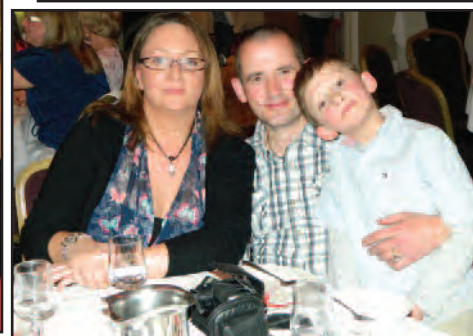
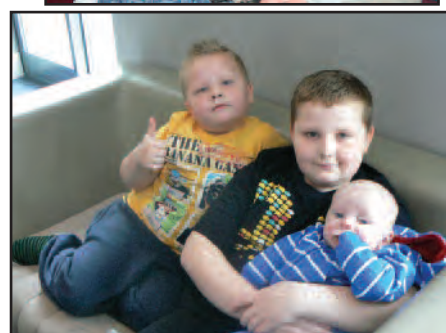


Our son James was sad to leave the conference, but he, like the rest of us, is already looking forward to the Members Conference in October.





A huge thank you to all the volunteers who helped out at the Parents Conference.



The Parents Conference was jam packed with workshops, presentations, technology, magic and fun.

From these photos it looks like everyone had a great weekend.

In the Spotlight - Self Infusion

Self Infusion is an important part of a person with haemophilia's life. Self infusion is when a person with haemophilia gives treatment (factor) to themselves, through a FREDDIE (port-a-cath) or more commonly a vein.

Before starting self infusion, a child with haemophilia is entirely dependant on some one else to get their factor. They are either unable to go on school trips or outings or one of their parents may need to go with them on every trip. This can lead to a lack of self confidence or even frustration as they just want to be like their friends. When a child starts to self infuse it is the next stage in them taking control of their haemophilia. They can now take care of themselves and that creates a feeling of independence and confidence. Self infusing for the first time, can bring fear which is quickly overwhelmed by pride and happiness. Starting self-infusion can be daunting for parents and children, especially when things are going well as they are.

In case you think your child is too young, the average age when children start to self-infuse is 7-9 years old, but there have been cases of younger children than this self infusing.

The best advice in relation self infusing is do it as soon possible, when the child is ready.

If your child is not ready to self infuse, try getting them to help you with the process - let them mix the factor etc. This will help them feel more comfortable when the time comes for them to self infuse.



Here, eight year old Adam Cox talks to Haemophilia.ie about his experience with self infusion.

My name is Adam Cox, I am 8 years old and I have severe Factor VIII haemophilia.

Last year my mam learned how to give me my factor in my veins. I had a port put in when I was 2 but because I was older and have very good veins it was time to take it out. In January this year my "freddy" was taken out. I was in hospital for a week. Now we use only the veins in my arms and hands.

Sometimes it's hard and can be sore, but my mam is getting better all the time and I'm helping her.

When we find a good vein my mam puts in the needle and I give myself the factor and take the needle out! One day I will do it all by my self but for now I'll just be a good helper to my mam!!

Adam



At the 2012 Parents Conference, IHS Staff Member Nuala Mc Auley spoke to Mary Kavanagh and Eibhlinn McLoughlin, Haemophilia Nurse Specialists from Our Lady's Childrens Hospital, Crumlin on Self Infusion.



This is the third year the self infusion workshop has taken place at the Parents Conference for the children. Why is this workshop so important?

MK: Self infusion is the next step in children becoming independent in giving their own factor. The earlier we start it and the more we get kids on board the easier it is to actually train them to do it themselves.

This year saw a self infusion workshop for the parents also, why is it important for the parents to learn about self infusion?

EML: It is very important to encourage the parents to change over to peripheral access as soon as possible. The shift very much has been to try and make them start as early as possible to use the veins as this is the first step in getting the children on board to self infuse. You have to get the parents on board before you can get the children on board.



What, in your experience, are the biggest challenges / barriers in self infusion?

MK: If parents are nervous children are nervous, it is actually easier to work with nervous children than with nervous parents. So firstly we need to get parents on board we need to get them over their own anxieties before we even start to train the kids.

What are the benefits of self infusion?

EML: It is much easier and quicker. It makes the child much more independent. It eliminates all the complications that goes along with a port – no risk of infection, no risk of blockages and no risk of breakage. It is much more portable, less equipment needed for peripheral access than port access. Once your port stops working you are already trained and you are good to go.

Mary, in your session with the Parents you spoke about the Vein Train – how is it going?

MK: The vein train is a training programme we run in OLCHC to help kids and parents become comfortable and confident in using veins for infusion. It is going great we have loads of tickets now, the carriages are all empty.

We have trained a lot of kids and parents, but there is always the option for people to come back. Last summer it was really busy as it was the first year of the vein train so there was loads of people coming at the same time. This year, it is not as busy so there are lots of places if people want to come along just give the haemophilia team in Crumlin a shout and they can set up an appointment to look at your child's veins. If the veins aren't suitable for peripheral access we will send you away until next year, if they are good for peripheral access we will start training you and have you up and running as quickly as we can.

Don't forget to contact the I.H.S. when your child self infuses for the first time and we will reward them with a certificate and gift voucher.

For more information on self infusion please speak to a member of the Haemophilia Team.



IRISH HAEMOPHILIA SOCIETY

First Floor
Cathedral Court
New Street
Dublin 8

Tel: 01 6579900

Fax: 01 6579901

Email: info@haemophilia.ie

Website: www.haemophilia.ie