

haemophilia.ie

Magazine of the Irish Haemophilia Society

Edition: September 2013

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



The Society at a Glance

Planned Giving
Contributors

→ **38**

Followers on
Facebook

↑ **413**

I.H.S.
Discussion
Groups

↑ **2**

Applications for
Educational
Grants

↑ **20**

Website Hits
(Jun - Aug)

↓ **3,334**

WHAT'S INSIDE:

- * Articles on Transition and Individualised Treatment. * Fundraising News.
- * Update on the Twinning Programme. * Interview with Dr. Barry White.





Ageing Conference

The Sheraton Athlone Hotel

15th - 17th November

Friday November 15th

19.15 - 19.30	Introduction
19.30 - 20.30	Vein Care

Saturday November 16th

10.00 - 10.45	Pain Management
10.45 - 11.15	Changing Bleeding Patterns
11.15 - 11.45	Tea & Coffee Break
11.45 - 13.00	Cardiac Issues
13.00 - 14.00	Lunch
14.00 - 14.30	Ageing - Getting your NCT done!
14.30 - 16.30	Optimising Management of Ageing with Haemophilia
16.30 - 17.30	Panel Discussion
20.00	Dinner

Sunday November 17th

10.00 - 10.45	Coping Skills
10.45 - 11.15	Tea & Coffee Break
11.15 - 12.15	Independent Living
12.00 - 13.00	Occupational Therapy
13.00	Lunch

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Special Guests The Vintage People



CONTENTS

- 4** CEO's Report.
- 7** Noticeboard.
- 8** Personalising Care in Haemophilia.
- 10** Running the show - read about Lucia Prihodova's fundraising efforts.
- 11** Dates for your Diary.
- 12** Cubs Club.
- 13** Kidlink Page.
- 14** Fundraising Fins - Kidlink member Jennifer Andrews and her swimming club the Carrick Fins swam a mile for the I.H.S.
- 15** Update on the Twinning Programme between the I.H.S. and VSCBD.
- 20** A one on one interview with Dr. Barry White.
- 22** Transition.



*Nuala Mc Auley
Administrative Assistant*

A Note from Nuala

Hello from the I.H.S. office! Welcome to the Autumn edition of haemophilia.ie This edition is jam packed with interesting articles and informative updates which I hope you enjoy reading.

There is so much to tell you about since our last edition!

At the Parents Conference in June some parents asked about the possibility of setting up support groups online. We had previously looked at this using a private discussion forum, but this did not work. So following this renewed interest we decided to set up two groups - one for mothers and one for fathers - on facebook. The groups, which were launched in July, are completely private ensuring that what is said in the group stays in the group. I am happy to report that the groups are doing really well, although the mother's group is more active than the fathers, but no surprise there!

The fundraising team have been kept on their toes this year with cycles to head shaves, marathons to swims, church collections to 80's & 90's night. A huge thank you to everyone who has organised, taken part in and supported the I.H.S., your help is very much appreciated. GO TEAM I.H.S.

The Better Together Video Campaign was launched on September 16th and once again the I.H.S. are taking part. This is our third year to take part. Last year we finished in the top 10, but this year we hope to make it in to the top 5 so keep checking www.haemophilia.ie for updates on the campaign and information on how to vote!

The office has been very busy, but the main function of the I.H.S. is member support and there is always someone in the office to talk to. So if you are having a tough time or just fancy a chat give us a call on 01 657 9900. Haemophilia is our name, support is our game!

Happy reading!

**Nuala McAuley
Sub Editor**

CEO'S Report

History Revisited

August is traditionally seen as the silly season, where news can be sparse and journalists often look back at old events or use freedom of information requests to generate news. During the month of August the Irish Times ran a series of articles on events in 1989 based on diplomatic cables and communications between the then US Ambassador to Ireland, Margaret Heckler and the US State Department. Ambassador Heckler commented during the course of her correspondence with the State Department on the performance of the then Fianna Fáil minority Government and Taoiseach Charles Haughey. She appeared to be of the view that they were doing a good job and were turning around the finances of the country, and she speculated that quite a period of time would elapse before an election would be called. Shortly after that, the Government did call a General Election following a Dáil defeat on a motion relating to haemophilia. In her correspondence, the Ambassador clearly regarded this as a strange issue on which to call an election and communicated to the State Department that it was not a good issue for the Government to go to the country on.

L to R: Former Taoiseach Charles Haughey with businessman James Malloy and former Ambassador to Ireland Margaret Heckler



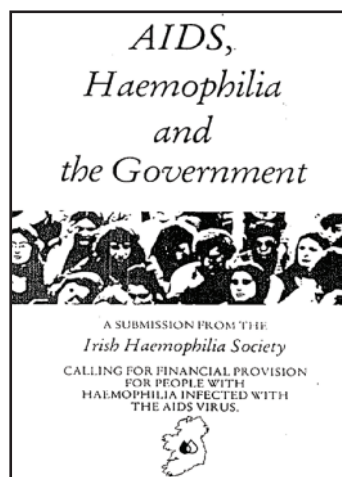
On reading this article I was able to vividly recall the events of those months in 1989. It was a strange and unusual time. In 1987 Dr. Barry Harrington and I carried out a survey of all of the 106 people with haemophilia who had



Brian O'Mahony
Chief Executive

been infected with HIV through blood products to ascertain their needs. There were clear and basic needs such as the need for insurance provision, travel costs to hospital, diet supplements and other basic requirements. We then drafted a comprehensive document called "Aids, Haemophilia and the Government" which we submitted to the Department of Health seeking specific assistance for people with haemophilia infected with HIV. In lieu of the provision of these we suggested an alternative might be to set up a trust fund in the amount of £400,000 a year for a three year period, and the trust fund could actually provide these requirements for people.

The year 1987 was my first as Chairman of the Irish Haemophilia Society, and this issue was a personal priority for me because I saw so many of our members struggling with the financial and clinical issues of HIV infection and Aids. This was my first experience of sending a detailed submission into the Department of Health.



The key publication produced by the I.H.S. in 1988

Our expectation was that following the sending in of the submission we would have a meeting with the department officials to discuss the specifics. This did not happen. Our submission was met with a deafening silence. Following months of delay, we then embarked on a deliberate advocacy and lobbying campaign to try to get the Government to take action to assist people with haemophilia with HIV. This was a major undertaking. It must be remembered that at the time the Society had a small shared port-a-cabin as an office and no staff apart from one secretary two mornings a week. All of this had to be done by us, as volunteers. The campaign was intensive. It included many letters to TDs and Senators, meetings with TDs, public meetings, media work and the involvement of several brave members with HIV highlighting their own stories. After the intensive campaign, we did eventually get a meeting with then Health Minister Rory O'Hanlon. His attitude was dismissive.

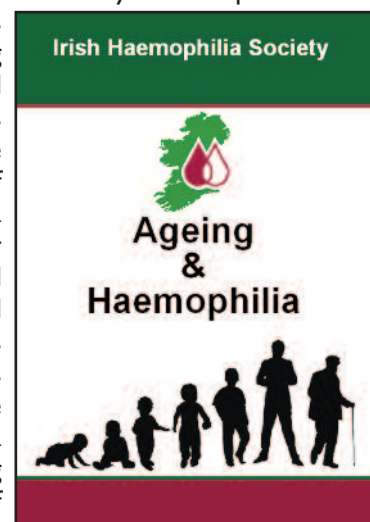
The campaign continued. We then managed to get a private members' motion put before the Dáil. We worked hard to ensure that this motion was supported by Fine Gael, Labour and all of the Independent TDs. It must be remembered that we needed all of these to vote for the motion if it was to have any chance of succeeding as it was minority Government. During the week leading up to the vote on the motion in the Dáil, I had many meetings in the Dáil with TDs, with opposition health spokespeople and with Government TDs to see if this issue could be resolved before a vote. The Government were inflexible and unwilling to move. Finally, the day of the vote arrived and Taoiseach Charles Haughey arrived back from a visit to Japan. He then threatened an election if the Government were defeated on this as he saw it as an important financial issue. Fortunately, the opposition TDs held their nerve, the motion was carried in the Dáil and the Government lost. Charles Haughey then called a General Election, went to the country and in the subsequent election, Fianna Fáil lost seats and had to enter a coalition with the Progressive Democrats. During the negotiations for the coalition between Fianna Fáil and the Progressive Democrats, I was involved in relation to specifying again what our requirements were. Following a lot of further meetings and difficult negotiations the Haemophilia HIV Trust (HHT) was set up with the Society involved, Chaired by Judge Mella Carroll and a sum of £1,000,000 was awarded to assist people with haemophilia with HIV. That fund set up in 1989 was a tremendous practical help and support to people with haemophilia in their darkest hours. It provided regular payments, paid for the items set out in the submission to Government, and others items such as funeral grants. This gave a financial cushion to people with haemophilia in their hours of greatest need. The HHT is still running effectively, providing assistance and support to people with haemophilia with HIV, and is now Chaired by Justice Roderick Murphy.

What was commented on by the article in the Irish Times was that the American Ambassador was greatly surprised that the Government went to the country on this issue. She was not the only person surprised at that time. This of course was a vital and major issue for the Irish Haemophilia Society, but this was not a huge national issue which you would normally think of in terms of causing a General Election. I do not for a minute believe that the Government went to the country because they had lost the Dáil vote which would have committed them to spend £400,000 a year for three years. This, in financial terms, was a very minor issue. In my view, the Government went to the country for a mixture of two reasons. Firstly, given their relative popularity at the time I believe they felt they could achieve an overall majority. Secondly, it was during that infamous election campaign in 1989 that, (as we now know from subsequent Tribunals of Inquiry), that builders and developers gave or were exhorted to give, large sums of

money to people like Charles Haughey, Pdraig Flynn and Ray Burke. The deep cynicism of a Government bringing the country on a path of austerity, going to the country ostensibly to preserve the financial integrity of the system, by denying assistance to a small number of people with haemophilia and in reality using the cover of an election to line their pockets was a grotesque example of political behaviour at its worst. I believed then, and I continue to believe, that our work and perseverance to success on this issue which was so vital to so many of our members was a fundamentally ethical and moral act which has set the tone for the Society in the 24 years since those fateful days in 1989.

Ageing and Haemophilia

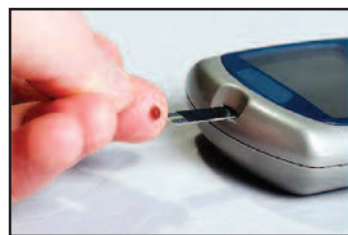
In November of this year, the Society will hold a conference on ageing and haemophilia. Last year we published a specific publication on this topic. There is growing international interest and communication on this topic. For the first time we have a generation of people with haemophilia who will live into their 50's, 60's, 70's and 80's and will therefore be subjected to the same health risks linked to increasing age as other members of the population. This is a welcome and exciting development, but of course it also poses challenges. In addition to haemophilia, bleeding and perhaps pre-existing co-morbidities such as orthopaedic or joint damage or infection with HIV or Hepatitis C which face many of our members in this age cohort, the normal trials & tribulations of ageing will be overlaid on this.



The IHS publication Ageing & Haemophilia

As men get older, the risk of coronary heart disease, cancer, liver disease, renal disease and other conditions increases. However, management of these complications in a person with haemophilia presents more challenges. For example, the possible requirement to take aspirin or warfarin for cardiac disease.

In the future those over 40 will have to look perhaps at more regular testing of their cholesterol and lipid profile, their blood glucose, their blood pressure, their prostate specific antigen and other tests to monitor and manage the risks of other diseases facing older people. In general men in Ireland are more reluctant to visit doctors than women. Bizarrely this is not the case in relation to people with haemophilia who visit their treatment centre on a regular basis, but they may have a more sporadic or limited relationship with general practitioners.



A key question in relation to the monitoring of the individual as they get older and the management of any conditions relation to ageing is, how this will be coordinated? I believe that there are three possible approaches which can be taken. Firstly, all the screening tests such as cholesterol, blood sugar, blood pressure etc. could be carried out by the haemophilia treatment centre in conjunction with the routine screening for factor levels and routine clinic visits. In this scenario, any complications or abnormalities detected would also be managed and coordinated by the treatment centre. The second option would be to have the treatment centre carry out the monitoring and screening tests and then refer the

individual to specific specialists such as cardiologists, nephrologists or rheumatologists if follow up is required. A third option would be for the screening and follow up to be carried out in the community by general practitioners. My personal view is that option 3 (having all the monitoring and follow up carried out by general practitioners) is not feasible or practical for people with haemophilia who have developed a long term existing relationship with the treatment centres. I believe we need to integrate the screening tests for diseases of ageing into the routine clinic phlebotomy profile for people with haemophilia. I believe that the management of any complications identified should either be managed by the centre in conjunction with different specialists or at the very least coordinated by the centre to make sure that people with haemophilia attend specified specialists who have, or will develop, a specific knowledge of the additional complications arising from dealing with their speciality in a person with haemophilia.

A new twist on regional meetings

In July, the Society, in conjunction with the haemophilia team from Our Lady's Children's Hospital Crumlin, organised a regional meeting for people with haemophilia and families in Carlow. In the past we have frequently held meetings in various towns and cities around the country and met members collectively and on a one to one basis. It was identified by Dr. Nolan and her team in Crumlin that there were quite a few new parents and young families with haemophilia who would not necessarily be members of the Society and who would not perhaps have sufficient degree of interaction to assist them in coping with haemophilia. It was decided to jointly hold a meeting to encourage families and parents to come together, to meet each other and to have an opportunity to have a discussion with the team from OLCHC and the IHS staff. Over 20 adults and children attended on the evening. Refreshments were served and a play therapist from Crumlin played with the children while the adults chatted with each other. I think this was a very informal and successful event which we will replicate with Crumlin in other areas of the country in the future.



**Brian O'Mahony,
Chief Executive**

World Federation of Hemophilia Congress 2014 – Melbourne 11th - 15th May 2014



The World Federation of Hemophilia (WFH) Congress 2014 takes place in Melbourne, Australia from May 11th to 15th 2014. Over 4,000 delegates from 120 countries are expected to attend. Congress attendees include haematologists, paediatricians, orthopaedic surgeons, physiotherapists, dentists, nurses, social workers, geneticists, laboratory technicians, scientists, psychologists, national member organisations, people with bleeding disorders, who, together, represent the comprehensive care team for people with bleeding disorders.

The Congress programme will include the latest scientific and clinical developments in diagnostic, bleeding disorder management and research. In addition, there will be a multidisciplinary programme that covers emerging topics related to inherited bleeding disorders.

The Congress will take place at the Melbourne Convention and Exhibition Centre (MCEC). Located on the banks of the Yarra River, the MCEC is only a short walk from Melbourne's central business district, numerous hotels, and a 20 minute drive from Melbourne Airport.

If you are interested in travelling to the Congress, visit www.wfh.org/congress

MOVEMBER

During November each year, Movember is responsible for the sprouting of millions of moustaches around the world. With their "Mo's" men raise funds and awareness for their chosen charity. Movember challenges men to grow a moustache for the 30 days of November, thereby changing their appearance and the face of men's health. For the entire month, these selfless and generous men known as Mo Bros, effectively become walking, talking billboards for 30 days. We want all you gentlemen to help raise funds for the Irish Haemophilia Society by taking part in 'Movember'.

If you are interested in taking part please contact Nina on 01-6579900 or Email: nina@haemophilia.ie



Brian O'Mahony Award - Call for Nominations

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

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

If you would like to nominate an individual (be it a member of the Society, a health care professional or a person from abroad) who, in your view, has made an outstanding contribution to the Society, please send in your nomination and reasons for nominating the individual to Declan Noone (declan@haemophilia.ie).



**Nominations should be received by
Friday, October 18th 2013.**

Personalising care in haemophilia -



It is an exciting time for Haemophilia care in Ireland. Improving patient care is to the forefront of our research focus in the National Centre for Hereditary Coagulation Disorders (NCHCD). Our aim is to personalise and individualise treatment for people with Haemophilia. The first phase of our state of the art research focuses on adults with mild, moderate or severe Haemophilia A.

Tailoring treatment to your body's needs:

If you have Haemophilia A and require surgery or have a bleed we use medications to boost your factor VIII level. These are dosed according to your weight and your factor VIII level. Your body gradually breaks down the medication and your factor VIII returns to your normal level. No two people are the same and this also applies to the rate at which your body breaks down factor VIII. Some people will do this very slowly and therefore should need less medication while others will break down factor VIII very quickly and need higher doses to prevent bleeding.

We know these differences exist – how can we use this information to improve your care?

Pharmacokinetics (PK) involves a series of blood tests through which we can find out the rate that your body breaks down factor VIII. Once we know your PKs it will become part of your patient record in the NCHCD. We hope that we will be able to use this information in the future to develop a treatment plan specifically for you. There are very few other areas in hospital medicine that are using this state of the art approach to patient care; we are delighted to offer this opportunity to our patients.



We started PK studies in the NCHCD in July 2013 and invited people with Haemophilia A to attend. We were extremely pleased to receive such an enthusiastic response to this project and would like to thank everyone who has already responded and attended.

As this is a national research study we hope to involve as many people as possible to get a true reflection of people with Haemophilia A in Ireland. The Cork Comprehensive Coagulation Centre is working with us to offer PK studies in Cork University Hospital. For participants travelling from other parts of Ireland to St. James' Hospital for PK studies the Irish Haemophilia Society has kindly offered the use of the patient apartment if required.

Taking this concept further: PERSONAL Clinical trial

The second phase of our research is to actually put PK dosing into practice. We will be offering all people with severe Haemophilia A on regular prophylaxis (at least 5 times per fortnight) the opportunity to use their PK results to individualise their prophylaxis. We will calculate out what the exact dose of factor VIII required by your body to ensure your factor VIII levels are always optimal. We hope to show that individualising prophylaxis is at least as good, if not better, than current prophylactic regimens.



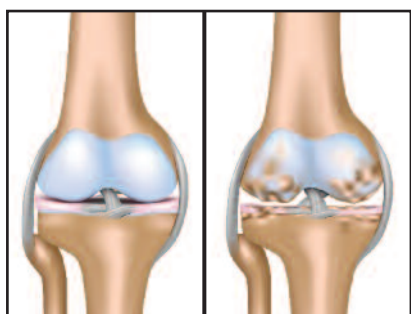
A state of the art approach

It is important to note that this is not a trial of a new drug, we will be using your current medication but matching the dose according to your individual requirements. This trial is called the PERSONAL trial (PERSONALising Factor VIII prophylaxis regimens: Efficacy of standard versus pharmacokinetically based regimens in adult patients with severe Haemophilia A).

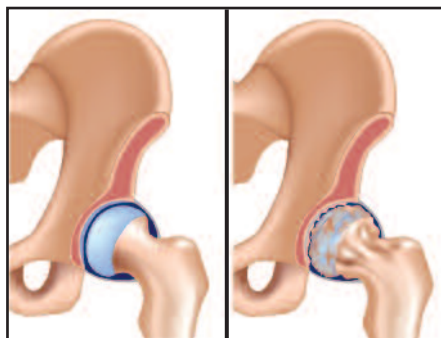
This innovative trial is extremely exciting. Not only is this the first trial of its kind but also we will collaborate with the world expert in PK studies and Haemophilia, Professor Peter Collins. We aim to start this clinical trial in December 2013. People who choose to participate in the trial will be involved for 18 months in total. For the first 6 months they continue on their standard prophylaxis and for the subsequent 12 months change to individualised prophylaxis.

From his trial we will study a number of outcomes. Firstly, how your body responds to the new personalised prophylaxis. Secondly, we will monitor peoples' activity levels and feelings about how prophylaxis affects their quality of life. We hope that by including this information we can build up a more holistic view of how people with severe Haemophilia manage prophylaxis.

Finally we will also offer regular MRIs and X-rays of elbows, ankles and knees to all participants on the PERSONAL trial. This will be combined with regular physiotherapy assessment. Through these joint health checks we hope to detect even subtle bleeds that may go otherwise unnoticed. This will help gain more information overall about joint disease in people with Haemophilia A.



Healthy Knee Joint Haemarthropathy



Healthy Hip Joint Haemarthropathy



Our national research opportunity:

This research offers Ireland the opportunity to move to the forefront of Haemophilia research. Not only do we hope that this research will be of benefit to patients in Ireland, but we aim that the results obtained may be used to help people with Haemophilia internationally.

No research can possibly be successful without the support of our patients. Involvement in any research is completely voluntary and choosing not to participate will in no way affect the care you receive. If however you are interested in participating we will be more than happy to provide you with more information or arrange to meet you.

If you are considering participating or have further queries we have a dedicated email address pkstudy@stjames.ie or call the National Centre for Hereditary Coagulation Disorders (NCHCD) in St. James' Hospital at 01 4162141 and ask to speak to Dr. Michelle Lavin.

Dr. Michelle Lavin
NCHCD

Running the show!

It all started quite innocently as a chat among friends

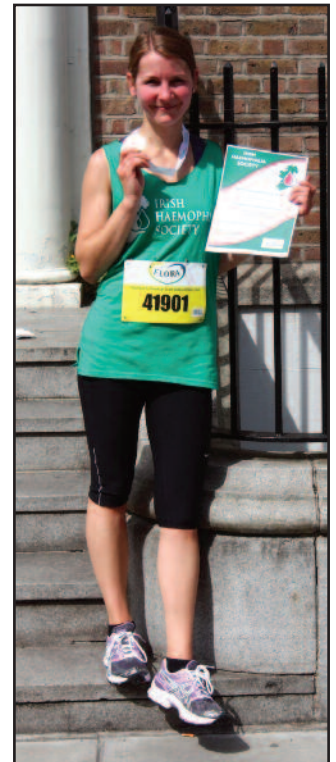
in the middle of February reflecting on our, so far, poorly executed new-years-resolutions. I was sure of two things – I wanted to get fitter, maybe even complete a half-marathon and I wanted to find a way to fundraise a few bob for the I.H.S. as it's been quite a while since I supported the Society. A friend mentioned she'd also love to run a half-marathon but, like myself, wasn't quite confident and just like that, a plan was born. We would both do three runs to build ourselves up to the half marathon and if we managed, we may even try the full one! The plan changed equally fast a couple of days later, when my friend announced that her doctor didn't think she should even attempt a 5km run because of her on-going laryngitis. And so after a talk with Debbie and Nina, I got myself a Mycharity page, new runners, a must-read McDougal's Born to Run and hit the streets to build up mileage.

At the start, my runs mostly turned out to be great opportunity to contemplate on "what was I thinking when I signed up for this?!" And then the money and kind words started to roll in and so did emails from Debbie, checking if there was anything I needed and so gradually it sank in to my mind that I can and I will do this. So I gathered info on how to train, what to eat (pre-race carb loading has proven to be one of my favourite things about running) and drink (goodbye coffee, hello cranky me), how to properly recover (using RICE more than my other half with a bleeding disorder) and got on with it.

And so I was off, first was the Flora Women's Mini Marathon, a 10k run along with other 40,000 women on one of the hottest days of the year. Second up was the Rock and Roll half-marathon, on a lovely cool morning with great music along the route. The final hurdle was the Frank Duffy 10 mile run, in the Phoenix park with a lethal 2 mile uphill run just before the finish line. In total, those three runs added up to just over 47km, 253 minutes of sweat, huffing and surprisingly exhilarating fun and so far €750 fundraised. In the few months I learned a lot about myself and about running (yes, we may all be born to run, but some of us not too fast or very far) and I rekindled my passion for the IHS, by promoting it's excellent and unique work among my friends and family.

I would love to say a huge thank you to the I.H.S. and all who have sponsored me, encouraged me and cheered me up along the way. You cannot imagine how much of a boost it gave me when I hit a wall or was just feeling a bit lazy. I mean it, it wouldn't have happened without you.

Lucia Prihodova



Lucia's first run was the Flora Women's Mini Marathon in June.



Feeling like a rockstar, after the Rock & Roll half marathon in August.



Lucia greets her number one fan and training partner Oliver at the finish line of the Frank Duffy 10 mile run.

Dates for your Diary

OCTOBER

Dates: 11th - 13th October

Event: Members Conference

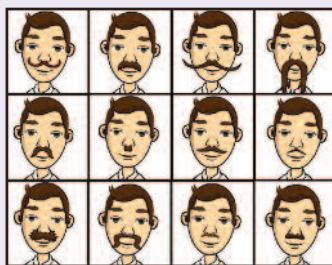
Venue: Bloomfield House Hotel, Mullingar, Co. Westmeath

NOVEMBER

Date: 1st - 30th November

Event: Fundraiser

Venue: Everywhere



NOVEMBER

Date: 8th - 10th November

Event: Parents Empowering Parents Conference

Venue: Clarion Hotel Liffey Valley, Dublin



NOVEMBER

Date: 15th - 17th November

Event: Ageing Conference

Venue: The Sheraton Hotel, Athlone



NOVEMBER

Date: 22nd November

Event: Voting Closes in the Better Together Video Competition

Venue: www.bettertogether.ie



MARCH 2013

Date: 7th - 9th March

Event: AGM

Venue: Lyrath Estate Hotel, Co. Kilkenny

Cubs Club

Hi and welcome to another edition of Cubs Club, this time it is all about sport!



It's good for everyone to play games and sports. It keeps our bodies strong and healthy.

When you have haemophilia, strong muscles are really important because they help to protect your joints from bleeds.

What sports do you like to play? _____

There are lots of fun sports that you can play with your friends in school and at home!

Can you find these eight games in our wordsearch?

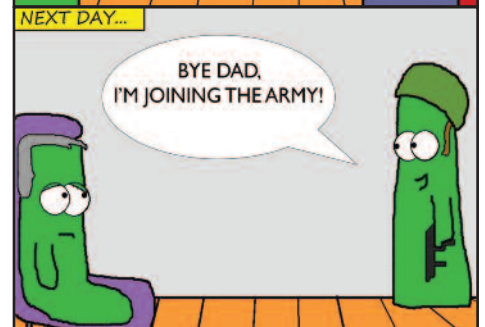
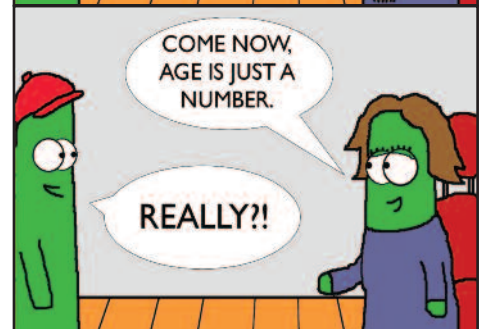
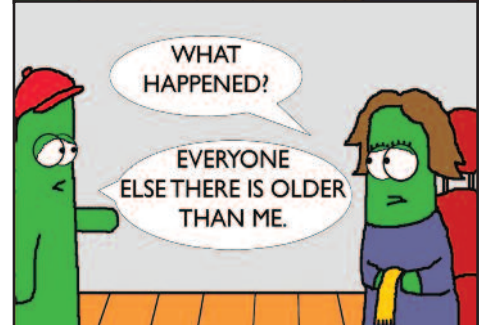


- Basketball
- Tennis
- Football
- Rounders
- Swimming
- Golf
- Running
- Cycling

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

The Slobs

by Conor Birkett



Log on to www.haemophilia.ie and see if you are correct, but remember to ask an adult for permission first!

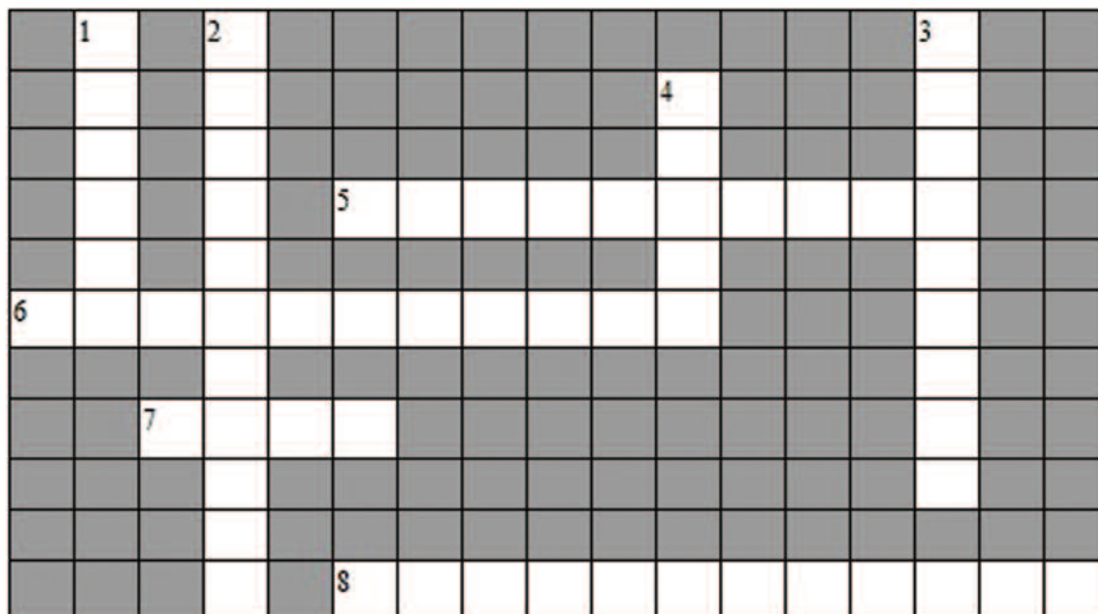
Kidlink Group

So it's that time of year again - everyone is back in school, new teachers, new classrooms, more homework!

What is your favourite thing about going back to school?

Sometimes you might miss school, or not be able to play sport because you have had a bleed. Have your friends ever asked why you can't play? If you would like to tell them about haemophilia, it is important for you to know all about it too!

Can you figure out the clues and solve the crossword below? They are all about bleeding disorders so you should know the answers!



ACROSS:

5. This helps your veins become visible (10)
6. Treatment to prevent bleeds (11)
7. The steps you take if you hurt yourself (4)
8. Being able to inject the factor yourself is called..... (4, 8)

DOWN:

1. Medicine to prevent bleeds (6)
2. A bleeding disorder (11)
3. When your veins are not big your medicine goes into a....(9)
4. This is where you inject your factor (5)

Log onto www.haemophilia.ie to see if you are correct, remember to ask an adult for permission first!

LAUGHTER LINES

What did the ghost teacher say to his class?

Look at the board and I'll go through it again!



Student: Sir should people be punished for things they don't do?

Teacher: No, of course not!

Student: Phew, that's good because I didn't do my homework!

Fundraising Fins!

Hi, I am Jennifer and I am 10 years old. I live in Leitrim with my Mum, Dad and my brother Callum, My two dogs Dill & Syd and my goldfish Bruce.

My brother Callum who is 9 years old has severe haemophilia, some times it is really hard as he doesn't always like having his medication, but if he didnt have haemophilia, then I wouldn't have met all the friends that I have when we go away on the haemophilia weekends.

I also wouldn't get to go to Barretstown. I have just come back from another great week, and I had so much fun and met lots of new friends. It was really special because I got to see my friend Aoife.

When my mum said she wasn't able to do her charity run this year, I decided that Callum and I would do a charity swim. I asked my swim teacher Fiona if we could get the whole club involved and she said that would be fine. We were going to swim a whole mile to raise money for the Haemophilia Society. Mum helped me organise the sponsor forms and then on the 19th June Callum's group (Aura Leisure Swim Club) did their swim, and on the 26th June my club, the Carrick Finns did ours.

It really was brilliant, and everyone raised lots of money. My friend Emma raised over €200.00. Emma also gave me two big teddies and I dressed them in Haemophilia T-shirts and we gave them to the 2 people who raised the most money by themselves.

I still haven't collected all the money in yet but so far we have got over €1,400.00. I think my friends are brilliant for helping me raise so much money for the I.H.S.

Jennifer Andrews



Top: Jennifer at the pool where the Swim a Mile fundraiser took place.

Middle: Jennifer and her swimming team, The Carrick Finns Swim Club, who helped raise over €1,400 for the I.H.S.

Bottom: Jennifer and her mum Sara present the sponsorship money to I.H.S. staff person Nina Storey!



Twining Reports

The I.H.S. visit's Vietnam

My colleague Fiona Brennan and I travelled to Vietnam during May this year to continue our collaboration with the Vietnamese Association. With a busy schedule planned for the week, we were determined to make full use of our time in Vietnam.



A progress meeting with Dr. Van, I.H.S. administrator Debbie Greene, Dr. Khan, I.H.S. volunteer coordinator Fiona Brennan, Professor Tri and Dr. Mai.

Our first meeting was chaired by the Director of the National Institute of Haematology and Blood Transfusion Centre in Hanoi, Professor Tri. During this meeting we were updated on the progress of the twinning programme, and indeed they have progressed extremely well. Although not a lot has changed with the factor situation and the percentage that the patient has to pay, a lot of work has been done which will become clear as you read this article.

Later in the day a workshop took place on volunteering. Fiona arranged to have all 35 volunteers separated into their respective groups to discuss the main needs of members in their provinces. The conclusions were similar: they need practical help and support for their members in their local areas. This session certainly gave the volunteers and chapter leaders a focus for future plans and activities.

The following morning we met with the Irish Ambassador Mr. Damien Cole and his Deputy Mr. Garvin McCann. This was a good meeting; the Ambassador is clearly very interested in this programme and offered assistance to us with some advocacy work in relation to the availability and cost of factor.

The afternoon began with a workshop on governance and prioritising activities and plans for the future. This session stirred up some interesting discussions and ideas about the future plans of the Society and its various chapters. I discussed the importance of consistent contact, reporting and guidance between the board and the various chapters. Fiona then discussed the qualities that their leaders should possess. There are some excellent voices and leaders in the organisation, who are passionate and ready to make a difference for people with haemophilia in Vietnam.



IHS staff members Debbie Greene and Fiona Brennan travelled to Hung Yen for a Chapter Leaders meeting.

The following day we travelled to Hung Yen which is a city approximately 60 kilometres outside Hanoi. We were welcomed by a group of 32 people made up of chapter leaders, people with haemophilia, parents and children. They were clearly delighted to see us, and appreciated us taking the time to travel to their city. This chapter is doing excellent work. In November 2011, they had 7 members, today they have 60 members. They meet on a monthly basis to chat, share experiences, exercise and to sing, which helps them stay positive. They all exchanged phone numbers to maintain contact.

They are a very strong group, with a very good chapter leader Mr. Hau who is a young man with haemophilia in his thirties and married with two children. Over the last year they have been able to help 3 men with haemophilia gain employment. This chapter is still very young, and clearly they are so keen to learn. They want to be educated; they want to get on with it as much as they can. They stay close and support each other. Some of them have been through college, which is great and they also mentioned some of the challenges that came with being a young man with haemophilia going to college in Vietnam. One young man is a teacher, another works at repairing phones, another is a hairdresser, and others work at IT. Mr. Hau spoke about his dream to help patients get jobs, to be educated, to obtain home treatment and to improve their lives as much as they can. I truly believe from what I heard that this is achievable, they are going in the right direction. I was very impressed by this chapter; they seem like a great group of people, they are very positive and focused. Previously when I visited Vietnam and when we spoke to chapter leaders I perhaps thought that some of our information and advice may have been just that little bit early for the organisation. However, they clearly listened to everything we said during our last trip, as a lot of suggestions we made are already happening.

The following day we visited Professor Tri in his office for a short discussion. Afterwards we had a round table discussion with Dr. Mai, Ms. Hanh, some chapter leaders, some volunteers, and some parents in relation to fundraising and a possible employment project. We spoke about funding for the organisation. Novo Nordisk have promised funding on various projects up to the year 2015 to include projects in the whole country, in areas like improving a registry of people with haemophilia, education and training for people with haemophilia, and their families, and for outreach across the country and training also for the medical profession, and publications. Baxter has now also promised to fund individual specific educational activities.



A planning meeting for future activities and strategies.

Over the course of the week we both could hear how worried people were about the lack of employment. Some jobs are advertised on their website but sometimes they are not suitable for people with haemophilia so the uptake isn't great. However, in the chapter of Hung Yen which we visited the previous day, they seem to be doing an excellent job trying to find work for people with haemophilia, so we suggested expanding this to other chapters.

We also had a discussion in relation to a home adaption project for people with haemophilia. Fiona mentioned items like handrails and equipment for homes would be of great assistance to some members with mobility difficulties. This would be such a worthwhile project; even a simple handrail would be of so much benefit to a lot of people with haemophilia. This will also be explored in the coming months.

Our conclusion meeting was made up of speeches, photos and gifts. Professor Tri thanked us very much for sharing our experiences, knowledge and enthusiasm. He thanked us for coming to his country and for our positive and friendly attitude, and our professionalism. He said haemophilia care is improving in Vietnam and in the coming years it will be even better. He thanked us for our friendship, and appreciated us sharing their culture, food and music during the week. Dr. Mai was also very appreciative of our visit and our assistance.

It was hard to believe but our work was done for the week. At times we really struggled with the heat (I won't mention one of the days it was so hot we lay down on the floor in the board room after lunch - true story as Fiona says). The week was intense, encouraging, and motivating. We also learned a lot. Everyone treated us so well, in fact at times like royalty. I think it was a very positive week with many good things happening. We had some very interesting discussions and debates, but we also had some fun particularly with some lost in translation moments, me nearly faintly eating a chilly one evening, and me finally mastering the art of using chopsticks!

Twinning visit to Ireland

On Wednesday 26th June we were delighted to welcome our twinning partners to Ireland for a short visit. For Professor Tri this was his first visit to Ireland.

A lot was packed into the 3 days which started with Brian O'Mahony accompanying our visitors to the National Centre in St. James's Hospital. The Centre Director Dr. Barry White, Dr. Kevin Ryan (Consultant Haematologist), and Dr. Vince Jenkins (Chief Molecular Biologist) welcomed our visitors. Many things were discussed during this visit including protocols on home treatment and genetics. It was then on to Our Lady's Children's Hospital, Crumlin where Dr. Beatrice Nolan (Paediatric Consultant Haematologist) gave our visitors a tour of the laboratory, bone marrow unit, haematology and oncology day ward, and St. Michael's ward, following which Dr. Mai gave a talk to the haemophilia team on haemophilia care in Vietnam. I think the team found the presentation very interesting.

A tour of the Irish Blood Transfusion Service (IBTS) had also been arranged. The IBTS Director met our guests and the tour was organised by Chief Scientist. Being Director of the National Institute for Blood Transfusion in Hanoi, Professor Tri was extremely interested in this tour and asked many questions.

We also arranged a Twinning Reception for Professor Tri and Dr. Mai in the office. Speeches were made by Professor Tri and Brian O'Mahony, after which a cake was cut to celebrate our twinning partnership being awarded the World Federation of Hemophilia Twin of the Year Award for 2012.

On the last day Brian O'Mahony, Anne Duffy and I had a very good meeting and discussed the new governance structure. Professor Tri mentioned that he is currently looking at a second staff person for the organisation, this is very encouraging. Sponsorship for various activities from Novo Nordisk and Baxter was discussed, as was the plan for Brian O'Mahony's visit in November. It is hoped that during Brian's visit a meeting can be set up with their Ministry for Health in relation to the factor situation in Vietnam and the percentage that patients must pay. Dr. Mai informed us that the Vietnamese organisation are also bidding to host the World Federation of Hemophilia Congress in 2020, and we wish them the very best of luck with the bid. We also discussed extending the twinning programme after 2014, as the Irish Haemophilia Society feel that this is a long term partnership, which has and is benefiting both organisations. We are very keen to continue with the twinning programme. We also spoke about the employment project that Fiona and I discussed during our visit to Hanoi in May. Although the visit was short, it was a very enjoyable visit, very worthwhile, and we hope that next year our twinning partners will visit Ireland again and perhaps stay for a longer visit.

The VSCBD is progressing in the right direction; it's great to see how far they have come in a year. We will continue to work and co-operate with our friends and colleagues in Vietnam and hope that when our twinning programme finishes that we will extend the twinning programme for many more years to come!



Above: Professor Tri gave a speech at a twinning reception which was held in the I.H.S. office.

Below: (L to R) Debbie Greene, Professor Tri, IHS CEO Brian O'Mahony, Counsellor Anne Duffy and Dr. Mai.



Reflections on our Twinning Visit

Nothing could have prepared me for my first trip to Vietnam, despite the lack of factor – I am still surprised by the positive attitude of the people with haemophilia that we met in 2012. Planning for Vietnam this year, I was more prepared – the challenges, the expectations (and presentations!) were all in place. The doctors and the team in Vietnam couldn't help but make a lasting impression on you, their dedication and kindest knows no bounds. It was for this reason that I was excited and eager to get back to Hanoi.

Arriving in Hanoi it still had the same impact on me as the first time. The noise, the crowds, the smell it is unlike any other place I have ever been and you can't help but want to be in the thick of it all. That evening we were greeted warmly by old and two new friends – Dr Mai and Ms Hang brought Dr Mai's two beautiful daughters to dinner with us. Even though we were 1000's of miles away from home – you couldn't help but feel right at home with Dr Mai and Ms Hang who looked after us so well for the duration of our visit.

On Monday it was down to business. Meetings with Professor Tri, Dr Khanh, Dr Van and Dr Mai to hear about the progress of VSCBD since our last visit in 2012, presentations to volunteers and people with haemophilia, meeting with the Embassy, travelling to Hung Yen, karaoke and visiting the in-patients (of which there were 30 in the wards at the time) to name but a few. I remember how emotional I felt when I first walked through the wards in 2012 and while it is still difficult and hard to accept, knowing that there is change and progress under way makes it that bit easier.

During a meeting with the team in the centre including some volunteers and chapter leaders to discuss the activities from 2012 and the challenges facing the organisation at the moment – we realised the work they have done since our last visit is phenomenal. It was a great opportunity for Debbie and I to find out exactly what we can try to help with. Due to the large size of Vietnam some patients in the countryside are isolated and the need for smaller more local organisations that can aid the patients living outside of Hanoi and HCMC is essential. The smaller chapters are doing a fantastic job at supporting and involving patients in their local area. Peer support and advice is so important when treatment is such a major issue, this is expanding all of the time in Vietnam.

I could go on to tell you about all of the presentations and the discussions that were held over the course of the week but instead I will tell you about the parts that struck me most. We travelled to Hung Yen which is about 2 hours from Hanoi. There are several patients in Hung Yen who have organised a Chapter/Branch which is going from strength to strength. After our presentations and lively, beneficial discussions we went to visit the homes of patients in the area. The first patient was the leader of the Hung Yen Chapter - Mr Hau. He is married with 2 children and his parents live with his family also. They own a small phone repair shop. The pride and the sense of achievement that is evident as this family welcomes us into their home is truly humbling. We sit in their shop, drink tea, look at pictures and it strikes me that someday in the future hopefully this will be the situation in Vietnam for all people with haemophilia - that haemophilia will not be such a huge burden on the whole family.



Above: Debbie Greene led a meeting on governance.

Below: Debbie Greene and Fiona Brennan with the chapter leaders.



We then visited the home of a young man with haemophilia close by. What strikes me about this visit is that Dr Mai has been here before – she speaks with kindness and compassion to the boy and his parents. Dr Mai genuinely cares and reaches out to her patients as much as is possible which is a fantastic quality and huge benefit to the patients. Ms Hang translates what Dr Mai says for Debbie and I – Dr Mai tells him he needs to get a job that is physically safe for him, highlights the importance of education and that she worries about him driving safely on his motorbike. It may seem like simple advice but Dr Mai is so sincere and both the patient and his parents listen attentively and appreciate all of the advice given by Dr Mai.



It is during these visits and the interactions in the wards with patients that, for me, make all of the work and planning for the twinning process worth every minute. I found it difficult to keep a sense of hope last year when you see how badly affected the patients and their families are by haemophilia but this year I felt a strong sense of hope, there is, as cheesy as it sounds, light at the end of the tunnel. The team in VSCBD are driven and determined to provide the best care possible for their patients. With such tremendous progress in so many areas, in such a short time, I can only imagine that this time next year the next report from the I.H.S. will be even brighter!!

Fiona Brennan
Irish Haemophilia Society



During each Twinning visit the I.H.S. staff visit the hospital wards. In Vietnam, patients are two to a bed. As treatment is not readily available hospital stays can last weeks. The I.H.S. is working with the VSCBD to provide education and games for patients during their stay in hospital.

Dr. Barry White

Dr. Barry White is no stranger to the haemophilia community in Ireland. The National Haemophilia Director and Consultant Haematologist can be seen at clinics in the National Centre for Hereditary Coagulation Disorders (NHCHD), but is also a regular speaker and guest at I.H.S. conferences and events. In March 2013 Dr. White was awarded the Brian O'Mahony Award for outstanding contribution to haemophilia care in Ireland.



Dr. Barry White
National Haemophilia
Director

Haemophilia.ie sat down with Dr. White to find out a bit more about the man who has helped shape the future for haemophilia in Ireland.

Background:

Barry White studied medicine in UCD before undertaking a doctorate in Trinity College Dublin, where he also earned a Masters in Molecular Medicine.

Dr. White began his career as an intern in St. Vincents Hospital and spent some time in Cleveland as part of his general training. Once he chose haematology as his speciality he began working in St. James's Hospital where, bar a two year period with the Royal Free Hospital in London, he has remained since.

So why did Dr. White choose to specialise in haematology? He explains:

"The main interest in haematology and haemophilia is that my mentor when I was training was Owen Smith who was the National Haemophilia Director at the time and I was influenced by him. The other thing I was influenced by was the fact that haemophilia and haematology is an interesting combination of not just clinical, but clinical and laboratory so you get involved in the full end to end management from the blood test to the treatment and the response. I suppose I just found it to be an area that I find interesting and enjoyable to work in."

Although he enjoys working in the field of haematology, Dr. White admits that he does become frustrated at the pace of which things move within the health system.

"I've sort of learned to understand that it is not always quite straight forward. We are spending public money, there are financial restrictions around the world we live in, the country we live in and that things take longer than they should sometimes."

However, the good can outweigh the bad and when asked about what he enjoys most about the job his answer was simple, the people. From the patients to the staff of the centres to the patient organisations, Dr. White believes that having cooperation between everyone is the key to bringing haemophilia care forward.



Dr. Barry White and I.H.S. CEO Brian O'Mahony
during the build of the new haemophilia
in-patient unit in St. James's Hospital

In 2009 Dr. Barry White was seconded by the HSE as the National Director for Quality and Clinical Care and a year and half later the National Director for Strategy and Clinical Programmes. His role within the HSE was to bring together front line clinicians and patient organisations to define how services should be delivered, measured and resourced in ways that would improve the key domains of health care which are quality, access and cost effectiveness. Dr. White achieved this goal, but admitted that although some of the programmes and systems that were created are working well, there are others which need some more time to develop. Dr. White enjoyed his time working with the HSE, but after a three year stint away from haematology said he was happy to get back to the NCHCD. Indeed he says his time with the HSE has taught him a lot.

When asked about his accomplishments Dr. White stated that he is just happy to have contributed to the development of services of haemophilia in Ireland. In particular he noted the development in staff and quality processes that have taken place in the last ten years.

Looking to the future Dr. White links his own aspirations to that of his aspirations for haemophilia care in Ireland.

"I think the area we need to improve on is access. I think we are ok on access during the regular day to the nursing staff, to that level of support. I think access to beds in a timely manner and access over a 24/7 period is still something that I think we have further work to do. As ever access for patients no matter where they are in the country with a rare disorder is always going to be a challenge, but my aim is to ensure we improve access."

The use of technology and e-health devices have helped to bring haemophilia care into the 21st century, but this is an area where there will be greater focus moving forward. But what does the future hold for treatment? Well there are lots of exciting prospects on the horizon with regards to treatment with new developments in longer acting factor products and gene therapy. These are areas which Dr. White thinks will be well underway by 2020.

"The expectation is that gene therapy will be in play, at least for Factor IX patients with severe deficiency. I think longer acting products, especially for Factor IX will be in use and I would hope for Factor VIII as well. I hope there will be a very significant focus on a bleed free environment for people with haemophilia."

Individualised treatment, as explained on page 8, is at the forefront of the NCHCD research at the moment, but by 2020 Dr. White thinks this will have advanced greatly.

"I think by 2020 what will have happened is a great advance at least in the pharmacokinetic response. It will take us a bit longer to work out all the complexities of human behaviour, how people can adjust to it and individual circumstances, but I think that will be well advanced."

There are a lot of improvements being made in relation to organisation of care and treatment, but there is one area which Dr. White would like to see more research into, inhibitors. He hopes that the future will bring alternative options for inhibitor patients even if it is just different product offerings.



Dr. Barry White with the National Haemophilia Council

Coming back to the present, Dr. White is hopeful that haemophilia care in Ireland will not be too affected by the current financial state of the country. The work carried out by the National Haemophilia Council and the Haemophilia Product Selection and Monitoring Advisory Board, both of which Dr. White serves on, has helped to improve haemophilia care while remaining cost effective.

"More people are being treated with greater volumes of product and yet at the same time our actual cost of haemophilia care has not gone up and that's recognised."

A high quality service with patients who find the level of care good and with plenty of people interested in working within the area of haematology and haemophilia is the legacy Dr. White wants to leave behind and with a long future ahead of him, this is something he will most likely achieve.

Nuala Mc Auley
Irish Haemophilia Society

Moving on...Transition to the Adult



The concept of moving on or transitioning from the familiar and trusted environment of the paediatric service at Our Lady's Children's Hospital, Crumlin (OLCHC) to the adult service at St James's Hospital, can bring about mixed feelings for families. There may be feelings of anxiety around meeting a new team of health professionals, the logistics of finding your way around a different hospital and even finding a parking space! For others there may be a sense of excitement and anticipation, in other words a fresh start.

What is Transition?

Transition is the process of planning, preparing and moving from children's health services to adult health services. In the case of most people with bleeding disorders living in Ireland, this involves a transfer of care from the paediatric team at OLCHC to the National Centre for Hereditary Coagulation Disorders (NCHCD) at St James's Hospital.



The transition process actually starts at the time of diagnosis and continues throughout childhood as children become more independent and begin to take ownership of the management of their bleeding disorder. Examples of this ongoing process can include; starting pre-school, encouraging a 10 year old to self-infuse and encouraging a 15 year old to have a discussion with their doctor on their own for part of a clinic visit.



While transition is an ongoing process that begins in early childhood, many of the big steps occur during the teenage years. Most young people move over to the NCHCD between the ages of 16 and 18 years. The health care professionals involved in the transition process are aware that this is often a period of significant change, whereby physical development and growth can be accompanied by many new emotional and social challenges.

The transition process may progress differently for each individual and family, for example it may take into account if a young person is undertaking state exams or siblings close in age who would like to transition together. While there are guidelines in place, the transition process can be flexible and tailored to meet the individual patient's needs.

What to expect at the Transition Clinic

The Transition Clinic is a designated outpatient clinic for young people at the NCHCD. Prior to the first Transition Clinic appointment at St James's Hospital, the team at OLCHC will have forwarded a transfer summary to the team at the NCHCD. This is useful for two reasons, it helps to plan clinics and it also gives us an idea of what health care professionals the young person may need to see on their first visit.

Health Service



Initially the young person will meet a doctor, a nurse and a social worker. Depending on their needs and concerns they may meet other members of the team such as the dentist, physiotherapist or psychologist.

At the first visit to a Transition Clinic, the young person will be given a tour of the centre and introduced to team members.

An important part of the process is meeting and getting to know the team who will support the young person in the adult service. Meeting new health care professionals and building a relationship of trust will take some time. Transition can be daunting and it is important to remember that the health professionals in both hospitals are there to support and guide young people and their parents throughout the process. This is a team effort that includes the young person, parents and healthcare providers.

Health care professionals at the NCHCD focus on adult health needs and medical issues, the team works directly with the young person. From the first Transition Clinic appointment, the young person will continue to be supported to take responsibility for their own health needs. While the young person will have the option of attending their appointment on their own or with a family member, they will be encouraged to speak on their own behalf and to meet with health care professionals on their own.

The young person will also be provided with relevant patient booklets along with the contact details of the NCHCD and that of the out of hours service. Return appointments are made at the desk before leaving. All patients receive a reminder of their appointment by text message if a mobile number has been provided.

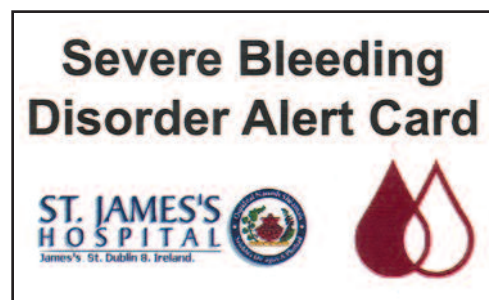
Normally the young person attends two Transition Clinics before attending regular adult clinics.

In conclusion

The transition to adulthood and adult services involves major changes for all involved. However, it is important to remember that moving on to an adult treatment centre, is one of the final steps towards independence and empowering young people in the management of their own bleeding disorder. It is a crucial step as they embark on their exciting journey into adulthood.

If you have any queries or concerns or would simply like some additional information on the Transition Clinic at the NCHCD, please do contact myself Olwen Halvey, Senior Medical Social Worker or Ann O'Sullivan Clinical Nurse Manager at 01 4162141.

**Olwen Halvey
NCHCD**





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