

haemophilia.ie

Magazine of the Irish Haemophilia Society



We wish you a Merry Christmas and a Happy New Year!



From everyone at the Irish Haemophilia Society

Edition: December 2011

Office and Centres Christmas Opening Hours

The Irish Haemophilia Society



We would like to inform you that the offices of the Irish Haemophilia Society will close for Christmas on Friday 23rd December and will re-open on Tuesday 3rd January.

In case of an emergency, please contact Anne Duffy on 087 2320255.

A special thank you goes to everyone who volunteered at various events and activities during 2011. We very much appreciate all of your hard work.

A big thank you also goes to all those who helped the Society by fundraising during the year and we cannot forget those who sent in donations. We value your support.

Wishing you all a very Merry Christmas and a Peaceful New Year.

From the board and the staff of the Irish Haemophilia Society.

NCHCD



December 2011

Friday 23rd	08.30 - 16.00
Saturday 24th	Closed
Sunday 25th	Closed
Monday 26th	Closed Bank Holiday
Tuesday 27th	Closed Bank Holiday
Wednesday 28th	08.30 - 17.00
Thursday 29th	08.30 - 17.00
Friday 30th	08.30 - 17.00
Saturday 31st	Closed

January 2012

Sunday 1st	Closed
Monday 2nd	Closed Bank Holiday
Tuesday 3rd	08.30 - 17.00

When the NCHCD is closed, patients with a bleeding disorder, who have a bleed, should present themselves to Walter Stevenson Ward as per the evenings and weekends process.

Cork University Hospital



December 2011

Friday 23rd	08.30 - 13.00
Saturday 24th	Closed
Sunday 25th	Closed
Monday 26th	Closed Bank Holiday
Tuesday 27th	Closed Bank Holiday
Wednesday 28th	09.00 - 13.00
Thursday 29th	09.00 - 13.00
Friday 30th	09.00 - 13.00
Saturday 31st	Closed

January 2012

Sunday 1st	Closed
Monday 2nd	08.30 - 17.00

When the centre is closed, please contact CUH on 021-4546400 and ask for the Haematology Registrar on call.

Our Lady's Children's Hospital Crumlin



December 2011

Friday 23rd	08.30 - 17.00
Saturday 24th	Closed
Sunday 25th	Closed
Monday 26th	Closed Bank Holiday
Tuesday 27th	Closed Bank Holiday
Wednesday 28th	08.00 - 16.00
Thursday 29th	08.00 - 16.00
Friday 30th	08.00 - 16.00
Saturday 31st	Closed

January 2012

Sunday 1st	Closed
Monday 2nd	Closed Bank Holiday
Tuesday 3rd	08.30 - 15.00

A registrar haematologist will be on call at all times and will be available for any emergencies throughout the holidays.

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A Note from the Editor

Hello everyone,

Welcome to the December edition of haemophilia.ie. I hope you are all getting organised for the Christmas festivities. We have lots of interesting articles and information in this magazine and I hope you enjoy reading this issue.



Debbie Greene,
Administrator

Read all about the Members' Conference on pages 7, 8 and 9, and what a weekend it was. The evaluations that came back from members were terrific. We were delighted to hear that you all enjoyed the weekend and found it beneficial. It was the biggest ever attendance at a members' Conference. We had 85 adults and 52 children, along with staff, volunteers and speakers. Our next big conference is our AGM which takes place the first weekend in March 2012 in the Lyrath Estate in Kilkenny. Packs will be going out to members in early January.

Brian O'Mahony updates us on various issues in his CEO report on pages 4 and 5. On pages 12 and 13 you will find a moving and remarkable article written by a member who has travelled to Thailand for the past couple of years to volunteer in a school for young children.

Also in this issue you will find reports from the European Haemophilia Consortium Conference, the UK AGM, the Memorial Service and a fundraiser that took place in Cork recently. On page 16 you will find details of the recipients of the Grants and Scholarships. On page 17 you will find some information about the World Federation of Hemophilia Congress that takes place in Paris in July next year.

Don't forget to keep yourself updated with all our events on pages 18 and 19 where you will find "Calendar of Events" which includes the preliminary programme for the AGM 2012.

Finally, I would like to wish you all a very Happy Christmas and a prosperous New Year. Looking forward to seeing you all at the AGM in March.

Debbie Greene
Administrator

CEO's Report

During the course of 2011, we organised specific meetings for women with bleeding disorders and a conference for men with haemophilia aged 18 to 35. One day meetings for women with bleeding disorders took place in Dublin and Cork and were very much appreciated by those in attendance. In addition, prior to the meetings, we circulated our Women and Bleeding Disorders publication to every obstetrician and maternity unit in the country. However, the numbers who attended these meetings do not warrant repeating these meetings in 2012. Instead, we will integrate sessions for women with bleeding disorders into the programme for the main conferences.



Brian O'Mahony
Chief Executive

The conference for young men with haemophilia was a success. A total of twelve young men attended and fully engaged with the programme. Since the conference, 9 of the 12 have been in contact with the IHS staff, they are engaging more with the organisation and 4 have now become active volunteers. We will repeat this conference in 2012 in order to consolidate the sense of community among this group, increase their proactive engagement with their bleeding disorder and bring in other young adults and their partners.

Despite the economic situation, attendance at IHS conferences is increasing. Clearly, people are benefiting from the conferences. The attendance at our conferences is the highest of any of the developed countries when you look at the percentage of the members who attend. Typically, attendance between the 3 major conferences will be 360 which cumulatively represent 40% - 50% of the members on the mailing list. We are helped by geography and the relatively small size of the country, but also by the very strong sense of community we have worked so assiduously to foster. Our members vote with their feet. They are attending the conferences more regularly and in larger numbers because they are clearly benefiting from them. In contrast, despite the clear benefit of some of the specific meetings (such as those for women with bleeding disorders) for those who attend, these meetings attract a smaller group and would benefit from being integrated into the main programme at conferences. We have therefore decided not to organise specific conferences in the next 3 years for women with bleeding disorders, those with mild haemophilia or those with von Willebrands, but to integrate sessions on these topics into the main conferences. Our strategy of producing specific publications

on each of these topics in the course of the current strategic plan will continue. We will also organise a specific session for members and parents of children with inhibitors. This is a small but underserved group. In 2011, we sponsored the attendance of some members with inhibitors to attend a specific conference in the UK where the number of patients with inhibitors is sufficient to justify a conference. In the future, we can integrate lectures on this topic into the main conference programme.

Our conferences are working to full capacity. Due to the increasing number of children, of all ages, attending our conferences we have decided to add an additional children's group to our existing programmes. The ages and groups are as follows:

Creche; 0 – 3 years,	Cubs: 4 – 8 years
Kidlink: 9 – 12 years,	Youth: 13 – 17 years

This extra group and slight variations in ages of each group will allow for higher attendance and a more age appropriate and structured programme to cater to the needs of the children in each group. We are fortunate that we have volunteer driven programmes. Currently we have a group of 30 talented and dedicated volunteers, but with three weekend conferences a year, we are asking a lot from our volunteers. With this in mind, we have begun an ambitious volunteer recruitment programme which aims to recruit up to an additional 40 volunteers by the end of 2012. Volunteers will go through a selection process and interview. If accepted, they will be given induction training, training in our Child Protection Policy and will be Garda vetted. This will be co-ordinated by 2 of the staff. If you would like to volunteer or for more information contact Nuala in the office on 01 657 9900 or nuala@haemophilia.ie and she will be happy to help.



Data Collection

Haemophilia treatment works and can transform the quality of life of the child or adult with haemophilia or bleeding disorder. However, it is not enough to say that treatment works, it is increasingly necessary to prove this and to demonstrate the efficacy and benefit of treatment. In the current and probable future economic environment we face, it is important to be able to clearly demonstrate the

benefits of optimal treatment and care. The treatment centres should be collecting evidence based data on the outcomes of treatment. This involves, in the first instance, accurate and complete reports of home use of factor concentrate. It is vital that each person with haemophilia who is on a home treatment regime keep accurate and timely records of their factor concentrate utilisation and send this to the treatment centre as required. This is being and will increasingly be greatly facilitated by the handheld smart phones which are now used to scan the home treatment used and send the information back to the centres immediately. This facilitates better clinical management of haemophilia, allows for alerts in the case of any problem with the product and helps the centres to compile the evidence based data needed to demonstrate the effectiveness of treatment. The hand held phones are still in the process of being rolled out to all on home treatment, but when this is complete it will provide an excellent and comprehensive vehicle for demonstrating the effectiveness of treatment.

The centres should also, ideally, be collecting data on days missed from school, college or work in addition to the number of bleeding episodes and asking people with haemophilia to complete simple quality of life questionnaires (the simplest of which consists of only five questions and can be filled out in two minutes). This will allow the provision of optimal treatment to be linked to improvements in quality of life and ability to attend school, college, work and fully integrate into society.

The Society are also increasingly asking members to complete surveys or questionnaires. These fall broadly into two categories. The first are the evaluation forms we ask each attendee at our conferences to complete, these allow us to receive invaluable feedback on the conference programmes, organisation and venues and allow us to plan future conferences with programmes that meet your real needs. The second surveys are data collection to allow us to analyse the benefits of treatment and care and give us the ammunition we need to advocate on your behalf. For example, we are currently carrying out a survey of men with haemophilia between the age of 20 and 35 to ascertain their quality of life including their recent history of bleeding episodes, days missed from college or work and measurable quality of life parameters. We are also carrying this survey out in nine other countries with the active co-operation of their national haemophilia societies. This survey and the results when analysed should provide compelling evidence to demonstrate the benefits of optimal treatment and care and we hope to have this published in a peer reviewed journal. This type of data collection is extremely useful to us when advocating on your behalf with the Government and

the HSE on continued provision of optimal treatment for haemophilia.



Twinning with Vietnam

Our twinning programme with the Vietnamese haemophilia community continues to be active and productive. In September of this year, I visited Hanoi to lead and facilitate a number of workshops for the haemophilia patient organisation and volunteers. This included workshops on organisation and governance for their board and executive, workshops for volunteers to encourage them to become more involved and workshops on advocacy and action planning for the board and key medical, lay staff and volunteers. The workshops were attended by some 50 volunteers and board members and resulted in some real and concrete steps being undertaken. A rota of volunteers was established at the National Institute for Haematology and Blood Transfusion (which is the main treatment centre and also the headquarters of the Haemophilia Society). Each volunteer committed to giving one full day each month to the centre to assist those with haemophilia who attend or are in patients, introduce them to each other and build a sense of community. On any given day, between 30 and 50 people with haemophilia are either in-patients or visit the centre for treatment. Both adults and children are treated there by the excellent and caring team. There is a library and a room with a computer where some of the people with haemophilia congregate. The role of the volunteers will be to give them practical assistance, to introduce parents, children and adults to each other and to facilitate the type of community building which was such a strong feature of the development of care in Ireland in the 1970's when a national system of care started. This sense of community has remained, has sustained us and helped us to deal with the difficult times and celebrate the good times. I hope that a similar sense of community will now be built in Vietnam who are really just starting out on this journey to better care. A number of peer groups for young men, older men, mothers and children were also organised. This work will continue in 2012.

**Brian O'Mahony,
Chief Executive**

IHS at EHC



European Haemophilia Consortium Conference Budapest 7th to 9th October 2011

The venue could not have been more lovely, the Marriott Hotel, overlooking the Danube in Budapest. What a great conference, with plenty of excellent presentations. The 24th Annual European Haemophilia Consortium Conference welcomed nearly 300 delegates from all over Europe. Ger O'Reilly and myself represented the Society at the conference.

We arrived on the Friday afternoon and we were immediately impressed with the first lecture "Improving haemophilia care in Europe". It was also very interesting to hear about the "Economics of haemophilia care". Daniel Arnberg from Sweden and Keith Tolley from the UK gave great presentations that would make you think about cost versus health benefits. I was also surprised to hear that Sweden do not have a national registry. On Saturday the session on "Inhibitors" that Brian O'Mahony chaired was excellent. Brian also gave an overview of national tenders with examples of how other National Member Organisations (NMO's) tender, and pointed out that tenders are cost effective. Yuri Zhuylov spoke about the improving factor supply in Russia and mentioned that even though factor supply has improved a lot, some areas still have a very low per capita use because people do not want to change or go to a haemophilia centre for treatment. There was also a very good debate about prophylaxis that was both interesting and entertaining, which was chaired by Dr. Paul Giangrande from Oxford in the UK.

The attendance at the various lectures and presentations was huge, and of course over the years getting to know delegates it was lovely to meet up with people we had met at the last WFH Congress. The business meeting took place on Sunday morning and I was impressed that a lot of the Steering Committee gave presentations. During the business meeting Brian O'Mahony was elected President of the Consortium for the next 4 years. We wish Brian all the best in his new role. I know Brian has already been looking at a strategic plan for the EHC along with scheduling events for the coming years.

Thanks to the Hungarian NMO for all their efforts in organising a great conference. The next conference takes place in Prague from 26th to 28th October 2012.

Debbie Greene
Administrator



Left to right:
IHS CEO, Brian O'Mahony was elected EHC President at the Conference.
Ger O'Reilly and I at the exhibition area of the conference.
Mark Skinner, President of the World Federation of Hemophilia spoke at the conference.

My Members' Conference

Our trip to Galway was our third weekend we enjoyed with the Society. So not to break away from tradition we got lost yet again so five hours after leaving Derry we finally arrived at the hotel.

We were greeted with friendly faces and the tiredness quickly turned to excitement as we looked forward to the weekend ahead. I was pleased to learn that Orlaith, my friend I met at the clinic in Belfast was attending her first weekend. I just knew she would get as much as I do from the weekend. The topics covered were a main factor for us coming as I felt each would be beneficial for my husband Brian and myself.



The kidlink programme is always thoroughly enjoyed by Caolán and Demi-Leigh. They are fully entertained as long as swimming is on the cards they are more than happy.

On the Saturday the talks ranged from fitness and health to dealing with and recognising depression and helping to cope with it. We attended all of the talks as we feel there is always something beneficial may it even be something small.



The first talk was given by Dr. Joe Clarke and he told us that we should not let a bit of rain stop us from walking or running. My husband has been over using the phrase "what's a bit of rain" anytime I try and have a lazy day.

Personally I thoroughly enjoyed Jean O'Leary's talk, she truly inspired me on how she has overcome her experiences with depression and has learned to cope with the help of

the group "Aware". It was refreshing to hear Jean speak so openly about depression as it can be a subject with a lot of stigma attached.

As a carrier of haemophilia with a son and father who have severe haemophilia A, watching how they suffer daily I think it can be challenging. Patricia Byrne, Psychologist from NCHCD, showed me that it can be both normal and acceptable to have periods of feeling low and there's plenty of help available.

It was good to hear Patricia talk of how haemophilia can impact on the lives of people with haemophilia and their families. On a personal level Caolán would often question his haemophilia and wonder why he has it and not his friends?

We always speak openly with Caolán about his haemophilia, reassure him it will not affect him in the way it has his granddad and he will always be aware of the support available. Haemophilia will always be a part of his life but will never take over. We feel the Irish Haemophilia Society has helped us deal with this topic immensely, not just for Caolán but for all of us.

Speaking with Caolán about it helps him deal with the fact he is not the only person who has haemophilia. It is great for Caolán to see other children with haemophilia at the weekends-enjoying activities, games and programmes the same as other children. It is comforting for us to speak with and relate to parents and for Demi-Leigh to speak to siblings who understand how we feel. The positivity and sense of encouragement we receive is over-whelming.



The Saturday afternoon ended with a fitness session which was great fun, if my memory serves me correctly the women beat the men in the Wii boxing challenge!

This helped me realise you don't have to join an expensive gym or leave the house to get fit or enjoy fitness. We can incorporate fitness into a family activity where we all can have fun and exercise at the same time. I can do it in the comfort of my own house if Caolán isn't well and I need to stay at home with him.

While waiting for dinner Brian and Caolán went swimming and Demi-Leigh and I used this opportunity to rest. I met a man Paddy, within minutes of talking with him I found out he knew my uncle Denis. Denis also had severe haemophilia and never let it hinder him, he was my daddy's older brother and in the words of my daddy his "Mentor". Denis was a member of the society many years ago but he sadly passed away. It was nice for me to meet Paddy and talk about him and sharing memories, as Denis lived in Limerick and I didn't get the chance to see him as regularly. Paddy is a great character and he makes the society the success it is, the society unites all different wonderful people together.

We loved the evening meal and getting the chance to talk with everyone in a relaxing and friendly environment.

After an enjoyable meal Brian and I sat and watched all the young boys and girls playing and carrying on, laughing and smiling without a care in the world. It made us so happy and content watching the children. Caolán and Demi-Leigh were tired so we didn't get to play family fortunes but we all had an enjoyable day anyways.



Fortunately I had a fresh head on Sunday morning and attended the first talk which was given by John Stack. I had debated with myself about going to this talk as I believed I knew all there was to know about what I should and shouldn't be eating but boy was I wrong! John held my attention the whole time, I found the talk very beneficial and was amazed to hear all the information about nutrition and the right foods to eat. I think John can relate to each of us as a parent himself and it is so important for us to make wise food choices as it filters through to our children. My Daddy has always stressed the importance of keeping

Caolán healthy and slim so he doesn't put too much pressure on his joints. John is a Personal Trainer as well as a Food Nutritionist; he spoke of finding a healthy balance between exercise and a healthy diet.

I found his segment on strength training extremely interesting. I left the talk feeling quiet confident that there would be a new Sinéad in terms of eating patterns, but unfortunately the motivation has slightly wavered if only we could have bottled what John has!



The formal part of the weekend ended with a cooking demonstration. I watched in amazement, the chef made it look so simple and it tasted really good. I took down the ingredients; needless to say they are still pinned to the fridge. The weekend ended with a beautiful lunch, I love these times getting to chat with other parents, swap stories and just have a good laugh. We had the chance to chat with Jordan about his trip away, it was great to see the boys just living ordinary lives and not letting their Haemophilia get in the way!

It's always hard to believe when the time comes to go home, it goes by so quickly yet we learn and do so much. Fortunately Edward gave us directions for a quicker and more straight forward journey home and off we went with full belly's and a great feeling of optimism.

Each of the weekends has made us that little bit more confident in our future ahead. We are still cautious and never under estimate the seriousness of Haemophilia we have learned to relax a little and for this we are eternally grateful. We are already looking forward to March, it just can't come quick enough!

Go raibh mile maith agaibh

Le Meas,

Sinead Moore

52 is the Magic Number!

With 52 children booked in to attend the weekend, we knew it was going to be a lot of work, but luckily, as always the weekend turned out to be a great success!

On Friday night our Youth Group members and their volunteers packed onto the bus bound for a weekend of adventure and fun in Lilliput Activity Centre, Co. Westmeath. As I waved them off, I must admit I was a little bit envious of their trip, but back in the hotel we had a jam-packed weekend of activities ourselves.

The crèche group started bright and early on Saturday morning; there were a lot of very excited faces coming through the door. With 23 children and 9 volunteer leaders for the weekend the room was a hive of activity. Arts & Crafts had a Halloween theme – lots of pumpkins and spiders and masks were hung up around the room. The older kids in the crèche (4-6 year olds) had educational sessions with a puppet show and pictures to colour in, all relating to haemophilia. It was great to see their eager faces excited about the different sessions throughout the weekend. As is always the case with the crèche the kids and volunteers for that matter enjoyed movie time, story time and the occasional nap during the weekend!



The Kidlink group also had a Halloween themed arts & crafts session and I was amazed by some of the masks the kids and volunteers created – we have a lot of artistic children in our midst – it also gave them the chance to jump out at me every time I walked into the room, I need to remember that for next time!! On Saturday afternoon the Kidlink group went bowling and by all accounts the kids played better than the volunteers. With swimming and an education session the Kidlink group were kept very busy and all the children enjoyed themselves.



On Sunday morning the youth group returned full of energy (the same could not be said for some of the volunteers). IHS staff member Declan Noone was a leader with the youth group and here tells us exactly what they got up to:

“We arrived at Lilliput Adventure Centre at 10pm and we were straight into activities. First up was a night walk in the woods which was just the start of a wet and mucky, yet very enjoyable weekend. On Saturday morning, we started off gently with some orienteering and capture the flag in the woods - it was a lot of fun sprinting through the woods, ducking under branches, jumping over drains and applying very clever tactics by both teams. After a break, the group did some archery and some zip line followed by a warm lunch which was badly needed at that stage. Then the afternoon came with an obstacle course through some muddy pits and the piste de resistance bog hopping which the group got wet, mucky and frozen. All those sounds bad, it looked bad but I don't think I have ever seen a group enjoy something more. Smiles all round. To clean off we all headed to the lake for some canoeing before a hot shower and dinner. It didn't stop there either, that night there was a manhunt in the woods which was again a lot of fun. On Sunday morning, we all got up (verry slowly) and went back to the hotel, for some games and a quick talk from Fiona on haemophilia. Excellent weekend!”

I would like to thank all of our volunteers from all the children's groups for helping with another fantastic weekend; we could not have the weekends without you all!

Looking forward to seeing you all in March!

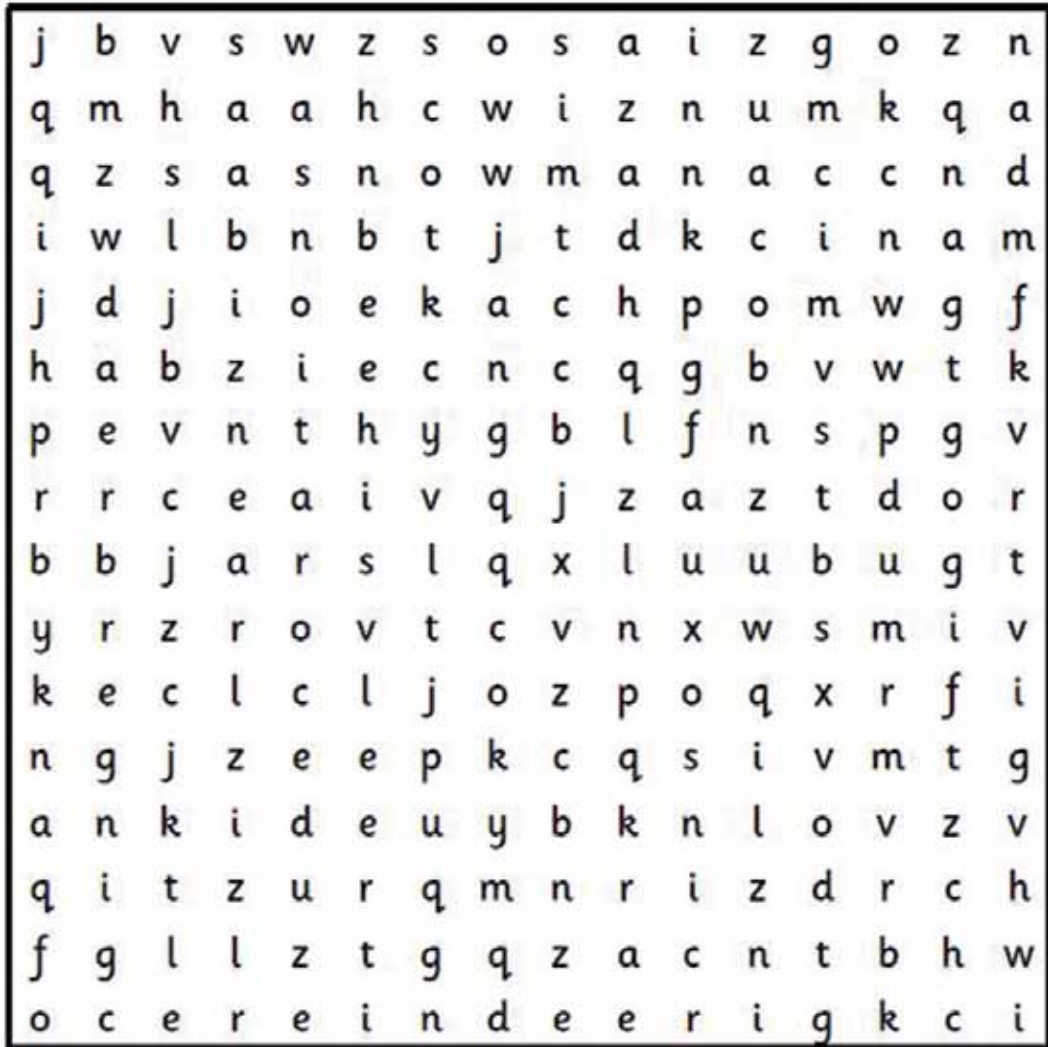
Fiona Brennan,
Childrens' Programme Co-ordinator



Kidlink Club

On the right are nine pictures, identify the pictures and then find the words in the wordsearch!

GOOD LUCK!



What goes
ho-ho whoosh,
ho-ho whoosh?

*Santa caught in a
revolving door!*

What do you
sing at a
snowman's birthday
party?

*Freeze a jolly
good fellow!*

What goes
"oh, oh, oh"?

*Santa walking
backwards!*

What goes:
now you see me,
now you don't,
now you see me,
now you don't?

*A snowman on a
zebra crossing!*

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Youth Group

M E R R Y C H R I S T M A S

How many words can you make out of “Merry Christmas”?

Give yourself a point for each letter in a word you make, e.g. cat would give you three points!

When you have finished, give the words to someone else to try and compare scores. Just remember to give everyone the same amount of time.

FIND THE SEVEN DIFFERENCES IN THE PICTURES BELOW.



What do you call an old snowman?

Water!

ANSWERS:
Wordsearch: The words you had to find were: (1) Cake, (2) Stocking, (3) Gift, (4) Decoration, (5) Gingerbread, (6) Santa Claus, (7) Reindeer, (8) Tree, (9) Snowman
Spot the Difference: (1) There is a light missing behind the tree on the left side. (2) The ball on the top branch is a different colour. (3) There is no nail on the top right hand side of the window. (4) The tree in the bottom right hand of the window is missing. (5) The hat on the doll on the left side is different. (6) The bow is missing on the red present. (7) The hat on the Santa doll is bent.

Volunteering Abroad

IHS Board member Brian O’Riordan made his second trip of the year to Sarnelli Orphanage in North Eastern Thailand this October. Here, he describes his experiences there.

Father Michael Shea, a Redemptorist priest and native of Wisconsin (and from good Kerry stock!), moved to the north east of Thailand to work with the underprivileged and neglected living in the area. He and his colleagues tended to the needs of the elderly, the sick and orphans, Buddhist as well as Catholic. Over the decades, Fr. Shea began to realise that the problem of AIDS was beginning to take a horrendous toll on the local population. A greater number of people were becoming infected, and so more and more families, particularly women and children, found themselves banished by their fearful and ill-educated villages. As the 90s wore on, Fr. Shea came across an increasing population of abandoned, and often infected, children. And so he established Sarnelli House, an orphanage for HIV infected and orphaned kids in the Nongkhai province.



Here I am with Tokyo, Nook and Bang Lek from the Orphanage

Over the years, children have come into his care from elderly, weak or impoverished grandparents, the social or prison service, other care homes and often villagers worried about the health of the child. Young girls have been rescued from prostitution or abuse, children have been found dying on the side of the road and one was discovered having been thrown into a rubbish dump. Today, there are over 150 kids thriving in six different houses, ranging from a three month old baby to young adults. The little ones play, run amok and cause mayhem, while the older ones go to school and learn trades. Over half of the residents are HIV positive but thanks to the advent of and access to anti-retroviral therapy, most are doing very well and fortunately none of the little ones are infected. The charity also operates an outreach programme, tending to local children who are still with their families.

I first heard about Sarnelli House from a friend while living in London and about three years ago, began to sponsor one of the girls housed there. I pay US\$20 a month and this goes towards her education, housing, food and any medication she may need. Her name is Fa and she and I began to write to one another almost immediately. I might occasionally send t shirts and a couple of pounds (or a Lady Gaga CD!) for her birthday or Christmas. Fa, in turn, replies with drawings and lovely letters of thanks. This year, I decided to pay a visit during their school holidays and at the end of March, took my first steps into a life changing environment. I was initially wary about how to behave around so many children. But my fears were unfounded. I was welcomed with open arms by the staff and the kids, all of whom completely stole my heart.



From left to right:
Mooksie, Wow, Bang, Bowling,
Nook and Joi Joi.

www.haemophilia.ie

The minute I walked into the compound, I was surrounded by curious Boy Lek, Auhn, Kedt and Puerk. They jumped into my arms and babbled, pointing at and leading me to the swings, where they exhorted me to push them higher. Each day, before I knew it, my hands were full of happy, affectionate kids. Children I had never met calmly took my hand

and stood with me, led me to play or dragged me off on an adventure or to do some colouring. We ran, we swam, I taught them English, they squealed with laughter at my pitiful Thai, we cycled, we coloured, we laughed, danced, sang, shopped and hugged. The visit flew by and it ended far too quickly. I got to finally meet Fa, who turned out to be a shy and sweet teenage girl. She had never met a foreigner before and with her lack of English and my non-existent Thai, we stood there awkwardly staring at the floor. I don't know which of us was more relieved when a translator came along to help us out. It was lovely to get to know her over my two visits. I also developed a very close friendship with little Tokyo, whose fierce intelligence and stubborn resilience impressed me greatly. She was quite poorly during my first trip and I spent a fair bit of time comforting her, as my mother did for me when I was a child. We struck up a fairly special bond, and now I sponsor her as well. Seeing her so healthy, strong and sassy six months' later was one of the highlights of my whole year. She is learning English so she can write to me and wants to be a doctor. Friends and family members support four other children, so now up to seven kids are walking around wearing Cork and Ireland t-shirts. So happy and healthy are the majority of the children that it is easy to forget how lucky they are to have found Sarnelli and how it has changed their lives. There is an infectious energy, boundless laughter and childish wonder in their lives and I savoured every single minute.

Sarnelli House employs over fifty local men and women, who work as house mums, cooks, nurses, gardeners and drivers. And the enterprise is expanding every year. This year, they hope to buy more land in order to grow their own rice, keep more animals and build a multi purpose hall. The head nurse is Kate Introna, a native of Australia who has been there for almost a decade now. Along with Fr Shea, Kate holds the show together and represents all that is good about Sarnelli House. They are truly remarkable people. The kids are the true heroes though. Many of them have been through more than most of us would dread to imagine and yet they live each day with a vigour and enthusiasm that we could all do well to learn from. I can't wait to see them again.

For more information, visit www.sarnelliorphanage.org



Clockwise from above center:
 * Bas and Peter.
 * Dtoey and Dtay.
 * Kedt, Purek and Ahtit.
 * Ice, Bowling, Nook and Bang Lek..
 * Nin Nate and Hippo.



UK AGM

Along with Pat Downey and Brian Byrne, I had the pleasure of attending the UK Haemophilia Society AGM & Conference which took place in Glasgow on the 5th & 6th November 2011. The I.H.S had a stand at the conference which was a great opportunity for us to display our recent publications and also gave us a chance to talk with other delegates attending the conference. At the conference Liz Rizzuto stepped down as Chairperson of the UK Haemophilia Society and the new Chairperson is Bernard Manson, I would like to wish them both well.



Board Members Pat Downey and Brian Byrne also attended the AGM.

The Conference covered a variety of topics from the services and information offered by the UK Society, to sessions such as 'Fit for Future Treatment & Care' with Debra Pollard from the Royal Free Hospital and Kate Khair from Great Ormond Street Hospital for Children. Other sessions included Physiotherapy, Advocacy, Benefits for Children and Adults and Relaxation Techniques.



Debra Pollard and Kate Kahir spoke on the issue "Fit for Future Treatment & Care"

Along with the presentations there was a workshop on 'issues for parents and young adults' and two 'personal stories'. The parents and young adults attending the workshop kindly allowed me to sit in on this session and it was very interesting to hear not only the various issues but how they can be overcome, it was a very positive atmosphere.

www.haemophilia.ie

The personal stories were from two mothers of young sons with severe haemophilia with inhibitors. The first mum, Maggie was born in the Democratic Republic of Congo, although her son Benny aged 11 yrs was born in London. Maggie described the difficult life her grandmother and mother had raising children with haemophilia in a rural village. Maggie has since approached the UK Haemophilia Society and with their help is currently setting up an Africans Mothers Support Group to help raise awareness of haemophilia in Africa. Maggie said **'We are blessed to be in the UK, where Benny can get the best treatment'**. The second mum, Assana was born in Cameroon and her son Fidel, aged 3 yrs was born in Italy. Fidel was 7 months old when he was diagnosed with haemophilia; Assana had no history of a bleeding disorder in her family. Although Fidel was born in a 'wealthy' city in Italy there was no haemophilia centre and Assana described the feeling of fear and isolation when she was handed a 'big, scary book' to read. She also spoke about the importance of financial help, which was very little in Italy compared to the UK. Assana had to pay for items such as painkillers and icepacks, which are free in the UK. Assana said **'Parents in the UK should know how lucky they are even compared to other European countries'**.

Haemophilia Scotland has recently formed a management committee and is looking forward to providing ongoing services and support to its members in Scotland, especially to those living in isolated areas and on the islands. This is a difficult time for their members as the Penrose Inquiry (Scottish Public Inquiry into Hepatitis C/HIV acquired infection from NHS treatment in Scotland from contaminated blood products) is ongoing.

I would like to take this opportunity to thank Chris James, CEO and all the staff in the UK Society for their warm welcome to myself, Pat and Brian.

Nina Storey
Administrative Assistant



Board Member Pat Downey and I with UK Haemophilia Society Chief Executive, Chris James.

Fundraising

My class, 3E in Christ King Girls' Secondary School, Cork, decided to do our CSPE Action Project for our Junior Cert on The Irish Haemophilia Society.

Last year, our CSPE teacher told us that we needed to do a project on a charity, which would be worth 40% of our Junior Cert exam. Everyone in the class put forward different charities and I suggested the IHS. I explained briefly to the class what the Society was and how it helped people and families around Ireland with haemophilia. After a few debates and a vote, the class chose the IHS as its charity.

The class was split into different groups to organise fundraising for the society, and getting a member of the society to visit our school to teach us more about haemophilia. The fundraising group came up with the idea of holding a cake sale and a raffle. We sold the cakes along with the raffle tickets one lunch-time in school, and we had the raffle a few days later. The whole event was a success and we raised money to present to the society.

When we went back to school this year, we had finished our fundraising, so we contacted the IHS office and organised a visit to our class by Declan Noone. On October 21st, Declan came to our school during a CSPE class. He showed us a presentation on haemophilia, how it is passed through families and how it can affect the everyday lives of people with haemophilia. He explained the work of the society, from the different publications released for patients to the AGM and Member's Weekends. The girls in my class were surprised to find out that one day they might have a son or a family member with haemophilia.

We all found Declan's presentation very informative and really enjoyed it. The class are now writing up information booklets on what we did and what we learned from our Action Project. I would like to thank everyone in the IHS office, in particular Declan, for helping us with our project and teaching us about haemophilia. I think a project like this is a perfect way for people my age to fundraise and get involved in a charity like the IHS.

Niamh Birkett



A huge well done and thank you to Bronagh O'Sullivan, left, sister of member Sinead Moore, second left, who recently took part in the 'Great Northern Run' which is a half marathon that takes place every year in Newcastle in the UK.

Bronagh very kindly did the run on behalf of the Society and raised a staggering €2,454.16. Anne Duffy and Debbie Greene met Bronagh and Sinead at the Regional Visit in Letterkenny on 21st November and were delighted to officially accept the cheque.

We look forward to seeing you both at the AGM in March in Kilkenny.



Congratulations and thank you to the 3E Class of Christ King's Secondary School, Cork for their fundraising efforts. Here the class present I.H.S. staff member Declan Noone with a cheque for €165.00.

Grants & Scholarships

I am delighted to announce that recipients of the grants and scholarships for 2011/2012 have been chosen. The sub group of the board met on the Friday evening of the October Conference, to discuss and adjudicate the various applications, which were then scored after which a final decision was reached. We had received a total of 21 applications which was encouraging, a lot of which were received online.

Some applications were exceptional and very well written. We do have some tips for applying on the website, so if you are applying next year I would like to encourage you to think about your application, check for typos, answer all the questions, give as much information as possible, and please fill out the application yourself.

I am now pleased to announce first, second and third place recipients for both awards:

Maureen Downey Memorial Grant

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

First Place:	Patrick Browne	€4,000
Second Place:	Sean McDonald	€2,000
Third Place:	Linda Coakley	€1,500

Margaret King Educational Scholarship

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

First Place:	Lorraine O'Connor	€2,000
Second Place:	MaryRose McCann	€1,500
Third Place:	Christina O'Sullivan	€1,000

We were pleased also to be able to make further payments to a number of applicants. In total an amount of €18,000 was paid out to grants and scholarships this year.

As you can see, it is very worthwhile applying. These grants really do help, and we would like to encourage you to apply next year. Don't forget even if you are a recipient this year, you can still apply next year. For those of you, who were unsuccessful, please try again next year.

Debbie Greene
Administrator



Memorial Service



A Memorial Service took place in the offices of the Irish Haemophilia Society on Sunday 6th November. We used the service that Fr. Paddy McGrath had prepared the previous year, as the hymns and readings were Paddy's favourites, and we wanted to honour him in some small way. His colleague Fr. Bernard did a lovely job with the service; it was reflective, respectful and focused on light.

During the service members were asked to place a red rose at the Memorial Sculpture in respectful silence. The Memorial Book, which contains the names of people with haemophilia who passed away, was placed on the altar. For those who were unable to attend the service, please be assured that your loved one was honoured during the service.

Afterwards light refreshments were served and everyone mingled over a nice cup of tea.

This service takes place on an annual basis, and for 2012 a date has already been set for Sunday 4th November.

Debbie Greene
Administrator

Noticeboard



NEW LOOK WEBSITE

On November 1st 2011 the Irish Haemophilia Society launched a new look website. Take a look and let us know what you think!

The navigation of the website is exactly the same, however the website has been refreshed with a new look and design which incorporates our new logo. It looks cleaner, fresher and more contemporary.

The content on the website is of very high standard and includes articles presentations and information from various international conferences and speakers as well as articles from people living with a bleeding disorder themselves or in their family.

The information is waiting for you, log on today at www.haemophilia.ie



The I.H.S. are lucky once again to have been offered places for our members to attend camps in 2012 including: camps for children with bleeding disorders, family camps and sibling camps.



If you think your child / children would be interested in attending any of the camps or you would like more information on family weekends, please register your interest by phoning Fiona in the office on 01 657 9900 or you can email at fiona@haemophilia.ie



World Federation of Hemophilia XXX International Congress 8th to 12th July 2012 – Paris



The 30th World Federation of Hemophilia Congress takes place in Paris from 8th to 12th July next year.

The most important international conference dedicated to haemophilia and related bleeding disorders which takes place every two years, comes to Europe. Bringing together teams of healthcare professionals this event provides an opportunity for the entire bleeding disorder community to discover the latest developments.

As the Congress is in Europe and within easy reach, we are asking all members to consider travelling to the Congress. The programme looks very interesting. Some of the medical sessions include talks on: Prophylaxis, Inhibitors, Rare Bleeding Disorders, Platelets, Longer Acting Factor, Gene Therapy, HIV and Hepatitis C, von Willebrands Factor, Clinical Trials, and New Products. The Multidisciplinary sessions also look good with talks on Family Issues, Quality of Life, Women's Voices, Preparing for the Future, Ageing, and Economics included on the programme.

If you would like more information take a look at the following website: www.wfhcongress2012.org, where you will find all the information on registration, hotels and more information on the programme.

You may also contact Declan (declan@haemophilia.ie) or Debbie (debbie@haemophilia.ie) in the office on 01 6579900 if you have any queries or questions.

AGM 2012 Preliminary Programmes

Adults Programme

Saturday 3rd March:

10.00 – 12.30 **AGM & Business Meeting**

12.30 – 13.30 Lunch

PROGRAMME 1

PROGRAMME 2

13.30 – 15.30 **Open Forum with:**
National Centre for Hereditary Coagulation Disorders
Our Lady's Children's Hospital Crumlin
Cork University Hospital

13.30 – 14.30 **von Willebrands Disease**
Dr. Paul Giangrande

14.30 – 15.30 **Mild Haemophilia**

15.30 – 16.00 Tea/Coffee

15.30 – 16.00 Tea/Coffee

16.00 – 17.15 **Clinical Trials**

16.00 – 17.15 **Inhibitors**
Dr. Paul Giangrande

Sunday 4th March:

10.00 – 10.30 **Update on Twinning**

10.30 – 11.30 **Orthopaedic Surgery**

11.30 – 12.00 Tea/Coffee

12.00 – 13.00 **The Irish Health Service**
Dr. Barry White, Director, N.C.H.C.D.



Creche (0 - 3 years)

Saturday
• Story Time
• Playground & Playroom
• Teddy Bear Picnic
• Movie time
• Games

Sunday
• Story Time
• Arts and crafts
• Games



Cubs (4 - 8 years)

Saturday
• Arts & Crafts
• Teddy Bear Picnic
• Movie time
• Games
• Educational Session

Sunday
• Nature Walk
• Drama
• Games



Kidlink (9 - 12 years)

Saturday
• Swimming
• Educational Session
• Cinema
• Arts & Crafts
• Games

Sunday
• Swimming
• Treasure Hunt
• Games



Youth Group (13 - 17 years)

Saturday
• Team Building
• Swimming
• Educational Sessions
• Orienteering
• Games

Sunday
• Group activity
• Cinema
• Educational Session

AGM packs and booking forms will be posted to members in early January.

2012 Calendar of Events

March

AGM & Conference

Dates: 2nd - 4th March

Venue: The Lyrath Estate Hotel, Co. Kilkenny



April

Regional Meetings

Dates: 23rd - 25th April

Location: Venues to be confirmed



May

Parents Conference

Dates: 11th - 13th May

Venue: The Sheraton Hotel, Athlone



September

HIS IHS

Dates: 8th & 9th September

Venue: Clarion Hotel Liffey Valley



September

Regional Meetings

Dates: 17th - 19th September

Location: Venues to be confirmed



October

Members Weekend

Dates: 14th to 16th October

Venue: Carlton Shearwater Hotel, Ballinasloe, Co Galway



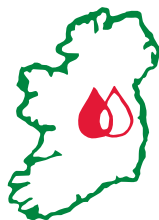
November

Memorial Service

Dates: Sunday 4th November

Venue: The I.H.S Office, 1st Floor Cathedral Court, New Street, Dublin 8





IRISH HAEMOPHILIA SOCIETY

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