haemophilia.ie

Magazine of the Irish Haemophilia Society

Working together to improve Haemophilia care in Ireland

Edition: September 2011

An online environment to talk, debate and share experiences of life with a bleeding disorder.

Register today at www.haemophilia.ie/forum

Irish Haemophilia Society Discussion Forum

SUPPORT IS JUST A CLICK AWAY!

Calling all Members in Galway and Letterkenny!

Regional Meetings are taking place on Monday November 21st in Galway and on Tuesday November 22nd in Letterkenny.

These meetings allow members to chat to I.H.S. staff members about events and activities and also gives an opportunity to raise any issues or queries. We will be writing to members in these areas to confirm venues and times for these meetings.

No registration is required, but R.S.V.P. is essential.

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A Note from the Editor

Debbie Greene, Administrator

Hello everyone, I hope you are all keeping well and that you enjoyed the summer holiday season! Welcome to the September edition of haemophilia.ie. This edition is packed with some excellent articles and information.

Read all about our innovative conference "HIS I.H.S.", our first ever conference for young men which took place recently in Dublin and was an astounding success. Well done to everyone involved with this event.

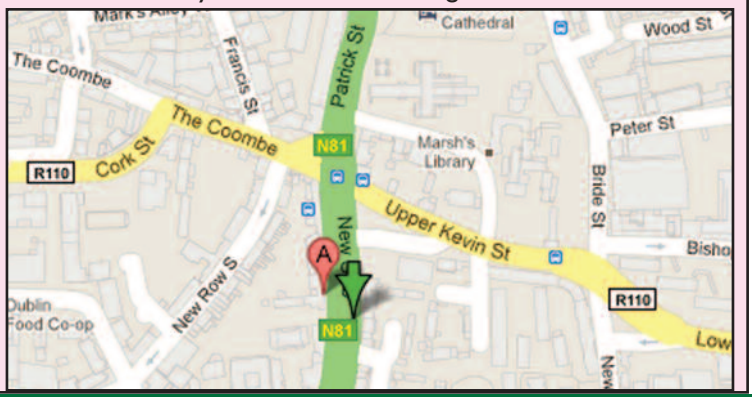
Staff member Fiona Brennan travelled to Hungary in August to a "Self Infusion Summer Camp" organised by the Hungarian Haemophilia Society, and chaperoned 2 young members of the Society. Read all about the summer camp on pages 13. Fiona also updates us on Barretstown on page 12.

Also in this issue you will find an article on "Dealing with Depression", written by a young woman. We all feel low at times in our life, feel like no-one understands us or that others are putting too much pressure on us. This article gives a real insight into what life is like living with depression. And don't forget the Irish Haemophilia Society has a counsellor available if you would like to talk to somebody, in the strictest of confidence.

It has been a busy few months in the office. Already we are looking at programmes and venues for our conferences in 2012. With registrations at our events on the increase, we must find bigger venues to accomodate our members.

And finally, please contact the office on 01 6579900 if you have any questions, queries, would like to talk to somebody in confidence, if you have a fundraising idea, an article for the magazine, or a suggestion for a publication. And don't forget you are all very welcome to drop into the office at any stage for a chat and a cuppa! We are always delighted to see members dropping in.

Debbie Greene, Administrator



CUH Takes Centre Stage

The official opening of the new treatment centre in Cork University Hospital (CUH) took place on Monday 25th July, 2011. The centre was officially opened by the Minister for Health & Children Dr. James Reilly T.D. Members of the National Haemophilia Council, board members, staff, and members of the Society were in attendance on the day, along with the hospital staff.

Tony McNamara, CEO of CUH welcomed the Minister and said the centre will provide services to adults and children with bleeding disorders, and will include investigation, diagnosis, management and treatment.

Dr. Susan O'Shea, lead Consultant Haematologist in the new centre then spoke about the new facility, which she is clearly thrilled about. Dr. O'Shea said that the opening of the new centre means that people with hereditary bleeding disorders in the Cork region now have access to a dedicated facility, which can deliver the highest standard of care, according to international guidelines.

Professor John Bonnar gave a great address. He very much welcomed the new centre, said he was delighted that patients with bleeding disorders in the Cork region now have appropriate facilities and privacy for their continuing care. He also pointed out that this development will allow the service to be enhanced with the provision of special clinics for genetic counselling, dental care, physiotherapy, counselling and education of all persons with bleeding disorders. He also spoke about the work of the National Haemophilia Council, the fact that it's a Statutory Body set up following the Lindsay Tribunal, and drove it home to everyone how hard everyone has worked to have better treatment, and better facilities. His address was very moving and very warm.

The Minister then spoke. He mentioned in all his years as a GP he only ever came into contact with one person with haemophilia. The Minister acknowledged the work of the National Haemophilia Council. He mentioned that the haemophilia service was an excellent example of centralised care. After his address he unveiled the plaque and then he mingled with everyone, and even had a quick chat with one of our junior members Conor Birkett.

What a great day, and what a great achievement. This centre will transform the quality of care for people with bleeding disorders in Munster.

Debbie Greene

Top left: *Minister for Health, Dr. James Reilly, T.D. unveiling the plaque at the official opening of the coagulation treatment centre in Cork University Hospital.*

Above: *Minister for Health, Dr. James Reilly, T.D. with Dr. Susan O'Shea, lead Consultant in the new centre.*

Left: *Members of the National Haemophilia Council, stand along side Minister for Health, Dr. James Reilly, T.D.*

CEO's Report

Brian O'Mahony, Chief Executive

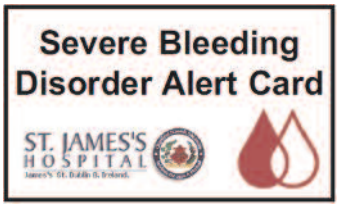
Bleeding Disorder Alert Cards

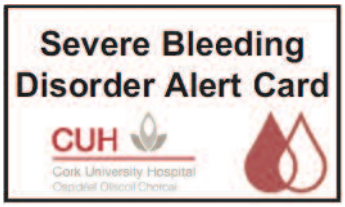
There is a clearly defined organisation of treatment centres in Ireland. The three Comprehensive Care Centres are the National Centre for Hereditary Coagulation Disorders in St James' Hospital, Dublin, Our Lady's Children's Hospital Crumlin and Cork University Hospital. There are secondary Haemophilia Treatment Centres in Galway University Hospital, Limerick Regional Hospital and Waterford Regional Hospital. All other hospitals around the country carry a minimum stock of factor concentrates in case of emergencies.

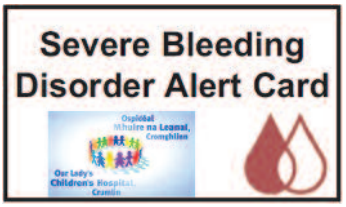
We have been concerned however, that if an individual with haemophilia presents at one of the non treatment hospitals in an emergency situation there may be delays in providing treatment. If an individual with haemophilia presents at an emergency department with a bleeding episode which requires treatment of factor concentrate, a number of delays can occur. Firstly, the triage nurse may not be familiar with haemophilia and may not be aware of the fact that factor concentrates should be given without delay. The doctor seen at the emergency department may be similarly unfamiliar with haemophilia and may order tests, x-rays or scans to confirm a bleeding episode is present before ordering factor concentrate. There may be a delay in locating the factor concentrate which is stored in the hospital. There may be a delay if a consultant haematologist in the hospital has to sign off before the factor concentrate is to be used.

In a normal scenario in an accident & emergency department when a person without haemophilia attends, the person is triaged, seen by a doctor, diagnosed and then treated. The difference with a person with haemophilia is that it is necessary to treat the bleeding episode with factor concentrate as quickly as possible. People with haemophilia have been issued with bleeding disorder ID cards by their Comprehensive Treatment Centre. These cards give contact details for the Comprehensive Care Centres. It is advisable for the person with haemophilia or the parent of a person with haemophilia, if they attend an emergency department, to ask the emergency department to contact the treatment centre that they attend for advice and information on how to treat their haemophilia. The health care workers in the emergency departments may be reluctant to do this. We have recorded a number of cases where people with haemophilia have been subjected to long delays in emergency departments before receiving factor concentrate because of some of the above mentioned scenarios. This is despite the fact that they would have asked the emergency department to contact their Comprehensive Treatment Centre for advice and information.

It is for these reasons that the Irish Haemophilia Society have produced specific **Severe Bleeding Disorder Alert Cards** for distribution and use by each of the three comprehensive care centres. These cards will be provided to you by your comprehensive care centre. You should carry this card in your wallet at all times. The wording on the card states that "the person who carries the card has a severe bleeding disorder, if he/she presents at your hospital for treatment you must immediately contact the relevant centre". It gives the telephone number to contact during the normal working day hours, after 5pm and at weekends. The fact that this card is issued by a treatment centre should carry more weight when presented to a doctor or triage nurse in an emergency department.







These cards will not replace the current bleeding disorder ID card but it is our view that they will greatly assist individuals with haemophilia when they have to attend other hospitals in an emergency situation. Please ask your treatment centre for one of these cards at your next visit.

New and Ongoing Developments in Science and Treatment

At the recent Conference of the International Society for Thrombosis and Haemostasis, a number of important developments and ongoing progress and research were discussed.

New Factor Concentrates

A lot of exciting research and development is taking place in relation to the introduction of factor concentrates which will have a longer half life and will need less frequent treatment. These products have been on the horizon for a number of years , but the research is finally getting to a stage where we will hopefully see the first of these products being licensed in the next 3 years.

New products go through various stages of clinical trials.

- **Phase 1** is where the basic safety and effectiveness is tested on a small number of people who do not have haemophilia to see if the drug is well tolerated.

- **Phase 2** is where the product is tested on a relatively small number of volunteers with haemophilia.

- **Phase 3** is where it is tested on a larger number of volunteers with haemophilia. After phase 3, the product is submitted for licensing.

Several of the products are now entering Phase 3 clinical trials.

The half life of a product is the time taken for 50% of the factor to be cleared from the body. For FVIII this is 12 hours and for FIX is 16 hours. For FVIII, this means that if you take an infusion giving you a rise of 50%, after 12 hours your FVIII level will be approximately 25% and after 24 hours 12.5%. Research has been aimed at finding ways of extending the half life so the factor stays in the body for longer so the factor is effective for longer. Different companies are utilising different approaches and technology.

In addition to the longer half life product developments, other avenues are also being explored.

Competition will also increase as many of the pharmaceutical companies are developing FVIII, FIX or FVIIa products similar to those on the market currently.

In the near future, we expect effective treatment with FVIII or FIX being possible with greatly reduced number of infusions. The possibility of FVIII prophylaxis once a week and FIX prophylaxis once every 2 weeks is no longer a distant possibility. This has the potential to transform haemophilia treatment in the future. It should be noted however that the companies who are developing these products need to be realistic in their pricing strategies when they come to market as they may be subject to health technology assessments before approval. The future also holds the prospect of more effective longer lasting treatment for inhibitors.

Prophylaxis

A number of presentations and a debate (on prophylaxis in adults) were presented on prophylaxis. Data comparing on-demand treatment in Russia to prophylaxis in Denmark showed that there was more joint damage and a lower quality of life among those on on-demand compared to prophylaxis for the same age.

In a debate on lifelong prophylaxis, Dr. Mike Makris from Sheffield argued that the majority of adults with severe haemophilia will do better on prophylaxis. There are no questions over the safety or efficacy of prophylaxis in adults. The questions relate to inconvenience (the number of infusions, this may be reduced with longer acting factor) and cost. In speaking against lifelong prophylaxis for adults, Dr. Kathleen Fischer from the Netherlands pointed out that in Netherlands and Denmark 22% and 45% of adults had successfully stopped prophylaxis although in Denmark the average number of bleeds per year increased in this group from 1.8 to 3.2.

This debate will continue. There is no clinical consensus at present that all adults with severe haemophilia should be treated with prophylaxis. Some individuals have a naturally milder bleeding pattern, even with severe haemophilia. Many centres and countries will take an individual approach where they look at the individuals bleeding history, target joints, activity levels and then decide on the best treatment. Also, in the Netherlands some 42% of young adults stopped prophylaxis but one third of them had to restart due to frequent bleeding episodes. (In a paper just published by the journal Haemophilia, authored by Declan Noone and myself, we looked at the quality of life in young adults in Sweden, Ireland, UK and France. The quality of life for those in Sweden was normal compared to approximately 75% of normal in the other 3 countries. This is due to the impact of prophylaxis on the young men with haemophilia in Sweden from childhood. This is a quality of life we should see replicated in those in Ireland who are currently under 15, who have always been treated with prophylaxis, if they stay on prophylaxis.

Quality of Life

The life expectancy of people with haemophilia in Denmark who are HIV and Hepatitis C negative was reported as 72.3 years compared to 74.1 years for the general male population. When those with HIV and/or Hepatitis C were included, the life expectancy average was 52.1 years. This has increased from 43.4 years from the period 1993-2006. In Sweden, the quality of life of 105 people with haemophilia was reported. Their median age was 44 years (range 18-84 years). 82% had a full time job. Only 3% were unemployed. 8% had retired due to haemophilia.

Brian O'Mahony

New Developments in Hepatitis C Treatment

A new generation of Hepatitis C treatment - called Protease inhibitors - have now completed their clinical trials and are in the process of being licensed for use in Ireland.

There are 2 protease inhibitors on the market - Telaprevir and Boceprevir. These products will not replace the existing treatment with Pegylated Interferon and Ribavirin - they will be used as a third drug in addition to those two for the treatment of Genotype 1 Hepatitis C.

Successful treatment is defined as the individual being virus negative 6 months after treatment is completed - known as a sustained virological response (SVR). Current treatment with Pegylated Interferon and Ribavirin have resulted in SVR rates of approximately 40-50% for Genotype 1 and 80-90% for Genotypes 2 and 3 so an additional treatment for Genotype 1 was a priority. An additional indicator of the possible treatment outcome is the individuals genetic type of a specific gene called the IL28b gene (type CC gives the individual the best chance of an SVR).

Clinical trials with both new products were encouraging. In those who have never previously had treatment the SVR (successful treatment outcome) rate varied from 67% to 90% with the best outcome in those with IL28B type CC gene. This is a very significant improvement when compared to the current treatment. In those who had a response to previous treatment but then relapsed, the results are also encouraging with SVR rates of approximately 85% irrespective of IL28B gene type.

In those with no response to previous treatments, SVR rates of approximately 30% were reported.

The duration of treatment can be 6 or 12 months. Side effects vary but can include fatigue, anaemia and skin rash.

These new treatments should be more widely available and used from 2012 in Ireland. It is encouraging to see this progress being made and it holds out the hope of better treatment outcomes for many in our community.

Brian O'Mahony

Fundraising

The current economic climate makes fundraising very challenging. We are hoping to continue in our efforts to raise funds but we do need your help! So far 2011 hasn't been the greatest of years for fundraising, however we have been able to raise €4,793 which is fantastic considering there is a recession on.

People in Ireland are very charitable and organising your own fundraising event is a great way to have fun to bring friends and family together and to raise funds. Fundraising has a positive impact.

Over the years friends and supporters of the Irish Haemophilia Society have been very generous by organising a wide range of activities from coffee mornings to dinner dances and from golf classics to gala balls.

If you are interested in organising a fundraising event, we can help with promotional materials such as posters, sponsorship cards and t-shirts. You will also receive full support from the staff in the office. We are all aware that fundraising is very difficult in today's climate, but we must increase our fundraising activities.

If you would like to help in any way, we would love to hear from you. Why not help us help you and remember; **"Every little helps"**

Debbie Greene

HIS I.H.S. Conference

In the last 20 years treatment for haemophilia has changed entirely. There are safe and effective products. There is an excellent home delivery service. With the NCHCD in St. James's, OLCHC in Crumlin and the new treatment centre in CUH in Cork, there are 3 comprehensive care centres that provide an efficient and good service with thankfully very few problems. So, in the day to day of a busy life we are very lucky that in most cases, haemophilia can be put to the back of your mind and you can carry on with the things that are more important in life such as family, friends and some might even say work. So is there a need at all to think about haemophilia?

The short answer of course is yes!! The slightly longer answer is yes, but only to prevent something that can be a minor issue from becoming a major one. In the past few years the IHS has had a number of queries from young men with haemophilia and von Willebrands about travelling. We have also had queries about services in colleges, work places and benefits available in relation to haemophilia. These queries usually arise when people push haemophilia a little bit too far to the back of your mind.

As a result of these queries, the IHS decided to hold the first HIS IHS conference for young men between 18 and 35years old. The conference was held in the Clarion Hotel, Liffey Valley in Dublin on the 10th and 11th of September. The conference had talks on a number of issues such as travel, work and college life and relationships. There was also an open forum for anyone at the weekend to discuss topics that were either not covered over the course of the weekend or to clarify some of the questions they had over the weekend.

Evelyn Singleton, NCHCD, gave a detailed presentation on the things you need to think about if you are travelling. Listed below are the topics that were discussed and some of the questions that came up:

- Where do I go to get vaccinations?
- Do I need factor beforehand?
- What does the EU Card/Health Insurance cover?
- Are there any issues in obtaining visas for travel or work?
- Where do I find out where the nearest treatment centre is?
- What happens if I don't have a travel letter?
- How long can my treatment be out of a fridge?
- How should I carry my treatment?
- Can I bring needles and syringes on the plane with me?
- There is no treatment centre near where I am going what do I do?
- If I need medical letters for a visa application where do I get them?
- Will they have treatment available in the country I am visiting?
- Is the product I am using available in the country I am visiting?
- Are there any conditions about travel insurance I should be aware of?
- What are my options if I want to immigrate?

The talk was very informative and created a lot of discussion and examples of problems that arose from "just not thinking about it". The overriding theme of the talk was that whether you have mild haemophilia, severe haemophilia or von Willebrands, whether you have bleeding into joints once a week or once every two years, taking some time and preparing

for any possible problems will save a lot of time, money and frustration in the long run. Just because it hasn't happened before doesn't mean it won't.

The second talk of the conference was on Work and College and the challenges of a lifelong condition. Patricia Byrne, Psychologist from the NCHCD talked about topics discussed such as importance of the balance between work and life and how this can be affected by haemophilia. There was also some discussion about disclosure in the work place. Do you need to disclose to your employer about your haemophilia and if you are going to disclose, when do you do it? Within the group there were a number of different ideas and opinions on how people have dealt with this issue in the past and some recommendations on the ways that worked well for people. Helen Carroll, Disability Officer, D.I.T. discussed issues in relation to college. In comparison to the work environment where disclosing can pose some problems, it was highly recommended that when in college that you inform the disability service in the college as there are ways of helping students out throughout their time in the college. There were some comments like "I don't consider it as a disability so I wouldn't think of registering". The speakers pointed out that haemophilia is a lifelong condition and although from day to day you may not have any problems and you may not even use the service once in the entire time you are there, if you are registered with the disability service from day one, if something comes up then they may be able to help. Two simple examples given were missing lectures due to hospital appointments or bleeds, you may be able to get free photocopying instead of writing out notes you missed. The second example was if you miss an exam. Generally in College you have 4 chances at passing an exam, so if you miss an exam in college it is considered a failure and you have 3 more attempts to pass it. However, if you are in hospital with a bleed for example, then they can help you make the missed exam a deferral so instead of 3 attempts you still have the 4 attempts you are entitled to. There are a number of other ways in which college disability services can help so contact them when you get to the college and see what services you can avail off. You can register with the disability service by ticking the box on the CAO form when you are applying for the college courses.

Saturday night offered the chance for people to get to know each other a bit better over dinner and a competition. There was a pool tournament with a prize of a pool table to take home, for the winner. The tournament was a lot of fun and showed some talent and for the beaten finalist some bad luck.

The final of the Pool Competition was a true test of skill.

Sunday morning continued in the same manner with an excellent discussion on the effects of haemophilia on a relationship. Questions were on a wide range of issues from disclosure to the practical and sometimes surprising ways haemophilia can appear in a relationship.

The first HIS IHS conference was another great success for the Society in a year with already four very successful conferences. The information available and the invaluable opportunity to talk to other people and ask questions, provides individuals time to get information on issues, that may be big or small, that may be for now or in the future and allows haemophilia to be thought about without it being something that becomes a surprise problem in the future. The aim of this conference was to get people to bring haemophilia just a little bit further forward from the back of their mind and it definitely achieved this. I would like to say to all involved thank you for making the conference such an excellent start to something that we hope will continue strongly into the future.

Declan Noone

COAGULATE!

Coagulation is the process by which your blood forms a clot to stop bleeding.

Number the pictures in the correct order to show how blood clots.

What do you get when you cross a giraffe and a hedgehog?
A tall toothbrush!

How do players stay cool during a match?
They stand near the fans!!

Clotting Factors form a fibrin net

☐

Platelet plug is formed

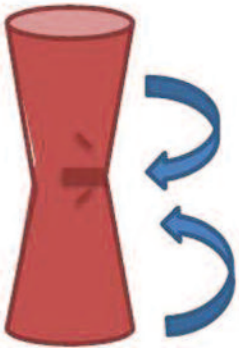
☐

Clot is formed

☐

A cut or tear in the blood vessel

☐



Blood vessels tighten

☐

Bleeding

☐

When will my port come out?

In time you will give your factor through your veins. As you get older your veins become stronger and it is easier to self infuse. There is no specific age that this will happen it can vary from child to child, but when this does happen your port can come out.

Answers: 1) A cut or tear in the blood vessel. 2) Bleeding. 3) Blood vessels tighten. 4) Platelet plug is formed. 5)Clotting factors form a fibrin net. 6) Clot is formed.

Youth Group

Can I go on school trips?

If you are planning a school trip your teachers can talk to your parents about any help that you may need. If you are self infusing, it will be easier to attend any school outings. If you are not self infusing yet then sometimes your Mam or Dad might come along on the trip to help out.

B	A	D	M	I	N	T	O	N	B	L	O	O	D	A	H
N	D	X	S	O	C	C	E	R	L	B	R	A	C	N	O
U	V	O	N	W	L	S	A	F	E	T	Y	N	A	K	S
R	O	E	L	B	O	W	G	N	E	S	W	I	M	L	P
S	C	F	A	C	T	O	R	S	D	Y	E	M	P	E	I
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A	V	O	N	W	I	L	L	E	B	R	A	N	D	S	E

WORDSEARCH:

Ankle	Badminton	Bicycle	Bleed	Blood
Body	Camps	Carriers	Clotting	Doctors
Education	Elbow	Factors	Fun	Gene
Haemophilia	Healthy	Hereditary	Hiking	Home
Hospital	Ice	Infusions	Inhibitors	Joints
Knee	Nurse	Port	Prophylaxis	Research
Safety	Skin	Soccer	Swim	Syringe
Tennis	Vein	Von Willebrands		

Barretstown

As most of you will know by now, Barretstown is a specially designed camp that provides activities and programmes of fun,adventure and support for children with bleeding disorders and other various conditions. Barretstown also provide family camps where parents and children can take some time out of the routine of daily family life to relax and have fun together in a safe and caring environment.

The Irish Haemophilia Society is very lucky to have an excellent working relationship with the staff at Barretstown. We have been offered a number of places by Barretstown for our members and so far any time we have had an enquiry we have been able to secure a place. Last year, we had significantly raised the number of children from the Society attending the Summer Camps and this year has been no different! Not only have we increased the number of children attending the camps we have also doubled the number of families attending the family weekends too!

Barretstown is a great opportunity for the young members of the I.H.S who are affected by Haemophilia – whether they are directly affected by a bleeding disorder themselves or they have a sibling with a bleeding disorder. It is a place where for a whole week or ten days, depending on the particular camp that the child is attending, the child has the opportunity to be around other children going through similar situations. It also gives the child the chance to be involved in activities they may not get to do otherwise such as high ropes.

Barretstown base their Camp programmes and activities on a Therapeutic Recreation Programme. This programme through activities and fun allows children to gain more self confidence, raise self esteem and realise that although their condition may affect certain aspects of their lives, they can still get the most out of their childhood. So that leads nicely onto the fun stuff!!

Any time I ask the children and parents of the I.H.S that have attended the camps what they thought of Barretstown I am inundated with stories and comments which are always more than positive, from stories and friendships with the caras, the other kids that they meet to the wide range of activities and even the food!! One member described it to me as 'what everyday should be like'.

It is undoubtedly daunting for children and parents for that matter, to be away from home for up to ten days, but after a few tears in the car about the possibility of feeling homesick on the way to camp, many campers have said they have had a few tears on the way home about leaving too!! The programme is jam packed with activities such as fishing, archery, theatre, high ropes, horse riding and canoeing to name but a few – there is literally never a dull moment for the campers and definitely not much time for them to feel homesick! Campers also get some 'free flow' times during the camp week which allows them to choose their favourite activity and have another go!

Family camps take place for the weekend only, with activities to bring the whole family together and time for parents to sit and chat with other families in similar situations. This is an important aspect of the Barretstown family weekends for parents, unfortunately life gets in the way and parents may feel isolated and when they finally get to speak to other parents, they feel relieved to have someone understand their situation.

If you have any queries in relation to Barretstown or would just like additional information, please do not hesitate to contact me you can email me, fiona@haemophilia.ie, or call me on 01 657 9900 or youbut don't take my word for it – here's what parent's have had to say:

"He was having difficulty with needles and was getting angry at his situation. When I collected him from the Camp I collected a different child. He doesn't feel different to anyone else now"

"He was beginning to feel like he was the only one in his world with a bleeding disorder; he is now much less bothered by the whole thing"

"He was having terrible issues with needle phobia, since he came back he is getting more involved and is much more relaxed and now I don't feel as anxious about it anymore either."

"He starting self infusing from the day he came back, I don't know whether it was watching other boys doing it or that I wasn't there to 'mammy' him but he hasn't looked back since"

"He had a ball, crying on the way up and then was crying coming home!"

"She wasn't too sure about taking part and was quite overwhelmed with it all by the time I was collecting her she had decided she wanted to come back every year and asked just could you arrange that?!"

Fiona Brennan

Hungarian Summer Camp

We were very lucky to have been offered two places at the Hungarian Summer Camp for boys with Haemophilia aged between 13 years and 17 years. The Camp took place from July 30th to August 6th, 2011.

The Camp is aimed at education, encouraging self – infusion, empowering and building confidence in the young members along with lots of fun and adventure. The Hungarian Haemophilia Society has been running this programme since 1992, with more than 600 children taking part.

When I was asked to travel to Hungary for the Summer Camp at Lake Balaton with two boys from our Society – I was extremely excited and only slightly nervous!! I had read about the camp on their blog and it looked brilliant. Jordan Sullivan and Thomas Burnell were chosen to take part in the summer camp having submitted letters of interest. In the weeks approaching the camp there were many things to think of – letters from the hospital to travel with needles and syringes, letters allowing the boys leave the country without their parents, sun cream and mosquito spray…but before we knew it I was standing in the airport saying goodbye to the boy's parents with two excited but very tired looking boys!!

We arrived on Friday 29th July, the camp for younger children was finishing up and they were preparing for the 13 – 17 year olds boys to arrive. The camp is situated on the shore of Lake Balaton (around 2 hours from Budapest) in wooden lodges; there was a communal kitchen area and 4 separate lodges for sleeping. The view was spectacular! On Saturday the Society had organised a family day for their members – watching all the families and leaders together I could tell that there is a great sense of community amongst the members, leaders of the camp and the children.

The boys camp officially started on Sunday – each day there was a self infusion session, physiotherapy session and then organised activities such as bobsleigh ride, swimming, boat trips, day trips to a hill top castle and an adventure centre trip to name but a few!! While all the teenagers preferred the activities, the self infusion sessions went really well. All the boys there, whether they were self infusing or learning to use their veins were so supportive of one another, offering their advice and even their veins for practise to the other boys! One of our own boys started to self infuse for the first time during the camp which as you can imagine was a very important occasion and hugely positive step. I am delighted that this is something which he has continued to do at home and we at the I.H.S. are very proud of him!

The Hungarian Society also organised lectures from two doctors which gave some really useful information on Haemophilia and related bleeding disorders in a child friendly way. They stressed the importance of knowing information about your disorder, physiotherapy and the importance of self infusion. The boys and I were very grateful to the leaders and doctors who translated everything for us.

The camp gave the boys the opportunity to be around other boys with haemophilia of a similar age but with a very different treatment regimes, it also gave the boys the opportunity to attend a summer camp with a special focus on haemophilia. From the moment we decided that we were attending the camp to the moment we left, Gabor and all of the leaders made us feel welcome and included in each activity.

Before we knew it Saturday morning loomed and it was back to Budapest to travel home. As we sat in the airport (the boys ate KFC and Burger King as if they had never eaten!!) and talked about the weeks adventures. It was clear that both Jordan and Thomas had benefitted in different ways from the camp, despite the fun and great activities they got to take part in, spending time with other children in a similar situation and learning about treatment in different countries had a positive effect on them, not to mention one of the boys learning to self - infuse.

I would like to thank the Hungarian Haemophilia Society for giving us the opportunity to attend the camp and for looking after us so well, also I would like to thank Jordan and Thomas for being such good travel companions!!

On the next two pages, Jordan and Thomas give their accounts of the trip.

Fiona Brennan

When I found out that I had got one of the places to Hungary I was really happy and excited to be going because it would be good to go to a camp with other people who have haemophilia. The night before I was going I didn't really sleep very well. The next morning I was up early because we had to be at the airport at 5.30. When we got there I met Fiona and Jordan. After we landed in Budapest we met Gabor the CEO of the Hungarian Haemophilia Society.

When we arrived in camp it was the last day of the younger children's camp so not many of the children from our group were there yet. After we went to an adventure centre which was all up high in trees. There we six different stages but we only got to do four. We had a barbeque after for tea, we had sausage and vegetables. After that we went to where we were staying that night as the camp was still full with younger kids so we couldn't stay there. When we woke up the next day we had to go back to the camp for breakfast. After breakfast we had free time for an hour, then we had physio for an hour. After lunch we went on a boat around Lake Balaton. After the boat we went swimming but the water was very cold so we didn't really enjoy it. We went on a trip to a place with a lot of rocks – it was really high up. It is called the sea of rocks because when it rained the bottom would fill up with water!

When we came back we started a table tennis competition and then we had dinner. The next day we went on another trip to a market and then to a rollercoaster ride that you could drive yourself, it was really fun and you went very fast. We had our last physio session on our last full day at camp; we did this physio in the lake. Later we played football in the astro turf pitch beside the camp. Later we had a party and awards night with awards for football and table tennis competitions. After that we went to bed because it was going to be a long day the next day. After we said goodbye to everyone we went to the airport and went home.

I would like to thank both the Societies for giving me this opportunity to go to this camp and meet up with all these other children with haemophilia and a big thanks to Fiona.

Thomas Burnell

Above Top: *Jordan and I get ready to climb!*

Above: *I scale new heights on the tree-top walk!*

Below: *The full group of campers and leaders!*

Below left: *Camp life included cooking around the camp fire!*

On the 29th July 2011 Fiona, Thomas and I travelled to the Hungarian Haemophilia Camp beside Lake Balaton. We flew out of Dublin Airport at around 6.30am. It was a 3 hour flight to Budapest. I was very tired because I had an early start that morning. We landed in Budapest at 10am Hungarian time. The airport looked lovely, it was like a museum.

Gabor the Hungarian Haemophilia Society CEO met us off the plane, when we got to the car it looked so weird because the steering wheel was on the left and we were driving on the right hand side of the road. Gabor drove us around the city of Budapest for an hour showing us the sites of the city. The buildings were beautiful, even the Irish Bars. We were stunned.

It took us 2 hours to drive to the camp at Lake Balaton. The lake was a lovely blue – green colour. The camp was nice, there were 4 cabins which slept ten people and 1 cabin for the leaders, the main building where we all ate and then there was a ping pong game area. Everybody was really nice. There was a bonfire in the middle of the camp site.

Over the first 3 days we went swimming in the lake which was fun, we went to adventure centre which was my number 1 favourite, and loads of fun stuff. Every day started with a chat about self – infusion, as I am only learning to use my veins this was a great help, I got loads of tips off the other lads too. The treatment in Hungary is a lot different from what we have, and they were all amazed to see a port a cath.

The people at the camp were cool; my favourite campers were Tommy, David, Dani, Zolan, Seany, Thomas and Yatsack. My favourite leaders were Bori, Tommy and Fiona. On the last few days we went swimming again, we went on pedal boats on the lake and then jumped off them. We went on a bobsleigh rollercoaster which was legend. We went on 2 day trips; we went up a mountain one day and to a castle the other day. It was lovely and the views were fab!

I had a ball there and I am going to miss everyone but at least I have photos. The only thing I won't miss is the food though.

I was tired going back to the airport and on the plane going home too. I was happy to get home but delighted to have gotten the chance to go. Thanks to all at the Society for giving me the chance to go and especially my mate Fiona.

Jordan Sullivan

Top: *Thomas, Fiona and I get down to work at the infusion workshop.*

Left: *. Thomas and I rock climbing! The group went on a lot of hikes, which we enjoyed.*

Far Left: *I self infused for the first time at the camp!*

Dealing with Depression

Depression is such a scary word isn't it? As soon as you say it people's reactions to you automatically change. Even just saying it in your head makes you feel uncomfortable. However, the harsh reality is that depression is an illness that a lot of people are affected by. Statistics state:

"At any one time in Ireland 400,000 people experience depression and that 1 in every 10 teenagers aged 13 to 19 experience a depressive episode". ***Aware***

Even with these figures in black and white, there is still a stigma related to depression. People are afraid to talk about it, mainly because talking about makes it real. I'm going to share my story of my life with depression with you and hopefully it will encourage you to be aware of the signs and symptoms both in yourself and your loved ones.

I was first diagnosed with depression at 16 - I know what you're thinking, what has a 16 year old got to be depressed about? To be honest, that is exactly what I thought. Growing up I was your average happy-go-lucky child, I had lots of friends and was involved in a lot of after school programmes like dancing, drama and sports. Then I started secondary school and had to stop some of these activities simply because I couldn't attend any more, I finished school at 3.30 and most of the activities started at 4 o'clock so I couldn't make it along to the classes. Looking back, I loved having all this new free time, but in reality it meant that I was losing touch with a lot of my friends and was giving up on activities that I really enjoyed and the free time I had on my hands, was free time I didn't know what to do with.

Then before I knew it the Junior Cert was upon me, I know nobody likes exams, but to me they were the worst thing in the world. Although I enjoyed some subjects and my teachers would always say I was a good student, I was not studious at all and had the attention span of a gold fish. Worst of all I'm a panicer! The night before the exams I would be cramming until all hours and then the morning of the exam I would be biting my finger nails worrying that I would forget everything.

Luckily that didn't happen and although my exams didn't say all A's, I did pass everything so a good result overall. I did transition year and I know a lot of people say it is a waste of a year, but I really enjoyed it. It gave me a chance to try new things and just relax and this is what I needed, because truthfully I just didn't know myself! It's hard to explain, but I didn't know what interested me, what I wanted to do and found it hard to motivate myself to do any activities outside school. I and the people around me just put it down to being a moody teenager. Deep down, I think I knew it was something else, but I didn't want to admit it as I was worried people would treat me differently.

Then one day in school, we had a speaker in from Aware, at the time I was just thought "great don't have any classes for a few hours", but during the lecture reality slapped me across the face – hard! Everything the man spoke about I could relate to and I'm not talking about 'sometimes we all have a down day'. He spoke about how some days you just don't want to do anything, not even think, you just want to sleep until you feel yourself again. You have no energy, can't stop crying and snapping at people for no reason. You feel tired even though you have slept for hours, feeling bored, but not wanting to do anything, poor concentration, anxiousness, low self esteem, feeling pains and aches with no actual cause. Every question this guy asked I knew the answer. I remember one of the girls in my class joking that I knew way too much about it and she was right, the person this man was describing was me. After the talk we were told we could speak to him individually. I asked my best friend to wait with me because I thought I needed to speak to him, as soon as I closed the door I broke down in tears. I don't even remember what I said, but I knew then and there that I was suffering with depression. The man advised me to speak to my parents and to visit my GP. Walking out of the room my best friend held my hand, she had known me since we were four and she had never once thought I was in any way sad or feeling down. I suppose I had just gotten used to putting on a face to the people I loved.

Telling my parents was one of the hardest things I have ever had to do in my life and I'm sure for them it was one of the hardest things they have ever had to experience. From my point of view telling the people who loved me the most in the world that I wasn't happy with anything in my life upset me even more. I could see the pain, sadness and worry in the eyes as soon as the words came out of my mouth. I remember crying and my Mam hugging me and saying she would make an appointment with the doctor the next day and my Dad telling me that everything would be ok and that I could always talk to him. I was lucky. The support I received then was what helped me see that I could overcome this illness. I wasn't alone, no matter how lonely I felt. I began to feel that there was a light at the end of the tunnel. The next day I went to the doctor with my Mam, the doctor said the best thing to do was start me on anti-depressants.

That was when I was 16 and since then I have been prescribed anti-depressants several times, I have also been to see counsellors and attended group sessions and lectures run by aware. My life isn't all doom and gloom, I could tell you about holidays I've been on, nights

out I have had, concerts and festivals I've loved and relationships I've had, but this is not an article about me, this is an article about my illness, which is a part of my life, but is not my life.

I still have days where I feel down, but this is normal. Nobody is 100% happy and bubbly everyday and if they are, I would be worried!! The important thing now is that I can recognise normal down days and distinguish them from times when I am feeling depressed. I do not know what triggers me to have a depressive episode, but then again nobody can foresee the future. Currently I am on anti- depressants, this is not a sign that I'm not happy with my life and it is definitely not a sign of weakness. Some people have heart problems, some people have haemophilia. I, like them, have a condition that I am getting treatment for. I know I will not be on anti-depressants for the rest of my life, but at the moment this is the treatment I need.

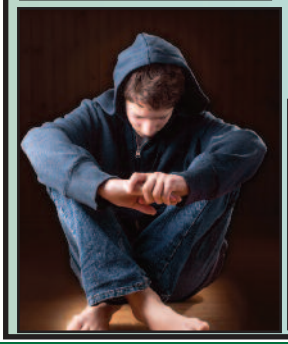
As I said at the start of the article people are afraid of depression and when you tell someone you suffer with it some people will treat you differently. I am lucky in that I have a group of close friends and family around me who know about my condition and have stuck by me through the good and bad times. I have accepted my illness and I think that is one of the toughest parts of having depression, finally facing up to it. I am more confident now in discussing my feelings and my condition with people, don't get me wrong I don't stop strangers on the street and start telling them my life history. But if there is a discussion about depression I feel confident enough in myself to talk about it and I am not embarrassed to tell my friends and family when I feel depressed, because these are the people who support me. It hasn't all been great I had a close friend who couldn't understand my condition and our friendship slowly faded away and although I was upset at the time at losing this person, the most important person in my life is me and I do not need people in my life who will make me hide a part of me or question myself.

Life with depression is hard, but the only way to help yourself or someone you love who is suffering with depression is to talk about it. Walking on eggshells or trying to shield them from all the negativity in the world is never going to work. I mean look at life now, you can't open a paper without hearing about budget cuts and recession and unemployment. There are always going to be obstacles and negative episodes in life, it is how we choose to face them that will get us through. If you feel like you or someone you know could be suffering with depression I would urge you to talk about it, it doesn't matter who – a family member, a friend, a doctor even a priest! Talking about depression is the first step to dealing with, trust me I know. Don't be ashamed of how you feel and don't take it as a sign of weakness or inability to cope, everyone in life has their own battle and this is yours.

For more information on depression please visit www.aware.ie

I wish everyone reading this strength and health. Remember talking is the best treatment!

The I.H.S. have a counsellor available to members, if you wish to make an appointment confidentially, please contact Anne Duffy on 01 657 9927.



MENTAL ILLNESS, AFFECTS MEN AND WOMEN EQUALLY.
AGE IS NOT A FACTOR.

If you think you or someone you know may be suffering with a mental illness, please talk to someone. Here are some useful contact details to have:

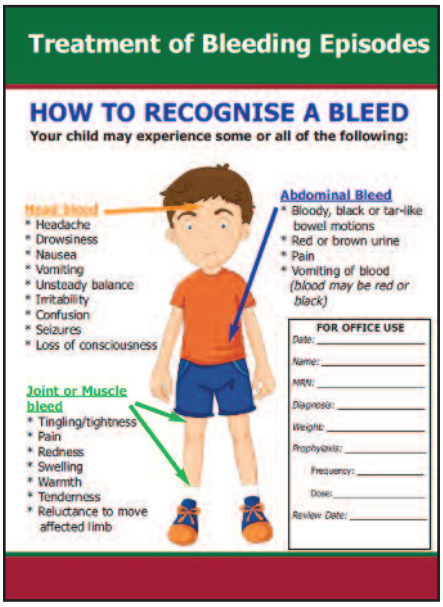
ANNE DUFFY,
Counsellor,
Irish Haemophilia Society
Tel: 01 657 9927
Email: anne@haemophilia.ie

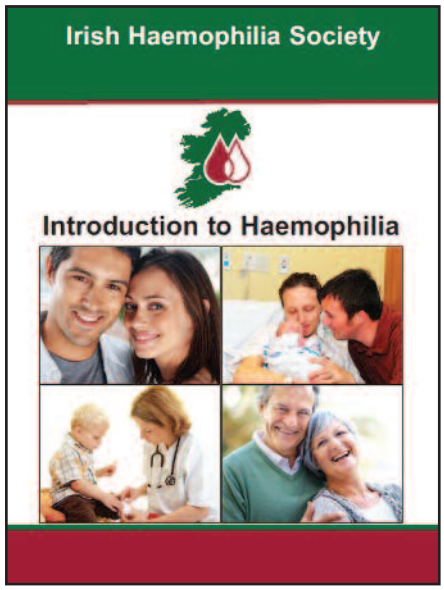
AWARE
Helpline: 1890 303 302
Web: www.aware.ie

SAMARITANS
Helpline: 1850 60 90 90
Email: jo@samaritans.org
Web: www.samaritans.org

Well Published

2011 has been a good year for publications. This is our third magazine and we produced our Annual Report 2010 back in April. We have also produced a children's version of our dental leaflet which is called "Dental Care for Children with Hereditary Bleeding Disorders", which we worked on together with the team at Our Lady's Children's Hospital Crumlin (OLCHC). We have also produced a very useful booklet called "Information for Teachers and Playgroup Leaders" which gives basic information about haemophilia and bleeding disorders in simple English. Don't forget members, a representative of the Society is available to give information talks to schools and crèches on request. We have just finished a leaflet and a poster in relation to the treatment of bleeding episodes. Both give very important information in relation to how to recognise a bleed and how to treat a bleed. Again we worked with the team at OLCHC on both these publications.





Fresh in from the press is an updated version of our booklet "Introduction to Haemophilia", a copy of which is being sent to all our members. We are also looking at putting together two separate "Introduction to the Irish Haemophilia Society" packs, one for adults and one for children. When complete these packs will be sent out to all new members and will include information about our services and support, membership, charter, publications, website and basic information. It is expected that these will be complete by the end of the year. Currently we are researching the possibility of producing publications on von Willebrands Disease and a Children's Publication which we will keep you informed about.

We prepare and design all our publications in house and then send them out for printing which cuts out the cost of designers and thankfully we currently have an excellent printer in Kilkenny who is very competitive in price.

What do you think of our publications? Do you have any suggestions for new publications? I would welcome any feedback or suggestions. Call me anytime in the office on 01 6579900 or email me at debbie@haemophilia.ie And don't forget if you come across an interesting article or would like to write something for the magazine, Nuala or myself would be delighted to hear from you.

www.haemophilia.ie

Website update

We are in the process of refreshing the look of the website. Our current website is nearly 3 years old and in this day and age technology is moving so quickly we felt we should look at reviewing the website. We will have a new look home page with subtle changes, but we will not be amending the layout and functionality of the website. We will be implementing a new design that will be easy and smooth while keeping the current layout of the website.

For those of you not familiar with our website the address is www.haemophilia.ie

The website is updated regularly with reports from events, presentations and informative articles.

Debbie Greene

Calendar of Events

OCTOBER

Members Weekend

Dates: 14th to 16th October
Venue: Carlton Shearwater Hotel, Ballinasloe, Co Galway

MOVEMBER

The weather report is in and in November it will be raining Men. Yes that's right November will officially become M-ovember and we are asking all the men of the I.H.S. to take part and fundraise for the I.H.S. by growing a moustache. 30 days is all we ask. In the battle of the sexes for the fundraising crown, the ladies have taken a huge lead with a fantastic turn out for the Women's Mini Marathon. So men here is the question, are you up for the challenge?

To register to take part in Movember or for more information contact Nina on 016579900 or nina@haemophilia.ie

NOVEMBER

Memorial Service

Dates: Sunday 6th November

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

NOVEMBER

Regional Meetings

Date: Monday 21st November
Location: Galway, venue to be confirmed

Date: Tuesday 22nd November
Location: Letterkenny, venue to be confirmed

March

AGM & Conference

Dates: 2nd - 4th March 2012

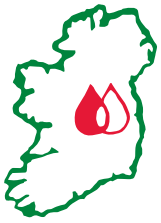
Venue: The Lyrath Estate Hotel, Co. Kilkenny

May

Parents Conference

Dates: 11th - 13th May 2012

Venue: The Sheraton Hotel, Athlone



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Website: www.haemophilia.ie