

# haemophilia.ie

Magazine of the Irish Haemophilia Society

Edition: September 2012

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



## The Society at a Glance

HIS IHS  
Attendance

11



Followers on  
Facebook

262



Registered  
Volunteers

40



Grant &  
Scholarship  
Applications

19



Website Hits  
(Apr - May)

3,797



## WHAT'S INSIDE:

- \* A report from HIS IHS Meeting
- \* Articles on needlephobia & vein rotation
- \* An update on the IHS Planned Giving & Fundraising campaigns



# IMPORTANT REMINDER

## Contact Details

Irish Haemophilia Society,  
First Floor,  
Cathedral Court,  
New Street,  
Dublin 8.

**Phone:** 01 6579900

**Fax:** 01 6579901

**Email:** [info@haemophilia.ie](mailto:info@haemophilia.ie)

**Website:** [www.haemophilia.ie](http://www.haemophilia.ie)

**Editor:** Debbie Greene

**Sub Editor:** Nuala Mc Auley

**Executive Board:**

**Chairperson**

Traci Dowling

**Vice Chairperson**

Brian O'Riordan

**Secretary**

Mary Hanney

**Treasurer**

Gerard O'Reilly

Brian Byrne

Eoin Moriarty

John Stack

Sarah Gilgunn

Michael Butler

**Staff:**

**Chief Executive Officer**

Brian O'Mahony

**Administrator**

Debbie Greene

**Counsellor**

Anne Duffy

**Office Team**

Nina Storey

Declan Noone

Nuala McAuley

Fiona Brennan

In the past 3 months, there have been specific cases where members encountered real difficulty because they did not have useful documentation with them, when needing treatment.

### **Case 1 :**

A member endured several hours of delay before assessment and adequate treatment was provided at a major Dublin teaching hospital. He did not have his Severe Bleeding Disorder Alert card in his wallet.

### **Reminder:**

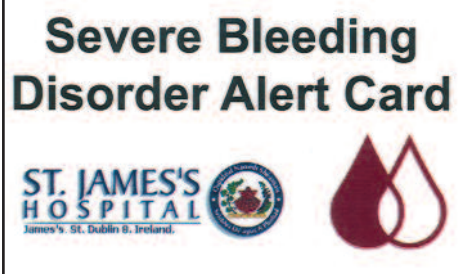
Please carry your Severe Bleeding Disorder Alert Card with you at all times.

### **Case 2:**

A member was billed for treatment with factor concentrate in an EU Country as they did not have an EHIC card.

### **Reminder:**

Please make sure that each of you has an EHIC card.



### **Case 3:**

A member who was hospitalised abroad had inadvertently not renewed his Travel Insurance available to HAA card holders.

### **Reminder:**

Please renew your travel insurance and do not allow it to lapse. Please also be aware that reminders are not routinely sent out.



**Please ensure you carry all the necessary documents with you at all times, particularly when travelling abroad.**

## CONTENTS

- 4 Administrator's Report.
- 6 IHS Accommodation Facility.
- 7 Update on the IHS Planned Giving Campaign.
- 8 Fundraising Facts.
- 9 Dates for your Diary.
- 10 Cubs Club.
- 11 Kidlink Page.
- 12 Back to School - Educating the Educator.
- 14 It's a Man's World.
- 16 In the Spotlight - Needlephobia.
- 18 Taking Care of your Veins.



*Nuala Mc Auley  
Sub Editor*

### A Note from Nuala

**G**reetings from the IHS office! Welcome to the September edition of haemophilia.ie. As sub editor I really hope you enjoy the magazine that we have put together - which includes interesting articles on needlephobia and vein rotation as well as updates on the IHS Planned Giving and fundraising campaigns.

I hope you all had a great summer? I know all of us in the office did. Although the weather was not great there was plenty going on to keep us entertained! In June some of the staff were lucky enough to witness the Olympic torch make the journey past the office. Staff and Board members of the Haemophilia Foundation of New Zealand visited the IHS in June. This was a great opportunity to share ideas and discuss challenges facing the organisations.

A huge well done to all our youth group members who had exams during the summer. We hope you all are happy with your results, but remember there are always options so don't feel too downhearted if your results aren't exactly what you wanted.

In July the staff, along with a number of members and board members travelled to Paris for the WFH World Congress. It was a very informative, and beneficial week. You can read reports from the Congress in the IHS Congress supplement enclosed, or log on to the website and read the blog that the staff wrote during the trip.

July and August saw all the staff in the office come down with a case of Olympic fever and discussions at breaks and lunch soon turned to our favourite events and athletes. It was great to see the Irish Olympians doing so well. Although boxing may not be a sport people with bleeding disorders should take up, there are many other ways to stay in shape and a list of recommended sports can be found on the website [www.haemophilia.ie](http://www.haemophilia.ie)

I will sign off now and let you read what I hope you will agree is a fantastic issue.

Happy Reading!

**Nuala Mc Auley**  
Sub Editor

# Administrator's Report

## Hepatitis C Treatments

Some good news! Since our last magazine and last Hepatitis C supplement, the Society has been working extremely hard with the hepatologists, St. James's Hospital, the Department of Health & Children and the H.S.E. to try and resolve the issues that had delayed the roll out of the new treatments for Hepatitis C. Thankfully the roll out of treatment to our members has begun. These new treatments for Hepatitis C (genotype 1) Telaprevir and Boceprevir were licensed late last year and look very promising.



Debbie Greene  
Administrator

she and can be contacted on 01 657 9900 or 087 232 0255. Preparing yourself for a lengthy course of any treatment demands thought, preparation and commitment which can in turn make the journey a less gruelling one, and no doubt you need to prepare personally and medically. If you need any assistance, please do not hesitate to contact Anne.

## HFNZ Visit

In early July Belinda Burnett and Coleen Mc Kay from the Haemophilia Foundation of New Zealand visited the I.H.S. During their visit we held several workshops on social media, outreach, youth development, volunteering and advocacy. Working with other National Member Organisations ensures that we are on the right track with the services and support we provide.



The IHS Staff with Belinda and Coleen from the Haemophilia Foundation of New Zealand.

## Publications

It has been a very busy year with publications. At the start of the year we discussed what publications were needed this year and came up with a list of 16 publications in total to be done. Already we have produced the "Spring, Summer and Autumn Magazines" and the "Annual Report", along with a new magazine supplement called "Positive News" which is an information magazine for people with haemophilia with Hepatitis C and/or HIV on treatment or considering going on treatment. It is hoped that we will produce two to three more information magazines this year for our members. You will also see enclosed with this magazine a supplement with various articles from those who attended the "World Federation of Hemophilia Congress 2012", in Paris in July. We also produced a publication on "von Willebrand Disease", which was circulated amongst the membership earlier on in the year. We also felt there was a need to put together an "Information Pack" / "Introductory Pack" for new members. I am pleased to say that this has also been complete which includes information on our services and supports, our charter, a



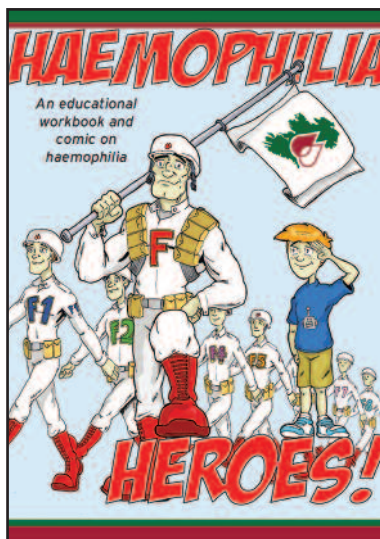
Positive News is an information magazine the I.H.S. produce to keep members up to date with new treatments and results.

Members who are going on treatment may have to attend St. James's Hospital frequently during their treatment, and we can see that this might be a significant burden to those from outside Dublin. With that in mind we can now offer members from outside Dublin accommodation in Dublin when required. For more information on this please go to page 6.

We are committed to providing practical support and assistance to our members who are on treatment or thinking of going on treatment. Our nurse / counsellor Anne Duffy is available to give support and assistance,

membership form, a list of publications, our booklet on “Introduction to Haemophilia”, and our contact details. Any new members now receive these packs either via ourselves here in the office or via the Our Lady’s Children’s Hospital Crumlin, the National Centre or via the new treatment centre at Cork University Hospital.

For me the most exciting publication we have done in a long time was the publication for children called “**H a e m o p h i l i a Heroes!**”. This is an educational workbook and comic for children with haemophilia. This publication has been a great success and the feedback we have received from members and from other National Member Organisations abroad has been terrific. A lot of thought and hard work was put into this publication particularly by Nuala McAuley and Declan Noone and I hope you agree it was very worthwhile. If any of you need an extra copy, don’t hesitate to give us a call on 01 6579900.



*Haemophilia Heroes is an educational workbook and comic for children with haemophilia.*

So we are eight publications down with eight to go. Although it is a big task, some might say goals are dreams with deadlines, and if you give me six hours to chop down a tree I will spend the first four hours sharpening the axe! Well fear not we have the axe sharpened and the text is almost complete for publications on “**Mild Haemophilia**” and “**Portacaths**”. Research is being done for a publication on “**Ageing and Haemophilia**” and a booklet for “**Siblings**”. Which just leaves the “**December magazine**”, two more “**Positive News**” information magazines and a “**Transition Workbook for Teenagers**”. In my opinion this is doable.

### **Fundraising**

Some of you may recall contacting Nina or myself in the office in relation to organising a fundraising event in the past, wondering if we were signed up to the “Mycharity.ie” website service. I am delighted to tell you that we have now signed up! For those of you who never heard of “Mycharity.ie”, they provide web-based fundraising and

donation services to charities via their website [www.mycharity.ie](http://www.mycharity.ie). For more information on this please go to page 8.

A quick reminder also to those of you who participated in the Women’s Mini Marathon in June, if you get your sponsorship money into us by the end of September you will be entered into a draw for a weekend away in Ireland for two people.

### **In-patient Unit in St. James’s Hospital**

Work on the new in-patient unit in St. James’s Hospital is well under way. I.H.S. CEO, Brian O’Mahony was lucky enough to view the unit with Dr. Barry White, National Director of Quality and Clinical Care in September. We will keep members updated on the progress of the new unit.



*Dr. Barry White, HSE & Brian O’Mahony, I.H.S. CEO take a tour of the new in-patient unit in St. James’s Hospital.*

**Debbie Greene  
Administrator**

# Accommodation Facility

We are pleased to inform you that the Society recently purchased an accommodation facility on the South Circular Road in Dublin 8 which is a 5 minute walk from the National Centre for Hereditary Coagulation Disorders (NCHCD). The facility consists of a two bedroom apartment and a separate one bedroom apartment. The apartments are available to:

- \* People with haemophilia or related bleeding disorders from outside of Dublin, when attending St. James's Hospital or Our Lady's Children's Hospital, Crumlin for treatment, for a hospital appointment or for a review clinic.

- \* An immediate family member, a spouse, a partner and / or children of the person with haemophilia or related bleeding disorder from outside Dublin, when attending St. James's Hospital or Our Lady's Children's Hospital, Crumlin for treatment, for a hospital appointment or for a review clinic.

The facility should be particularly useful if you are travelling up from the country to make an early hospital appointment, or if you are attending hospital appointments on consecutive days.

A nominal fee of €10.00 per booking per night will be levied to offset the cost of cleaning and routine maintenance. There is one car parking space available so on any given night there will be a space available on a first come first served basis.

If you would like to book the apartment please contact Anne Duffy on 01 6579900 / 087 232 0255. If Anne is not available please ask for me or any member of staff and we will deal with your query or booking.

**Debbie Greene**



# Planned Giving Appeal: An Update

As of September 2012 - 30 members have signed up to the planned giving appeal:

<b>April 2012</b>	<b>Signed up Members</b>	<b>7</b>
<b>May 2012</b>	<b>Signed up Members</b>	<b>9</b>
<b>June 2012</b>	<b>Signed up Members</b>	<b>9</b>
<b>July 2012</b>	<b>Signed up Members</b>	<b>26</b>
<b>August 2012</b>	<b>Signed up Members</b>	<b>30</b>

\* Two members have increased their previous monthly contribution amounts.

\* Nine members have given once off contributions.

\* Nineteen new members are making monthly or annual contributions.

**We hope that you - the members of the Society - will play an active role in allowing the organisation to thrive in the future by positively considering donating to the Society for a five year time period on a planned basis.**

**We are asking members to consider committing planned monthly or annual donations to the Society at a level which they can afford for a five year period.**

Of the funds raised, 75% will be allocated to the cost of purchasing the accommodation facility in Dublin and 25% will go to our overseas development fund.

## Donation Levels

<b>Platinum</b>	<b>€1,000 annually or €80 per month</b>
<b>Gold</b>	<b>€600 annually or €50 per month</b>
<b>Silver</b>	<b>€300 annually or €25 per month</b>
<b>Bronze</b>	<b>€100 annually or €10 per month</b>

The Planned Giving campaign was formally launched at the AGM and Conference back in March. We hope that you will consider participation in this planned giving campaign to allow us to work for a better future for you and for all those with haemophilia and related bleeding disorders.

Many thanks to those of you who have signed up.

**Debbie Greene**

IRISH HAEMOPHILIA SOCIETY LTD  
Cumann Haemifile Na hEireann

## 5 Year Planned Giving Appeal

Irish Haemophilia Society Ltd.  
First Floor, Cathedral Court, New Street, Dublin 8, Ireland  
Telephone +353 1 657 9900. Facsimile +353 1 657 9901  
Email info@haemophilia.ie Web www.haemophilia.ie

# Fundraising

The I.H.S. are now live on the [www.mycharity.ie](http://www.mycharity.ie) website!

[www.mycharity.ie](http://www.mycharity.ie) provides web-based services to charities and fundraisers alike to make it as easy, simple and as safe as possible to raise money for charity. The website offers charities the ability to take donations directly online. In addition it offers anyone who wants to organise a fundraiser the opportunity to create their own unique fundraising page, which allows you to raise money for a charity which is easy, safe and secure.

Fundraising is easy on [www.mycharity.ie](http://www.mycharity.ie). You just go to the home page [www.mycharity.ie](http://www.mycharity.ie) and click on "create a fundraising page". You will then be brought through a short sequence of pages where you:

1. Choose your event date and name.
2. Choose a charity (which is hopefully the I.H.S.).
3. Fill in some details about your fundraiser and how much money you would like to raise.

That's it! You then just email the link from your page to everyone you know or who you think might sponsor you, and the money comes directly to ourselves, it couldn't be simpler.

Some of the benefits to the person fundraising are that its easy to set up, it requires minimal effort, there is no need for sponsorship cards, there is no counting, storing or lodging of cash, and you don't have to chase cash from people who promised to sponsor you.

By using this website you are also helping us because there is no overhead cost to the charity, funds raised by you go directly into our bank account and this in turn reduces administration.

If you would like more information on this, have a look at the homepage of our website and click on the [www.mycharity.ie](http://www.mycharity.ie) logo, or give Nina or myself a call in the office on 01 6579900.

The main fundraising event for the Society is the Women's Mini Marathon, however another fundraiser that is really starting to take off all around the country is 'Movember' when during the month of



November men grow a moustache to raise funds for charities. Last year we were delighted that members raised €1,320 which was really well done. So gentlemen if you have always wondered what you would look like with a moustache why not give it a go and raise money for a good cause at the same time! This is a fundraiser that we want to see going from strength to strength, but we really need your support.

For more information on this fundraiser please contact Nina in the office on 016579900 or [nina@haemophilia.ie](mailto:nina@haemophilia.ie).

**Debbie Greene**





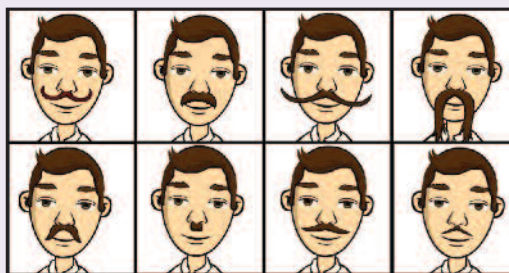
# Dates for your Diary

## OCTOBER

**Dates:** 12th to 14th October  
**Event:** Members Conference  
**Venue:** Heritage Hotel, Portlaoise

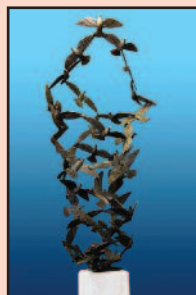
## NOVEMBER

**Date:** 1st - 30th November  
**Event:** Fundraiser  
**Venue:** Everywhere



## NOVEMBER

**Date:** 4th November  
**Event:** Memorial Service  
**Venue:** I.H.S. Office



# 2013

## MARCH

**Date:** 1st - 3rd March  
**Event:** AGM & Conference  
**Venue:** The Osprey Hotel, Naas



## JUNE

**Date:** 14th - 16th June  
**Event:** Parents Conference  
**Venue:** Johnstown House Hotel, Meath



## OCTOBER

**Date:** 11th - 13th October  
**Event:** Members Conference  
**Venue:** The Bloomfield House Hotel, Mullingar

# Cubs Club

Welcome to the Cubs Club!!

You have all settled back into school now or maybe some of our Cubs Club members started big school for the first time this year.



School can make you feel really happy or a little bit scared sometimes but remember making new friends can be a lot of fun!!! Why not draw a picture of some of the new friends you have made?



**Riddle me this!**  
 What is white when  
 it's dirty and black  
 when it's clean??  
 Answer at the bottom of  
 the page.

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

There are twelve words hidden in the wordsearch, can you find them? We have given you eleven words, can you identify the missing word? Here's a clue..... it's a subject!

- |       |        |       |        |
|-------|--------|-------|--------|
| Art   | Book   | Desk  | Fun    |
| Paper | Pencil | Read  | School |
| Sing  | Snack  | Spell |        |

Log onto [www.haemophilia.ie](http://www.haemophilia.ie) to get the answer!

**REMEMBER:** Ask an adult before logging on!

# Kidlink Group

## Self Infusion – so what’s it all about?

When you are young if you need factor regularly the doctors might decide to insert a port – a – cath (you might know it as a Freddie!) under your skin to help give you the factor. When you get older your veins will become stronger, and your parents will learn how to give you factor through your veins instead of your Freddie. You can help your parents with this in the beginning by mixing the factor, putting on the tourniquet and helping them to look for a good vein.

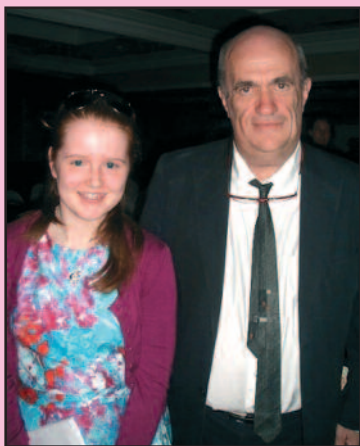
Eventually, when you are ready, you will learn how to do this yourself. It will take some practise but when you can do it, getting your factor will be much quicker and you will be able to go on school or sports trips with your friends. Don't forget the first time you self – infuse, if you ring the office the I.H.S. will send you out a certificate and a voucher for all your hard work!!

Remember....practice makes perfect!!!

Now that we have talked about self infusion can you find the words below in the word search?

- Bandage
- Bleed
- Gauze
- Journal
- Needle
- Sterile
- Syringe
- Tape
- Tourniquet
- Vein

T	E	U	Q	I	N	R	O	U	T
G	G	A	O	G	D	O	A	B	A
L	A	N	R	U	O	J	L	E	S
T	D	U	Q	A	N	A	S	N	S
A	N	J	Z	T	U	V	Y	A	T
P	A	E	E	E	L	E	R	Z	E
E	B	O	E	N	O	I	I	O	R
U	E	B	R	D	T	N	N	R	I
E	I	O	A	R	L	P	G	F	L
D	E	E	L	B	N	E	E	B	E



### Molly has the Write Stuff

Congratulations to Youth Group Member, Molly O'Mahony who won "The Under 14 Creative Writing" category in the Listowel Writers' Week.

Molly's story, "The lonely life of Anthony Apostrophe" can be viewed on the IHS website [www.haemophilia.ie](http://www.haemophilia.ie)

Molly is pictured left with Listowel Writers' Week President and bestselling author Colm Tóibín.

# Back to School - Educating the Educator

Parents worry, this is a well known fact. During pregnancy they worry if the baby will go full term and if he/she will be healthy. When the baby is born they worry about the child's eating and sleeping habits. Each new stage of a child's development brings a new set of worries, none more so than the school going age.

There is no doubt about it, the first day a child starts school is a huge milestone. In fact it is many things, it is; scary, strange and an emotional day for all involved. Not surprisingly it is usually more nerve wracking for the parents than the child. Will they make friends? Will they survive a day without me? All these worries and fears are natural, but it is important, as parents, not to alert the child to your anxiety as this will make them more nervous.



When a child has a bleeding disorder these anxieties are heightened. Will he/she know to tell the teacher if he/she has a bleed? Will the other kids pick on him because he has a bleeding disorder? What if he/she falls in the yard and bangs their head? Will the teachers know what to do?

Whether your child is starting school or going into a crèche/playschool for the first time their first day can be hectic. The child can be excited or nervous or a combination of both.

It is hard to manage your nerves while trying to deal with a hyper child, so put yourself in the shoes of the teacher - a first day with 25 or more excitable children and many anxious parents, they will talk and reassure you that your child/children will be ok, that's if you can hear them over that one

child who is screaming. The first day is not the time to try and educate the teacher on your child's bleeding disorder, they have a lot to deal with. Before your child starts school get in touch with the principal and offer them information on your child's bleeding disorder.



The Irish Haemophilia Society have an information booklet and posters for teachers and playgroup leaders. The information booklet can be given to the school for them to read, and the poster can be given for display in the classroom or in the staff room.

I don't like to use this word, but in the recession, cuts have been made to the education sector which means added pressure on teachers and school resources, but the education, safety and comfort of the student is always paramount. If you have given the information and still have some concerns, make an appointment with the teacher and/or the principal. If the school wants, or if you would like to offer, a member of the Irish Haemophilia Society Staff can go to the school/crèche and talk about bleeding disorders and what that means for the child and for them as the supervisor. Haemophilia and von Willebrands Disease are the most common bleeding disorders, but are still rare disorders. The likelihood is that the school/crèche will never have had a child with a bleeding disorder in their care and will be looking for information. You do not need to educate the school team alone, the I.H.S. are here to help make the transition of a child into a school/crèche as easy as possible.

As the school may not know about bleeding disorders they may have some misconceptions i.e. that the child needs one to one care, that the child will not stop bleeding if they get a paper cut or that the child should not be allowed to play in the yard with the other children. Remember this is new to them and it is natural for them to ask questions, once they have the information they will understand there are no limitations to what your child can do.

Make sure that the school/crèche has the correct contact information for you in case of emergency, don't just leave one contact number, there is always an occasion when you can't answer your phone so better to be safe and have a back up for you, just in case!

It will be an adjustment having your child in crèche or at school and naturally it will take some time to settle into a routine and for you to stop



worrying, or at least worry less. Give yourself time, but remember the I.H.S. are always here if you need to talk – not just about bleeding disorders, but about life!

\* Show your child where you will collect them at the end of the day, they need to know you are coming back.

\* Teach your child the important information i.e. who they should tell if they have a bleed.

\* Be on time – in dropping off and picking up. It is scary for a child to walk into a class full of new people. It can be scarier to walk into a class that has already started. The child will be anxious to see you when class is over; try and be there waiting for them. Seeing other parents and not seeing you could make them anxious.

\* Give them time – after school they will want to tell you everything – from how nice their teacher is to who their best friend is – set aside time for them to tell you their life story, don't push them for information they will want to tell you themselves.

Tips to help your child settle in school/crèche:

\* Talk to your child about starting school/crèche knowing what's ahead can help them prepare.

\* Does your child know any other children starting in the school? If so tell them there will be children they know there. Sometimes the fear of the unknown scares us the most so knowing there will be a familiar face can help ease first day nerves.

\* Tell your child about your first day at school or read them a story about someone starting school (happy stories only).

\* Take your child to school on their first day. Starting school is stressful and having a parent to hold their hand will help the child relax.



\* Be patient – the first day will have an air of excitement, but after a week of early mornings, uniforms and learning, the fun might wear off and be replaced by a tired, grumpy child so be prepared and remember, we all have mornings like that!

Tears and tantrums might be part and parcel for a child starting school, but fear and fretting for the parents

should not be. Hopefully with this information and with the support of the Irish Haemophilia Society you might feel more relaxed.

**Nuala Mc Auley**

### Treatment of Bleeding Episodes

#### HOW TO RECOGNISE A BLEED

Your child may experience some or all of the following:

**Head/Abdominal**

- \* Headache
- \* Drowsiness
- \* Nausea
- \* Vomiting
- \* Unsteady balance
- \* Irritability
- \* Confusion
- \* Seizures
- \* Loss of consciousness

**Abdominal Bleed**

- \* Bloody, black or tar-like bowel motions
- \* Red or brown urine
- \* Pain
- \* Vomiting of blood (blood may be red or black)

**Joint or Muscle bleed**

- \* Tingling/tightness
- \* Pain
- \* Redness
- \* Swelling
- \* Warmth
- \* Tenderness
- \* Reluctance to move affected limb

Irish Haemophilia Society

### Information for Teachers & Playgroup Leaders

**FOR OFFICE USE**

Date: \_\_\_\_\_

Name: \_\_\_\_\_

MOR: \_\_\_\_\_

Diagnosis: \_\_\_\_\_

Weight: \_\_\_\_\_

Prophylaxis: \_\_\_\_\_

Frequency: \_\_\_\_\_

Dose: \_\_\_\_\_

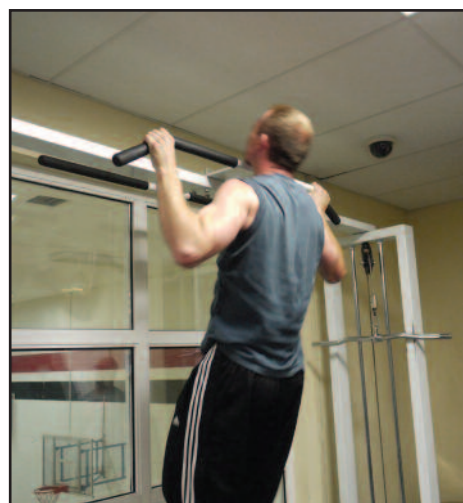
Review Date: \_\_\_\_\_

If your child has started school or creche and you would like some information or support contact the office on 01 657 9900 or [info@haemophilia.ie](mailto:info@haemophilia.ie)

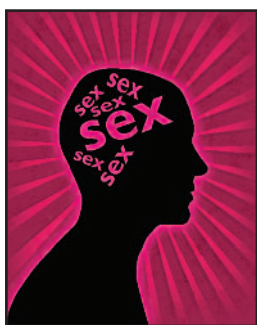
# HIS I.H.S. 2012

The second HIS IHS Conference took place in the Clarion Hotel Liffey Valley in Dublin on September 8th & 9th 2012. This conference is for men between the ages of 18 and 35 and discusses topics relevant to this stage of life. The first meeting in 2011 was very successful and as a result the meeting was held again this year. There were three sessions over the weekend and an open forum.

Saturday morning started off with a session on fitness, health and sports within the context of haemophilia. John Stack, a trained personal fitness coach (as well as an IHS board member) talked about the many doors that have been opened up for people with haemophilia to play a variety of new sports as a result of having good levels of treatment. He focused on the use of resistance training and benefits that it has shown to provide in relation to better fitness, reduced bleeds, improved balance and improved quality of life for people with haemophilia. He also pointed out that although resistance training can be sports specific, it can be used in a more general sense to improve strength in the muscles around the joints, improve imbalances that may be there either as a result of daily living or the problems after bleeds. It is important to consider your age, haemophilia severity, medical history and treatment regimen when thinking about starting a fitness regimen and if during a new regimen an injury does occur it is important to rest and recover before starting the regimen again and to ask why did the injury happen? At the end of the session there was a workshop demonstrating a few simple exercises focusing on good technique and the progression of each exercise to more difficult versions.



*John Stack led a session on fitness & health which included a presentation and some practical demonstrations.*



The second session on Saturday was haemophilia and sex which was facilitated by Donal Hegarty, a Family Psychologist. The session began with a presentation adapted from information presented at the WFH Congress in Paris this year. It discussed a number of reasons for sexual performance issues but focused on problems relating to physical limitations for people with haemophilia as a result of bleeds or reduced range of motion in certain joints. This can lead to uncomfortable positions or in some cases pain. The discussion talked about how best to communicate issues relating to haemophilia with a partner. The session expanded on how to have the conversation and suggested other alternatives that could be as enjoyable for both the person with haemophilia and their partner.

On Saturday evening there was a dinner and a quiz which offered plenty of opportunity for the guys to chat and discuss the day and generally get to know each other.

On Sunday morning, Pat Stagg from Citizen's Information gave a talk on benefits that are available and how to avail of the services provided by Citizens Information. He discussed how the system is changing all the time but it is important to keep up to date with the benefits you may be eligible for. He also said that with people going back to school and wages being reduced that entitlements and benefits may now be available that previously were not. He did stress however



*The IHS Publication on Benefits*

the importance of checking if a new benefit or entitlement may affect one that you are already in receipt of, as the departments providing the benefit may not provide this information. If you do have any queries on any aspect of benefits, entitlements or even consumer or employer issues you should contact Citizens Information and they will help you as much as possible in finding the information you need.



*The group took part in an Open Forum on Sunday morning.*

The last session of the weekend was the open forum. The main topic that came up during this time was the importance of the right travel insurance and preparing for your trip abroad. The Irish Haemophilia Society over the last 3-4 years have dealt with an increasing number of calls in relation to travel insurance where individuals thought that they were covered and were not or they went to the wrong services with in the country and had problems or received excessive bills for treatment. The Irish Haemophilia Society recommends reading through the details or asking the insurance company or brokers about specific issues. There is also a list of haemophilia treatment centres globally, available on the World

Federation of Hemophilia (WFH) website. We would also recommend printing out or putting the details of the nearest centre to your destination into your phone in case of an emergency as well as carrying your Severe Bleeding Disorder Alert Card and the travel card available from the IHS with you.

Overall the weekend was a great success due to the sessions and the topics that were covered but more so to do with the group that attended. There was a lot of discussion and comments in all the sessions and the guys really seemed to get a lot from the weekend. We would like to thank everyone who attended the weekend and hopefully we will see you all again soon and hopefully some new faces as well.

Presentations from HIS IHS and all IHS conferences and events can be downloaded from the website [www.haemophilia.ie](http://www.haemophilia.ie)

Copies of the IHS Travel Card & A Guide to Benefits & Allowances for Adults with Haemophilia can be downloaded free from the website or you can contact the office on 01 657 9900 or [info@haemophilia.ie](mailto:info@haemophilia.ie)



*Some of the delegates that attended HIS IHS 2012*

**Declan Noone**

# In the Spotlight - Needlephobia

**N**obody likes getting injections, but for some people the mere mention of an injection causes crippling fear. These people suffer with needle-phobia, a condition which approximately 10% of the population have, although the numbers may be considerably higher as those who suffer severely with the condition may not attend doctors due to the fear caused by their phobia.



Needle-phobia is a recognised condition that is further broken down into categories:

#### \* Vasovagal

The most common type of needle-phobia, sufferers fear the sight, thought and feeling of needles and needle like objects.

#### \* Associative

The second most common type, this is caused by a traumatic event whereby the person has experienced or witnessed someone close to them undergo a painful procedure. The individual then associates needles with the negative experience and pain.

#### \* Resistive

This is when the fear is not necessarily about the needle, but about being controlled and/or restrained.

#### \* Hyperalgesic

People with hyperalgesic needle-phobia have a hypersensitivity to pain and perceive the pain of an injection too unbearable to tolerate.

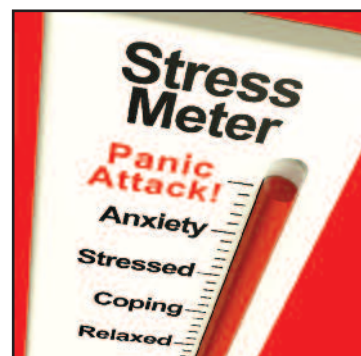
#### \* Vicarious

This involves a person experiencing the symptoms of needle-phobia without actually being touched or injected, often people with this will become anxious when witnessing someone getting an injection.

Many people don't understand the depth of a sufferer's phobia, this is because people find it hard to differentiate between a fear and a phobia. A fear is an emotion that everyone will experience in their life, but that can be overcome. A phobia is an anxiety disorder where a person has an irrational fear of a certain object or situation. Although the fear is classed as irrational, to the person with the phobia it is a natural reaction. Phobias are not easy to overcome. People with phobias often experience negative reactions to their condition; they are laughed at, mocked and told to "get over it". This attitude does not help the person with the phobia at all, it can actually have the opposite reaction and set the person further back in their recovery. If you know someone who suffers with a phobia it is important to try and support them and to do this you need to know what they experience.

When a person with a phobia is put in an anxious situation their heart rate will accelerate and their blood pressure will rise. As they become more anxious in the situation they can experience shaking, sweating, an upsurge in emotions such as crying or screaming. Some experience dizzy spells and light headedness, this is caused by a sudden drop in blood pressure as the anxiety takes over. The heart rate can also decrease rapidly and in extreme cases can cause the person to lose consciousness. However, a person with a phobia does not only experience symptoms when put in a situation, the mere thoughts can cause panic. For example, if a person with needle-phobia must attend the doctor, they can imagine that they will need an injection, and this can lead to anxiety, loss of sleep, change in appetite, loss of concentration and panic attacks.

Some people do not recognise phobias and if a person feels their phobia is not being accepted they can become angry. It is important for a person with needle-phobia to feel comfortable, they should speak to the doctor and explain their situation. Doctors deal with patients constantly and should be understanding of the patient's condition.





However, if you feel that your doctor is not taking you seriously don't feel trapped, speak to another doctor or a nurse.

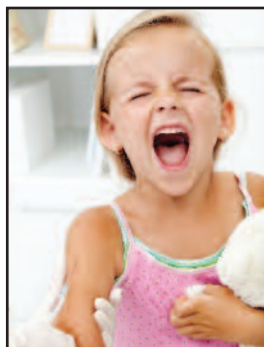


For a person with haemophilia or their family, needle-phobia can present a lot of problems. Prophylaxis means two to three infusions a week and more when a bleed occurs. Unfortunately in most cases of people with needle-phobia who have a bleeding disorder themselves or in the family there is little option, but to face the phobia. This will not happen overnight, but there are steps to take in conquering the phobia; the first step is to talk to a doctor or nurse about your phobia and they can come up with a programme to help you. Some methods that have worked for people with needle-phobia include:

- \* Hypnosis
- \* Counselling
- \* Anxiety Medication
- \* Desensitization
- \* Aversion therapy; where the patient is gradually reintroduced to needles

Not every treatment will work, everyone is different so what works for one may not work for you, but don't lose faith. It may be a long process, but the result will be worth it.

It is common for children to be afraid of needles, but most will outgrow this fear. The way this fear is handled and the subject dealt with the child can help prevent needle-phobia.



Holding a child down to infuse them will only add to their anxiety and stress. It may be necessary for the child to get an infusion, but if the child is on prophylaxis it is not practical for the child to be continuously held down. There are methods to try:

Diversion - knowing that a needle is coming, the child can become so intense that a breakdown occurs. Keep the child occupied and divert their attention from what is ahead. Although they may still get upset, it will be less severe for them.

**Buddy** - Have a set toy or doll that the child can have when getting their infusions, this will comfort and soothe them.

**Show and Tell** - Often the child can think this is something only they go through. Arrange to have blood taken or get an injection yourself and have your child there to help you, seeing you be strong will have an impact on them.

**Involve them** - Let them mix the factor and put on the tourniquet themselves, involving them in the process will make it feel less forced.

**Take it slow** - most people have the mind set of I'll do it quick and get it over with. Rushing can lead to accidents and make the child more anxious, take your time and move at a relaxed pace this will make the child more relaxed.

**Bribery** - if all else fails tempt them with something; an ice cream, a trip to the park etc. This may trigger an association of injections with rewards and help calm the fear. Just be careful not to get caught in a trap of constantly buying presents.

For a parent suffering with needle-phobia it is important to try to hide your fear from your child as they can pick up on your anxiety and can become more nervous.

Approximately 80% of people with needle-phobia have a member of their immediate family (parent, child or sibling) who also suffers with this phobia. An episode of needle-phobia can affect those present as well as the patient themselves. There is strength in numbers, so get involved in your relative's recovery or get them to get involved in yours!

To anyone suffering with needle-phobia, please know that it can be overcome, don't lose faith.

Good luck!

**Nuala Mc Auley**

**References:**

1. [www.needlephobia.com](http://www.needlephobia.com)
2. [www.needlephobia.co.uk](http://www.needlephobia.co.uk)
3. [www.contactmusic.com](http://www.contactmusic.com)
4. <http://en.wikipedia.org/wiki/Trypanophobia>
5. Snoop Dogg's Fatherhood Episode 1

# Needlephobia: Overcoming my fear for my son

In September 2006 our son was diagnosed with severe haemophilia A. This was the first experience of haemophilia for our family.

Also, I have always had a fear of needles. So the challenge began for me with the insertion of a port-a-cath for our son and training for administering factor for me as a parent.



I needed to suppress my fear to enable myself to hold the gripper needle, and pierce his skin with it to administer the infusion. In the beginning my body reacted to this fear with trembling sweaty palms and forehead, increased erratic bowel motions, and butterflies in my stomach. Despite my excessive stress response symptoms I did not display any of them to my son; he was totally unaware of his father's distress. As the practice of infusion continued every second day the stress response became less difficult until they dissolved altogether.

Five years have passed since we became trained in the procedure of administering factor. We have experienced inhibitors which delayed our progress initially with use of the port and required more frequent visits to hospital, head injury's which required unscheduled extra infusions at inopportune moments, in all of these extra on the spot experiences to give our son factor, adrenaline took over and my phobias disappeared.

Now my son is of an age where he will begin vein training. This is progress for him as the chance of an infection is greatly reduced, and it is how he will be able to self care as he grows up, but this has thrown a curve ball to my well practiced routine as I need to re train this time to enter my sons vein, not a great idea for one with a fear of needles to start with.

With the portacath the image of a pincushion helped me to detach from, to some extent, exactly what I was doing; I was able to focus on getting the needle into a circular area of the portacath. Now I have no such image and looking for a vein in my child is very real. I am unable to detach from what I am doing; this has resulted in a return of the familiar stress response, but now I am using it in another way. My body's reaction has heightened my sensitivity to the situation and I sense a strength in myself to move forward with the vein training.

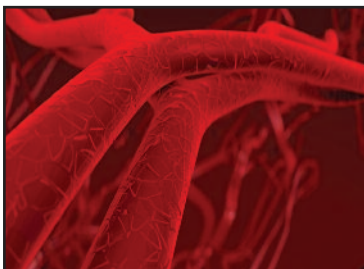
My advice to others who find themselves in similar situations regarding the use of needles is to take control of the fear, don't let the fear control you. There is no limit to what you will do for your child's wellbeing.

**Anthony O'Connor,  
Parent of a child with Haemophilia**



# Taking Care of your Veins

A child with a bleeding disorder is well educated to understand the important role their veins have in their body, as they get infusions of factor. However, an adult with a bleeding disorder can often forget the importance of veins, and more importantly vein care.



Veins are blood vessels that carry blood around the body. But for people with bleeding disorders they are much more; they are lifelines that literally carry factor around the body. Most children will have a port-a-cath inserted until their veins are strong enough to take regular infusions. However, once a vein becomes strong there is no guarantee it will stay strong forever. Veins, like most tools, can become damaged because of overuse, so it is important to take care of your veins as you grow older – it is never too late to start.

Why is it important to look after your veins?

It is important to prevent certain complications such as:

- \* Infections
- \* Sclerosis (hardening of the tissue)
- \* Collapsed veins (As a result of overuse the vein swells and becomes blocked - this can take weeks to recover).

Some examples of how to maintain good veins include:

#### \* Vein Rotation

Find three or four veins that are easy to access and rotate between them when administering factor. If you have time to take your factor, use the more difficult vein. Never rush when giving an infusion. You may find you are much quicker when using the easy or “reliable” vein, but if you overuse this vein it won’t be reliable for too long.

#### \* Arm Exercises

Keeping fit and healthy helps strengthen muscles and joints which can help develop good veins.



#### References:

Home Care: The Road to Independence, The Canadian Haemophilia Society  
Looking after the Veins, WFH Monograph, Peter Jones

#### \* Vein Exercises

The staff at the haemophilia treatment centre can help with some exercises to help build veins, but you can try the following:

Secure a tourniquet to your arm and squeeze a fist or a rubber ball in your hand. Repeat this twice a day every day for no longer than 5 minutes at a time.



#### SECRET TIPS!

If you are in hospital for infusions or blood tests, ask the nurse/doctor **not** to use your “reliable” vein. Staff are trained to access more difficult veins and this will provide some rest for your reliable vein.

It is important to know what not to do:

**DO NOT** infuse into an area that is swollen, inflamed or sore to touch.

**DO NOT** put pressure on the injection site until the needle has been removed.

As we grow older we begin to see changes in our body. Our skin can wrinkle and sag, our hands become less steady and our eyesight can deteriorate. All of these make infusing more difficult. Therefore, the importance of good vein care is vital

So don't wait until it's too late, take action today and take care of your veins.

Nuala Mc Auley



**IRISH HAEMOPHILIA SOCIETY**

First Floor  
Cathedral Court  
New Street  
Dublin 8

Tel: 01 6579900

Fax: 01 6579901

Email: [info@haemophilia.ie](mailto:info@haemophilia.ie)

Website: [www.haemophilia.ie](http://www.haemophilia.ie)