haemophilia.ie

Magazine of the Irish Haemophilia Society

Congratulations to all who took part in this years Mini Marathon!

Edition: Summer 2008

Announcing: Members Weekend 17th - 19th October 2008

VENUE:

The County Arms Hotel,
Birr,
Co. Offaly.
Tel: 057 9120791
Email: info@countyarmshotel.com
Website: www.countyarms.com

PRELIMINARY ADULT PROGRAMME

Saturday Morning

Health Supplements & Haemophilia
40th Anniversary DVD
Barretstown Gang Camp

Saturday Afternoon

Men

Being Active: This session will include a physiotherapy presentation followed by hydrotherpay exercises and individual physiotherapy consultations.

Women

Time for you: This is for mothers, sisters, daughters, carriers, grandmothers, wives/partners to get together for discussion followed by a Belly Dancing Workshop

Sunday Morning

Debate: "Are there limits to my life activities"
Open Forum

CRECHE

All activities for our younger members will be organised by our experienced creche supervisors for the duration of the weekend. The creche is available to children up to six years of age.

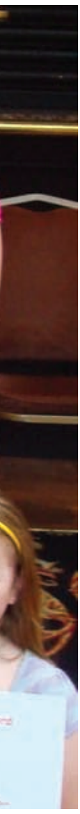
KIDLINK

The Kidlink Club is open to children from seven to eleven years of age.

AGED 12 YEARS & OVER

Adventure Weekend for children aged twelve years and over at the Birr Outdoor Centre.
For further information please see website
www.oec.ie/birr

Booking forms and further information will be posted out to all members in September. Places will be limited for this weekend. For further updates please keep checking our website:www.haemophilia.ie



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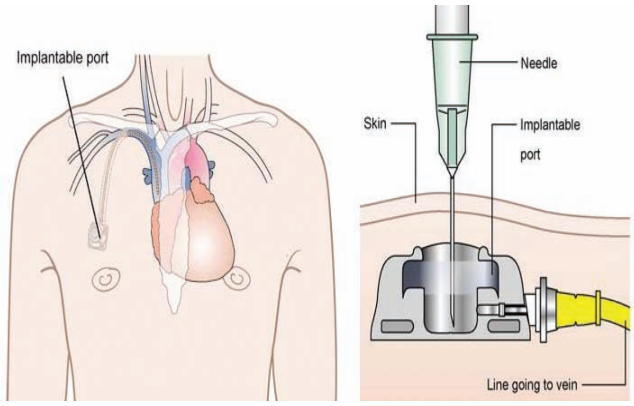


A Message from our Chief Executive

Brian O'Mahony

WFH Congress Istanbul

The WFH biennial Congress took place in Istanbul, Turkey from June 1st to 5th. Eight delegates attended the Congress from the Irish Haemophilia Society including 4 staff and 4 board members. In addition, a large number of members and spouses attended as well as many health care workers from Ireland. A full report on the Congress is included as a supplement with this magazine. For those delegates attending the Congress for the first time I was again struck by their increased awareness of the disparity in care between the developed and developing countries. This is an awakening which always occurs when people attend a Congress for the first time, and the true reality of lack of access to care in developing countries is humanised by meeting people from many countries throughout the world who do not have the same access to care that we have in Ireland.

In my report on the Congress you will see quite a large section on prophylaxis. There were a number of very good sessions on prophylaxis during the Congress. It is becoming increasingly apparent that not only is prophylaxis the optimum therapy for haemophilia but also prophylaxis from early childhood allows a child to grow up without joint damage, allows the child to get a good education, and the adult to get good employment, and leads to a totally different quality of life than that which was a reality just 10 or 20 years ago. It is also apparent however that adherence to the prophylaxis regime is very important and that years of good work can be undone by not taking prophylaxis at the approved doses at the right intervals.

I hope you will enjoy reading the supplement with many reports and photos.

Some scenic images of Istanbul

Medical Issues

Included in this magazine is an article on the use of port-a-caths. This is a device used to allow for frequent infusion in children who are on prophylaxis, in place of using peripheral veins. This article has been produced by the Haemophilia Care Team in Our Lady's Children's Hospital in Crumlin. We thank the team at Our Lady's for allowing us to reproduce this article which we hope will be useful for many parents.

Following the proposal from St. James's Hospital to the HSE, strongly supported by the Irish Haemophilia Society, St. James's Hospital have just purchased a Fibroscan machine. This will add an additional means of monitoring liver disease in people with haemophilia who have Hepatitis C, and should mean that there will be a less frequent recourse to liver biopsy. This is a very welcome development, and the Fibroscan should be available for people with haemophilia in the next few months.

October Members Weekend

The October Members Weekend has now become a regular and integral part of the I.H.S. calendar. The weekend this year will take place from 17th to 19th October in the County Arms Hotel in Birr, Co. Offaly.

The topics to be covered this year include lectures on 'Health Supplements' on 'Being Active', a talk on 'The Barretstown Childrens Camp', as well as a debate on the topic of 'Are there limits to my life's activities'?

There will be hydrotherapy and individual consultation with a physiotherapist. For the ladies on Saturday afternoon there will be a 'Time for discussion', followed by a 'Belly Dancing Workshop'.

As usual the teenagers and young adults will also have a separate weekend event at the nearby Adventure Centre.

Details along with booking forms, will be sent out to all members in early September.

New Staff

Patricia O'Connor has left the I.H.S. to take up a role at the Blackrock Clinic. We wish Patricia all of the very best in the future. I am delighted to be able to announce that 2 new staff started working for the I.H.S. at the beginning of July.

One of the new staff members, Declan Noone, will be very familiar to members. Declan has just completed his masters in medical engineering and we are delighted that he will be joining the Society's team.

The second new member of staff is Nuala McAuley. Nuala previously worked in administration at St. Patrick's Athletic Football Club and in joining the I.H.S. I believe she is now joining a better team.

Declan Noone

Nuala McAuley

Parent's Information

Port-a-Caths in Children with Haemophilia

Dr. Beatrice Nolan, Consultant Haematologist,
Our Lady's Children's Hospital, Crumlin

It is recommended that all children with severe haemophilia who are over two years of age or have had two joint bleeds receive regular doses of coagulation factor concentrate to prevent spontaneous bleeding and reduce the risk of long-term side effects. This is called prophylaxis. For children with severe factor VIII deficiency this involves injection of coagulation factor concentrate into the veins three times per week, for children with severe factor IX deficiency twice per week and for children with severe factor X deficiency once to twice per week. In small children and children with poor veins repeated intravenous injections can be very difficult and a port-a-cath or "port" is needed until the veins have developed. By the time your child is ready to start prophylaxis you will have discussed intravenous access and ports many times with your haemophilia team.

What is a Port?

A port is a special device, which is used to allow easier, more dependable access to your child's veins. It is made up of an injection port and a long hollow tube. The injection port is attached to one end of the tube and sits underneath the skin on your child's chest. The other end of the tube is placed in a vein close to your child's heart. When your child needs an injection a special needle is inserted through the skin into the injection port using a sterile procedure allowing access to his/her veins.

What happens when I decide my child needs a port?

When you and the haemophilia team have decided your child needs a port he/she will be referred to the surgeon who will send you an appointment to come to the surgical clinic to discuss the procedure. The surgeon will explain the procedure, the alternatives and the risks involved and answer any questions you may have. A date for the procedure will be arranged and you will receive notification of this date from the Admissions Department.

Please remember this date will be subject to the availability of a bed and you will need to confirm this with the Admissions Department before coming to the hospital. Although every effort is made to avoid cancelling procedures it is sometimes unavoidable!! It will be necessary to bring your child to your haemophilia centre the week before surgery to have a blood test performed to check for inhibitors. The haemophilia nurse will organise this.

How is a port inserted?

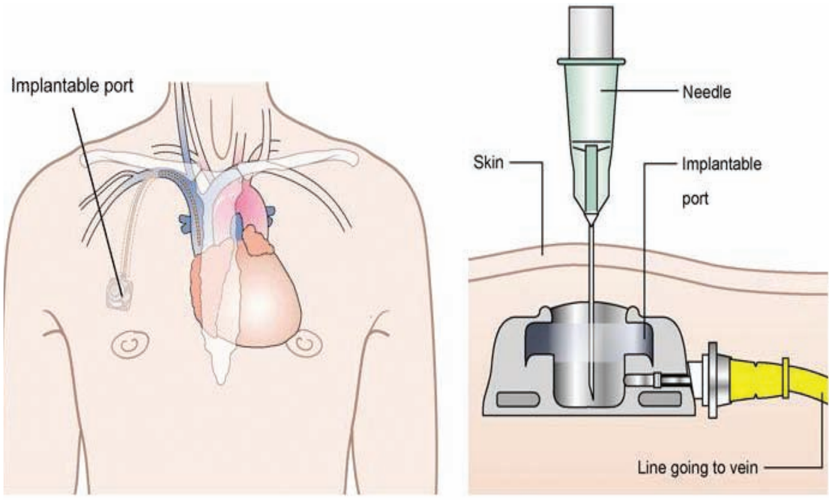
Your child will go to theatre and have a general anaesthetic for the operation. He/she will be in theatre for about two hours in total. The surgeon will insert the port. This usually takes about 30 - 60 minutes. The rest of the time is spent putting your child to sleep and waking him/her up again.

What happens when I take my child to hospital to have a port?

Admission: Children with haemophilia who need a port have the procedure at Our Lady's Children's Hospital in Crumlin. A six-day stay in hospital is usually required. Your child will be admitted to the hospital the day before the operation. You will need to phone Admissions that morning to confirm there is a bed available and confirm the time of admission (usually 2pm).

On arrival to the hospital you will attend the Admissions Office and from here you will be directed to the ward. Parents are welcome to stay either by the bedside or in parents' accommodation. Further information is available in the patient's handbook that will be provided by one of the haemophilia team.

Assessment: When you arrive on the ward a nurse will carry out a nursing assessment. A surgical doctor will examine your child.



Consent: The doctor will explain the procedure, answer any questions you may have and ask you to sign a form declaring that you have received sufficient information and you are giving your consent for the procedure. Do not sign this form unless you are happy you have all the information you need to fully understand the procedure. During the course of the evening or night a specialist nurse from the IV team will put in a cannula and take some bloods. Your child will need to fast for the operation. He/she will not be allowed food after 2am but may have a drink of clear fluids up until 6am the morning of the operation.

The morning of the operation

A dose of coagulation factor concentrate will be administered to your child to bring his / her factor level up to normal. A blood sample must be obtained from your child post factor administration. Once this blood is taken your child will be attached to a drip, which will administer coagulation factor concentrate for the next five days to keep his/her levels normal. He/she will have regular blood tests to make sure the infusion is maintaining his/her factor levels. As soon as the factor levels are confirmed your child will be taken to the operating theatre. All children with haemophilia having a port inserted will be in the theatre department before midday. One parent may go to theatre and stay with the child until he/she is asleep.

After the operation

After the operation your child will be sent back to the recovery room until he/she is awake and ready to go back to the ward. A nurse from the ward will collect your child from the recovery room. You may go to the recovery room with the nurse. Your child may be irritable when he/ she first awakens. This may be due to the anaesthetic or because he/she is sore or hungry. There will be a bandage over the wound to prevent bleeding and infection. This bandage should not be removed for 48hours. There will usually, but not always be a needle in the port.

If there is there will be a short tube with a bung on the end coming from the port. If there is a needle in the port it may be used immediately if absolutely necessary. Factor level cannot be taken from the port. On return to the ward the nurses will closely monitor your child, his/her pulse and blood pressure, the wound and the coagulation factor infusion.

Your child will receive pain relief medication during the procedure and should continue to have pain relief regularly for 24 to 48 hours afterwards. Paracetamol is usually sufficient but codeine may be required. It is important that your child has sufficient pain relief so he /she can move normally and not become stiff.

As soon as your child is awake and alert he/she can have something to eat and drink. It is a good idea to start with clear fluids and a light diet in case he/she is sick after the anaesthetic. As soon as they are tolerating food they can eat normally. The factor infusion will continue for five days after the surgery to ensure your child's factor levels are normal until the wound is healed. This means he/she will be continuously attached to a drip, which will restrict his/her mobility for five days. Please bring toys or books to help amuse your child during this period. The wound is generally closed with a dissolvable continuous stitch with steri-strips (plastic stitches) on the outside for added strength. The steristrips should be left in place and allowed to fall off of their own accord. This may take 10 days.

Long term care of the port

The haemophilia nurse in your centre will teach you how to care for your child's port.

[Many thanks to the team at Our Lady's for allowing us to publish this article]

Notice

Reminder to report Coagulation Factor Concentrate Reactions, Product Defects and Wastage

If you, or your child are on Home Treatment and experience any of the following:

Side effects to the Coagulation Factor Concentrate: i.e. dizziness, rash, general feeling of being unwell or nausea either during or following administration of the factor.

A Product Defect: i.e. notice a particle suspended in the reconstituted factor concentrate.

Accidental wastage of a vial of Coagulation Factor Concentrate: i.e. the water does not transfer into the power vial.

For Adults please report to:
Evelyn Singleton, Haemovigilance Officer
N.C.H.C.D., St. James's Hospital
Phone: 01 410 3000, Bleep 268
Direct Line: 01 410 3518

For Children please report to:
Bridin Brady, Haemovigilance Officer
Our Lady's Children's Hospital, Crumlin
Phone: 01 409 6100, Bleep 8734
Direct Line: 01 409 6647

What if something happens and I'm not there?

Primary school, secondary school and college can be stressful for all involved with or without haemophilia. What if something happens and I'm not there? Do people know what to do if something happens? Are they doing ok in class? Are they making friends? Bullying? When haemophilia is involved in the process, other problems arise for kids and adults. One of the big ones for the kids is, why do I have to be different? So how do you reduce the worry, even just a little bit?

Let's clear up one of these questions straight away. Something WILL happen. Murphy's Law or whatever you want to call it but no matter how well you plan something will happen. Quick example, I used to play soccer at break time with the other kids. One time I was asked to stand at the post. No problem I had done it before so it was no big deal. The ball gets crossed in hits me in the face, pushes my head back against the metal post, and I got concussion. So I stopped playing for a while and I felt isolated. About a month later I was sitting watching a game of volleyball from the sidelines just leaning back against the wall.

Suddenly somehow my head developed a personal gravity field and pulled the volleyball directly to my face knocking me back against the wall and again I got concussion. So what was better, not playing and feeling isolated or playing and having the same thing happen? From working with kids over the years, and as parents you know these sort of incidents are common, it's rarely the things you plan for that are the problem.

So what can you do to prevent it? Nothing! You can only really put the best possible plan in place. Thankfully with prophylaxis, spontaneous bleeds are reduced and factor levels are in the best range they can be. The quality of the kids lives today are greatly improved so they can take part in a lot of activities and reduce the feeling of isolation. So what else can you do to reduce stress to yourself, the teachers and the child when something does happen? Explain to the teachers the facts and what they need to know about haemophilia such as what to do if the child is limping or complains of being sore, (i.e. ice, rest, & call parents) and how immediate contact with the parents is important especially for head or back injuries.

If your kids are going to school for the first time and you are not sure about all the details you should give or if you have any queries, contact us at the Society. We will be happy to help.

This is a hint which you may choose to ignore, but my personal opinion is not to let the child know you talked to their teachers, for two reasons. Firstly, it can create the feeling with the child that they are being

watched, which isn't a nice feeling and secondly (speaking from experience) if the child knows what the teacher has been told they might use their haemophilia to get out of certain things. One common worry with children is the want to fit in or feel "normal" (forgive me for the term but I think you know what I mean). With prophylaxis this is easily achieved when it comes to school activities, sports and generally being more involved on a physical basis.

However, and this is just a thought, sometimes with kids trying so hard to be part of the group they end up hiding their haemophilia, and are afraid of the others finding out and want it to just go away by ignoring it. I am not suggesting the child should tell everyone they meet but encourage them to be proud of who they are, including their haemophilia and to be comfortable with all that surrounds it.

The earlier this starts the more interest they will have in self-infusion and taking responsibility for themselves which has a knock on effect if something does happen at school or when the parents aren't around. Continue this throughout primary and secondary school and it will continue into college and for the rest of their lives.

So, what are the worries for college if you are sending your kids off for the first time in September? I will only look at haemophilia related problems and not ones like how to make a slice of bread and a tin of sweetcorn last for 3 days. Firstly, I just want to mention that most college's have a number of services that you can access.

The major areas that parents seem to worry about are: what if they get knocked unconscious, don't get a vein, or don't take factor. Ok being knocked unconscious, apart from being prepared with medic alert badges and the medic alert cards from St. James's, there isn't much you can do about it no matter where you are.

I realise you are parents and that it is your right to worry, but it should be the same as with your other kids and not more so because they have haemophilia.

If they do not get a vein then they can try another and if that doesn't work then there is always the option to go to the local hospital and it can be administered as long as you bring the medicines and the boxes they come in are brought in. I'm glancing over this because it does happen all the time.

I started self-infusing at 9 and almost always got a vein. I went through a period in my leaving certificate year where I couldn't get a vein for about 6 months.

> **"One common worry with children is the want to fit in or feel normal"**

Once you lose that confidence it can be hard to get it back but it happens us all, and it always comes back, so don't worry you will get it in the end.

And finally the issue of not taking factor or as I like to call it haemophilia related optimism. Lets be honest none of us want to take a shot ever and that never changes. We have all used the phrase "maybe it will go away" or "maybe it's just tired". When your kids are away they will eventually realise that it doesn't and it's not just tired. This is one of those lessons they have to learn themselves and you can't really help with unfortunately. They will figure it out themselves some night they want to do something and they ignore it and then end up coming home early or going to the hospital but at the end of the day by its their choice. They will figure it out.

In case you are wondering about sports for kids in school or college this is a discussion for another day but staying fit is a huge benefit. An active lifestyle encourages healthy muscle and keeps a good range of movement and I personally see a reduction in bleeds as well as the obvious social benefits.

In summary, parents this is a hard time for you in general sending kids to school for the first time or changing schools or college but with current treatment and educating the kids on haemophilia, you shouldn't have any more worries than normal. Kids, don't worry about school or college and haemophilia.

Just be yourself and it will all work out…..eventually!

Declan Noone

Moving out of home!

Hi all, I'll start be introducing myself - I'm Erin, a 17 year old guy with mild / moderate haemophilia A. Like a lot of people around my age, I finished school, started working, made a lot of new friends and really started thinking about moving out of home. I worked out all the things I would need to move out - a lot of my clothes, furniture for my room, and as nobody else had really thought of it, a little and a big pot for pasta. Then I realised that I would need to organise how I would get my factor. When I moved out I didn't actually move very far, about 20 minutes away. So getting my factor didn't really change much, it was just a longer drive to the local hospital. The bigger challenge was telling people I was staying with that while it might look a bit weird I was going to have to keep my factor in the fridge.

With something like haemophilia I have found that it is best to keep those surrounding you as well informed as possible, so I sat them all down and explained that there would be some times when I would sit at the kitchen table with a bunch of needles, and the little boxes in the fridge would diminish. They asked the usual questions "Will you bleed to death?" and "Is there anything we can do to help?" The first question I laughed at and explained "No, I'm just about as likely to bleed to death as you are", and the second I said that I really appreciated it, but all they would really need to help with would be to be a little patient if I needed to use the kitchen table for 20 minutes. Other than explaining it to my mates, living out of home has been a lot of fun, and my treatment regime has changed only in that I now travel further for my factor, but that's about it.

Erin James

[Article from Youth News June 2008 - Haemophilia Foundation of Australia]

Haemophilia Doesn't Stop You!

Noel O'Brien from Portlaoise went to New York on May 22nd 2008 to compete in the Olympics for the Physically Challenged. He took part in a number of events: track and field, and he came home with four gold, two silver and two bronze medals. He did extremely well and took part in every challenge he encountered.

The Olympics has been running for the past 20 years and he is the only person with haemophilia to our knowledge in Ireland to have taken part in those years.

Noel has shown haemophilia does not stop him from living life to the highest. Noel's family are extremely proud of him and we send him many congratulations on his achievements!

Congratulations Noel!

Grants & Scholarships

Attention Scholars!
It's that time of year again.

Applications are now invited for the **Maureen Downey Memorial Grant** and the **Educational Scholarship** for the academic year 2008 - 2009.
Please forward applications together with details of your third level course applied for, and eligibility for the grants to:

Margaret Dunne
Irish Haemophilia Society
Cathedral Court
New Street
Dublin 8

Applications can also be sent by email to: margaret@haemophilia.ie

Maureen Downey Memorial Grant
2008 - 2009*

This grant is made available to a person with haemophilia to help fund the cost of their third level education. Any person applying for the grant must have been accepted on a course in any University, RTC or other third level institutions.

The grant is in the amount of €4,000.

Educational Scholarship
2008 - 2009*

This Scholarship is being granted to assist with the cost of third level education, for an immediate family member of a person with a bleeding disorder, i.e. sister, brother, mother, father, son or daughter. The person applying for this must have been accepted on a course. The Scholarship is in the amount of €2,000.

CLOSING DATE IS FRIDAY 26TH SEPTEMBER 2008

** Depending on the number and quality of applications received, the I.H.S. Board may, at their discretion, award additional grants in lower amounts.*

Colm Connolly who won the Maureen Downey Memorial Grant in 2004 with Pat Downey

Aisling Begley who was the recipient of the Educational Scholarship in 2004 with Margaret Dunne

Fundraising

Women’s Mini Marathon
2nd June, 2008

Congratulations and many thanks to all of you who took part on behalf of the Irish Haemophila Society in this years Mini Marathon. We really appreciate the continuing support of members and friends who support this fundraising event by taking part or by sponsoring a participant. The overall numbers taking part in this annual event continues to grow with a reported over 40,000 runners and walkers this year.

In the serious race the winner was Annette Kealy from Dublin who finished in an incredible 35.45 minutes, with second place going to Pauline Cleary from Offaly in 36.05 minutes. Third place went to Siobhan O’Doherty from Tipperary at 36.10 minutes. While these are incredible times for these super athletes, the main focus for the majority of those taking part is the ability to go out and have a good day, while raising funds for so many different worthy charities.

Every year one or two staff members have attended in Buswells to make sure that participants are sorted with a T-shirt and to organise the refreshments with the hotel. It is always a very enjoyable day and we welcome the opportunity to meet with members in what is always a very relaxed and friendly atmosphere.

Unfortunately this year the WFH Congress week clashed with the Mini Marathon, and we were unable to have a staff person there. We would like to apologise to all of you who expected to see one of the ladies there, particularly if there was anything you needed to speak to us about. We are grateful to the two volunteers Trish Cox and Declan O’Mahony, who stepped in at the last minute this year. We appreciate that people have given up their Bank Holiday to support us, and it is our intention to always have a staff person in attendance on the day.

Margaret Dunne

Fundraising

Barry Harris Memorial Walk

Bina Harris

The Barry Harris Memorial walk has taken place on St. Stephens Day every year for the last 13 years. The walk was started originally by Bina Harris in memory of her husband Barry. Each year the walk starts in the village of Creggs on the Galway - Roscommon border and the walk goes up, down and around the local Mount Mary, which is a total of 10km. People of all ages, shapes and sizes take part and every year at the half way mark there is a quick pit-stop for some sandwiches or a hot whiskey to keep everyone warm until they reach the end. From the small beginning of a local charity walk it has grown from strength to strength each year, now raising over €30,000 a year for 15 local and global charities. The IHS has received €11,300 over the last 10 years.

We would like to acknowledge and send a big thank you to Bina and all the organisers and walkers who have supported this event and have helped raise very important funds for the Society throughout this time. Your support is very much appreciated. Keep up the great work!

Declan Noone

Living Life to the Highest!

Stephen McEvoy Junior from Athy in Co. Kildare recently did a Parachute Jump in aid of the Society, and raised €1050.

Along with fulfilling his dream it was great that Stephen was able to raise funds for the Society. Stephen skydived from approximately 10,000 feet at a speed of around 120 miles per hour.

We would like to send our thanks to Stephen and his family for their support. Congratulations and well done Stephen!

Debbie Greene

Stephen McEvoy

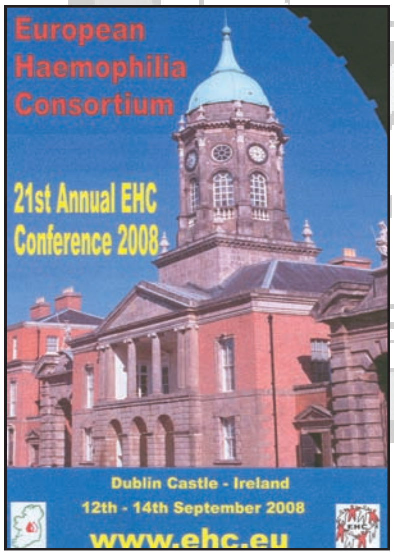
Calendar of Events

SEPTEMBER

European Haemophilia Consortium Conference

Dates:
Friday 12th to Sunday 14th September

Venue:
Dublin Castle



The 21st Annual Conference of the EHC takes place in Dublin, from September 12th to14th 2008. We are delighted to be hosting this event and look forward to welcoming a mix of respresentatives from industry, regulatory authorities, medical professionals and national haemophilia societies throughout Europe.

The venue for the conference is Dublin Castle and the programme includes lectures on the following:

1. Toward a European Standard of Care
2. Haemophilia & Patient Mobility/Migration in the EU
3. Education, Integration & Participation-The Irish Model of Care
4. From Survival to Quality of Life- Setting National Treatment Goals & Targets
5. Reproduction & Haemophilia
6. Psychosocial Aspects of Haemophilia

We hope this conference will prove to be an opportunity for delegates to meet each other, to build friendships and to contribute to lively discussions.

SEPTEMBER/OCTOBER

Regional Visits

Monday 29th September: Cork

Tuesday 30th September: Limerick

Wednesday 1st October: Galway

Thursday 2nd October: T.B.A.

The Society is organising another set of Regional Visits later on in the year, and we would encourage you to attend these meetings to hear updates on the Society's activities and to discuss any issues of concern.

The venues will be confirmed as soon as possible, and meetings will take place in the evenings. Representatives from the Society are also available for individual meetings with members in the afternoons, prior to the evening meetings.

Keep checking the website for further updates on the venues.

OCTOBER

Members Weekend

Dates:
Friday 17th to 19th October

Venue:
County Arms Hotel, Birr, Co. Offaly

Our third Members Weekend which has become a great success takes place from 17th to 19th October. On page 2 you will find details of the Preliminary Programmes for this weekend.

Calendar of Events

NOVEMBER

Service of Remembrance

Date: Sunday 9th November

Venue:
Offices of the I.H.S.

As part of the commemoration of the 40th anniversary of the Irish Haemophilia Society a 'Service of Remembrance' will take place in the offices of the I.H.S. on Sunday 9th November.

We would like to invite you and your family to our Service of Remembrance in memory of all deceased members of the Irish Haemophilia Society.

If you cannot attend in person please be assured that your loved one's first name will be included on the list of remembrance.

NOVEMBER

Hepatitis C / HIV Update

Date: Wednesday 12th November

Venue:
Offices of the I.H.S.

The Society has organised an update meeting on Hepatitis C and HIV treatment. This will be held at the I.H.S. office in Cathedral Court, New Street, Dublin 8 on Wednesday 12th November.

Take this opportunity to meet the experts and update yourself on HIV and Hepatitis C treatments. We will be writing to members in October confirming speakers for this meeting.

NOVEMBER

Peer Support Post Tribunal Workshop

15th & 16th November

We organised a Post Legal Workshop last year which was very successful. We are hoping to organize a further workshop this year.

The aim of the workshop is to bring members and their partners together who have completed the Compensation Tribunal process.

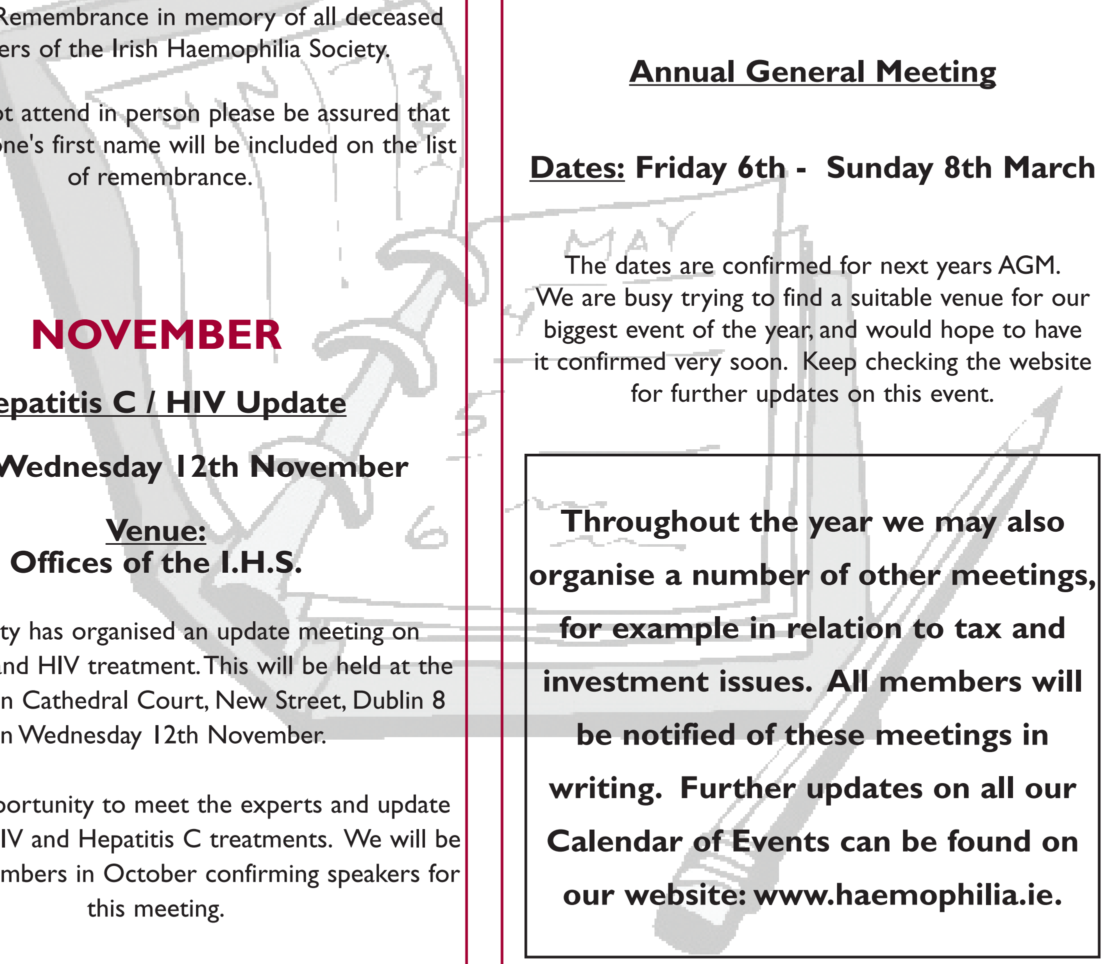
MARCH 2009

Annual General Meeting

Dates: Friday 6th - Sunday 8th March

The dates are confirmed for next years AGM. We are busy trying to find a suitable venue for our biggest event of the year, and would hope to have it confirmed very soon. Keep checking the website for further updates on this event.

Throughout the year we may also organise a number of other meetings, for example in relation to tax and investment issues. All members will be notified of these meetings in writing. Further updates on all our Calendar of Events can be found on our website: www.haemophilia.ie.



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