haemophilia.ie

Magazine of the Irish Haemophilia Society

AGM Gallery

Edition: March 2011

PARENTS WEEKEND

May 20th - 22nd 2011

Fitzpatrick Castle Hotel, Killiney, Co. Dublin

For the third year in a row, the Irish Haemophilia Society in association with Our Lady's Children's Hospital Crumlin, the National Centre for Hereditary Coagulation Disorders at St. James's Hospital and Cork University Hospital are organising a Parents Weekend Conference. Crèche facilities and supervision for the children will be in place for the duration of the weekend to facilitate parents attending the programme.

Preliminary Programme

Saturday May 21st:

09.30 – 10.30	Developments in Prophylaxis
10.30 – 11.00	New Developments in Factor Concentrates
	OR
09.30 – 11.00	v WD Issues in Childhood Years
11.00 – 11.30	*Coffee*
11.30 – 12.30	What to Expect when you are Expecting
12.30 – 13.00	Role of the Community Haemophilia Nurse
13.00 – 14.00	*Lunch*
14.00 – 15.30	Bullying
15.30 – 16.00	*Coffee*
16.00 – 17.30	Self Infusion

Sunday 22nd May 2011:

09.30 – 11.30	Mother and Father Workshops
11.30 – 12.00	*Coffee*
12.00 – 13.00	Introduction to PEP Programme
13.00 – 13.15	Barretstown Talk
13.15 – 14.15	*Lunch*

SAVE THE DATE

Reasons to attend the Parents Weekend:

* Receive up-to-date information from the Haemophilia Care Teams.

* Long lasting friendships are forged between parents going through similar situations.

* Meeting other children with haemophilia enhances personal growth for children.

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A Note from the Editor

Hello everyone,

Welcome to the March edition of haemophilia.ie. This issue includes articles and photos from our recent AGM, which we are delighted to say was a great success.

Attendance at the various sessions was excellent and the AGM itself was very exciting with the election of officers to the board. A special thank you goes to the all members who attended, the board, volunteers and staff for all their hard work over the weekend.

As you will see on page 2 of the magazine we are already planning our next conference which is the Parents Weekend. This takes place over the weekend of 20th to 22nd May in Killiney. We would like to encourage as many parents of children with haemophilia and related bleeding disorders to attend this conference as possible, in particular those with severe factor deficiency, as it is an extremely informative and a very worthwhile conference to attend.

Also in this issue you will find articles on "Ageing and Haemophilia", and we are hoping to produce a publication on this subject next year. Read also about the opening of the new haemophilia treatment centre in Cork which is a fantastic achievement for everyone involved. Of course we have our Kidlink Club pages which are full of games and jokes. We were also very grateful to two members who wrote excellent articles in relation to von Willebrands Disease from their perspectives.

And don't forget members, if you would like to write an article for the newsletter or website contact Nuala on 01 657 9900 or nuala@haemophilia.ie.

Finally, don't forget to keep us in mind if you are planning any fundraising activities in the near future. Hope to see you all soon, and remember pick up the phone if you have any questions, queries or require support, that's what we are here for.

Debbie Greene.

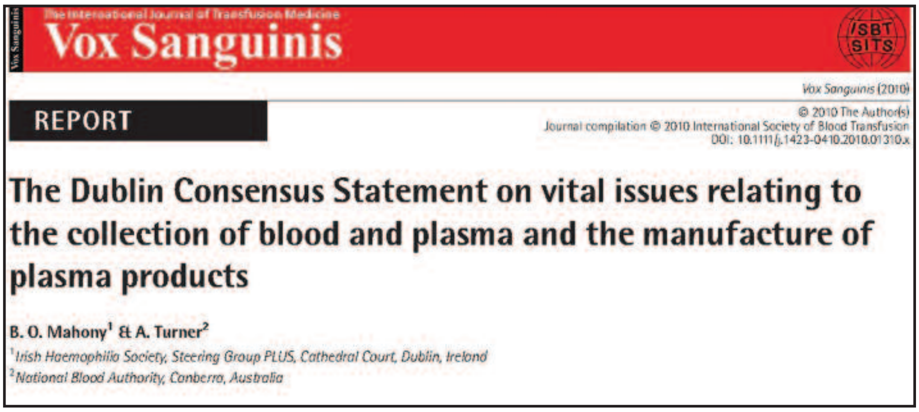
CEO's Report

Consensus Conference

In January the Irish Haemophilia Society hosted a conference on behalf of the Plasma Users Coalition (PLUS) on major issues in relation to blood and plasma globally. In Ireland, we are fortunate that we have access to recombinant factor concentrates for Factor VIII and Factor IX deficiency. However, it should not be forgotten that persons with rare bleeding disorders and with von Willebrands Disease are reliant on plasma derived factor concentrates and that people with haemophilia are still more likely than members of the general population to require blood or plasma transfusions in the future. It is worth reiterating that the plasma derived factor concentrates currently on the market have an excellent safety record, but we are all aware of course from the past, of the need for a safe and adequate supply of blood, plasma and products manufactured from plasma.

There is continuing debate globally in relation to blood transfusion services, plasma collection, the concerns of donors and the rights of patients. There is clearly a need for the collection of more plasma and for the manufacture of more plasma derived therapies. Despite this, there continues to be an ongoing debate about the idea of collecting plasma from paid donors. There has also been a very large emphasis from many of the transfusion services and plasma collection services in relation to the rights of donors as opposed to the rights of patients. These debates have been going on in the background for many years and many people have taken dogmatic and ideological positions.

The Plasma Users Coalition, which is a coalition of organisations, including the European Haemophilia Consortium, the World Federation of Hemophilia and the global organisation representing primary immune deficiency patients, have been concerned that for some time that the rights and requirements of patients were not being listened to or factored in to these discussions. To that end, in 2010, I organised a conference in Dublin to bring together the major stakeholders in relation to these issues and this led to the publication of the Dublin Consensus Statement, a set of principles in relation to blood and plasma collection globally. The conference was a major success and led to an agreement and a dialogue which has continued. A further conference took place in January of this year. This conference was even more successful than last year's. Participants included patient organisations from Europe, the USA and Canada, the Plasma Manufacturing Industry, the Not for Profit Plasma Industry, Blood Banks, the National Blood Authority from Australia, the International Society of Blood Transfusion, the International Donor Organisation and the European Division for the Quality of Medicine (an official EU body). The participants agreed on an updated Consensus Statement, which has now gone back to each of their organisations for their consideration and hopefully their endorsement. The updated statement is stronger than last year's statement. It sets out key principles in relation to patients, donors, co-operation between all the sectors and global utilisation of donated blood and plasma. Crucially, it states again that the absolute focus of the Blood Establishments and Plasma Industry must be the patient. This might seem an obvious statement, but we believe that this was not the absolute focus in the past. The principles are designed to ensure



Vox Sanguinis

The International Journal of Transfusion Medicine

Vox Sanguinis

ISBT SITS

Vox Sanguinis (2010)

REPORT

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The Dublin Consensus Statement on vital issues relating to the collection of blood and plasma and the manufacture of plasma products

B. O. Mahony[1] & A. Turner[2]

[1] Irish Haemophilia Society, Steering Group PLUS, Cathedral Court, Dublin, Ireland
[2] National Blood Authority, Canberra, Australia

The Dublin Consensus Statement

that while the rights of donors are respected and donors are never put at risk, the underlying principle should be that patients are entitled to expect that all of the key stakeholders and sectors will support their need for access to safe, effective and sufficient products. Following an endorsement process, which should take some three months, the new Dublin Consensus Statement should be published in May. The Irish Haemophilia Society is delighted to have contributed to and assisted with leading this vital process.

Ageing and Haemophilia

At the recent Irish Haemophilia Society AGM, one of the guest speakers, Dr. Craig Kessler from Georgetown University Medical Centre in Washington, DC. delivered a lecture on the topic of "Ageing and Haemophilia". This is a topic which the Irish Haemophilia Society will be addressing in more detail in the coming years. Our new Strategic Plan allows for the production of a specific publication on "Ageing and Haemophilia" which is targeted to be produced in 2012. In 2013 we are planning to hold a special conference on "Ageing and Haemophilia".

Dr. Craig Kessler, speaking the 2011 I.H.S. AGM on "Ageing & Haemophilia".

We are now seeing the first generation of people with haemophilia who are going to live long enough to start experiencing the normal problems that men in middle and older age develop with their health. Dr. Kessler pointed out that the major causes of death in American men are cardiovascular disease and cancer. In the haemophilia population, in the 1980s and 1990s, HIV and Aids were the major causes of death in people with haemophilia in developed countries (untreated or inadequately treated bleeding continues to be the major cause of death in people with haemophilia in developing countries). In the last ten years we have seen a shift to a point where one of the leading causes of death is now liver disease, related to Hepatitis C. Hopefully, with new and better treatments emerging in the coming years for Hepatitis C, this trend may be reversed. For many men with haemophilia over the age of 45, the whole concept of issues relating to ageing and the impact of haemophilia now become important.

Risks relating to heart disease, cancer, kidney disease, diabetes, respiratory diseases and mental health problems need to be addressed in the haemophilia population, as with any other population. Several studies published in Europe have demonstrated a lower risk of cardiac disease in people with haemophilia than in males in the normal population. This was long thought to be the case due perhaps to the fact that as the blood of a person with haemophilia does not clot as readily, there will be a consequent lower risk of heart attack due to a blood clot. However, this potential advantage, if it was real, is minimised by the use of Factor Concentrates, whereby the person would have a more normal factor level for a greater proportion of the time.

Indeed, Dr. Kessler showed data from a study which was carried out in the United States in the mid 1990s showing that people with haemophilia have a higher relative risk of heart disease, liver disease, renal disease and non HIV or liver related cancers. The data from the USA is at odds with the data published from European studies and this difference can not be readily explained. It may be due to the different methods of data collection or it may be due to a different lifestyle pattern in the United States. In data published in the United Kingdom in 2007 the average life expectancy of all males in the UK in 1999 was 78 wheras the average life expectancy of males with severe haemophilia was 63 and of those with mild or moderate haemophilia was 75. Data from the UK also showed that people with haemophilia have a higher risk than the general population for death from bleeding or from intracranial haemorrhage (that is not unexpected). They also had a higher risk than average of death from liver cancer, from liver disease or from Hodgkin's disease. The increased deaths from liver cancer or liver disease are not unexpected given the prevalence of Hepatitis C in the population. The increased risk of Hodgkin's disease was more surprising and Dr. Kessler postulated that this may be associated with the fact that prior to the 1990s people with haemophilia tended to be treated with large quantities of intermediate purity plasma derived factor concentrates, which contained a lot of diverse proteins. These could have increased the challenges to the immune system and could be linked to the later increased risk of diseases such as Hodgkin's. Interestingly, the United Kingdom data from 2007 showed a lower risk of heart disease in the haemophilia population when compared to the general male population.

Dr. Kessler also discussed the potential impact of Highly Active Anti Retro Viral Therapy (HAART) in HIV Positive people with haemophilia and the fact that wheras this therapy has been excellent at controlling HIV it may lead to an increased risk of dementia. Many of the therapies used to control and manage risks of heart disease such as the use of statins or aspirin have to be looked at in light of the underlying haemophilia. The importance of good diet and an appropriate exercise regime were also discussed. There is an emerging issue in the general population, known as Metabolic X Syndrome, which includes obesity, high blood pressure, high fasting blood glucose, high levels of cholesterol and triglycerides (fats) in the blood and a fatty liver. This combination is a recipe for disaster and certainly will put any person with this combination (including persons with haemophilia) at higher risk of heart disease, diabetes or serious liver disease.

The topic of "Ageing and Haemophilia" may seem rather depressing and the news may seem to be uniformly bad. That is not the case. Ageing is inevitable. What we are seeing is, for the first time, the beginning of the accumulation of evidence and data on the impact of ageing on a population of men with haemophilia. Heart disease, cancers, liver disease, kidney disease, diabetes are all conditions which increase in a population as they get older. It would be nice to think that people with haemophilia will never age and will live forever, sadly that is not the case. People with haemophilia need to be proactive in relation to their health. We should all ensure that we are tested on a regular basis for any abnormalities in our cholesterol, blood pressure, glucose levels and that screening for prevalent male cancers such as colorectal and prostate cancer are carried out at appropriate intervals and not ignored. We should look to maintain a balanced lifestyle to include diet and appropriate exercise and we should work with the healthcare professionals to maintain good health. I know that the National Centre for Hereditary Coagulation Disorders (NCHCD) will be examining the whole issue of "Ageing and Haemophilia" and looking at an appropriate clinical response in relation to helping people with haemophilia to prevent the onset of diseases of ageing, to diagnose any problems early, to monitor and maintain health and to treat appropriately. This is a topic we will be returning to on future occasions.

Brian O'Mahony

Getting Older? Prepare or Fall

Many people fail to prepare their homes for changes in their body's ability to do what it always could. When we are young and agile we don't think twice about the height of steps, how low to the floor electrical sockets are, how narrow a path or doorway is, how much we stretch to reach everyday objects. However, it is well documented that the home is the most common place for accidents due to trips and falls, so instead of considering adjustments after you end up in Accident & Emergency, why not take a good look around your home now? When looking around the home, we should consider not only safety, but also convenience, considering how our body is now and how it is likely to be in the future.

Recently we moved house because our children had flown the nest and we wanted to try living in the countryside. Since we both have arthritis in our lower joints, and we are in our fifties, we decided a bungalow would be more appropriate than a two storey house.

However, the bungalow we decided upon had two steps at the front and back doors that were almost twice as high as conventional steps! A builder told me that a step should be no more than 6” high, so we had him rebuild them. Another feature of the house was that some windows had top openings only. They were quite comfortable for the previous owner to reach but we have to stand on a step-up to open and close them! Other windows in the house have side-openings which are more appropriate for people of any height.

When adding an en-suite we had the builder put in a shower with as low a threshold as possible, as well as a grab rail inside the shower. We also had a grab rail put over the bath to assist stepping in and out, as bathrooms are the most common places for people to slip. When people’s lower limbs become weaker, balance reduces, so it is vital to be able to steady oneself in potential fall areas, typically steps, stairs and bathrooms. Another feature we added to the en-suite was a motorised velux window. The ceiling is quite high so stretching with pulley strings or a pole to open and close it would be quite awkward. Fixed and removable shower and bath seats are easily available so consider if you would benefit from them.

Kitchens are the most used room in a house so consider various alterations that can improve your ease of use and particularly your safety: worktop heights, low level grills instead of eye level, lever taps are easy for arthritic hands, adequate electric sockets to prevent trailing leads or co stantly moving items around. Pot drawers are more accessible than low presses, which require kneeling or crouching to reach into. Larder presses can have pull out trays so stretching to the back of them is avoided. For higher presses, don’t stand on a chair, buy foldaway steps with a high grab bar for balance and with slip proof steps.

Steps and stairs should be in good condition, particularly if carpeted. Ensure that the hand rail is also in good condition and securely fitted. Floor tiles and lino are lethal when wet, so consider having good door and hall mats to eliminate slipping or sliding. Kitchen tiles can become wet around the sink and back door of the house, so deal with these areas also.

Pathways and doors through the house should be adequately wide and unobstructed. Hallways and stairs should not be used for storage as stepping around and over objects requires good balance. If possible have a direct path from your bed to the bathroom. Walking around a bed or other furniture during the night, with poor balance, when not fully alert and possibly in the dark, is preparing for a fall!

Occupational Therapists are trained to identify dangers and make recommendations to alterations in your home to ensure your safety, so consider a consultation. It is not necessary to move from a two-storey house to a bungalow to eliminate climbing stairs, get a stairlift or consider converting the lower half of the house into an apartment.

Conversions and extensions can be expensive but health board grants are available. Conditions include an Occupational Therapist’s report and means test. For older people there are schemes whereby the local authority rehouses people in “independent living” secure units or apartments and purchases their house at a reduced price. These units are carefully designed and often includes wardens and personal alarm systems.

Written by a member of the Irish Haemophilia Society,
February 2011

If you would like any advice or have any issues in relation to “Ageing and Haemophilia”, please contact Anne Duffy on 01 657 9900 or anne@haemophilia.ie

Celebrations in Cork

It is fair to say that everything we read nowadays is doom and gloom; elections, the economic downturn – enough!

Well thankfully we have a reason to smile, because after years of hard work and planning, a Haemophilia Treatment Centre is opening in Cork University Hospital. On Wednesday February 16th the Irish Haemophilia Society staff travelled to Cork where they, as well as members and their families, were given a chance to view the new facilities before the official opening, which is due to take place in April.


IHS staff members Declan Noone and Nuala Mc Auley with IHS CEO Brian O'Mahony & Haemophilia Nurse Specialists Norma Collins & Helen Browne at the open day of the new Haemophilia Treatment Centre in Cork University Hospital.

The Open Day attracted more than forty people. Tony Boloney, magician, was on hand to entertain the children with magic tricks and balloon animals. For the adults, Consultant Haematologists, Dr. Susan O'Shea and Dr. Clodagh Ryan were on hand to answer any queries people had. Haemophilia Nurse Specialists, Norma Collins and Helen Browne were also in attendance giving individuals guided tours of the facilities and explaining the benefits the centre will provide not only for people with bleeding disorders, but also their families.

The new treatment centre will offer a drop in service, treatment services and clinics. With a separate entrance and its own car parking, the centre is specifically designated for people with haemophilia or related bleeding disorders and is fully accessible. The centre itself is newly refurbished and has been developed and laid out with the patient in mind. With four treatment rooms, a reconstitution room, a meeting room, a waiting room, a secretary's office and a nurses' office, the centre is spacious and well equipped and is sure to improve services for people with bleeding disorders by providing patients with a fast and efficient service in a safe, secure and welcoming environment.

I spoke to those in attendance on the day and got their views on the centre and the improvements they see the centre having on patient care. To view the full report on the Open Day please see the website, www.haemophilia.ie.

Nuala Mc Auley

Left: Tony Boloney, the magician entertained the children at the open day
Above: I.H.S. staff members Nina Storey, Anne Duffy and Declan Noone chat to members at the open day

What do you think of the centre?

The building looks wonderful. They have had a good haemophilia team at Cork University Hospital for a number of years including a new consultant haematologist in the last year. The staff are here. What they have lacked is the physical infrastructure. That is now in place. The centre looks excellent.

(Brian O'Mahony, CEO, Irish Haemophilia Society)

I think it looks great, I was here when it was just a shell and to see it now is fantastic.

(Gareth Presch, Administrator, National Haemophilia Council)

I am very impressed, both by the fact that it is here is great, but also the layout: it is very easy to get around, its bright, there is natural light coming in, the windows are big. At the moment it is clean and pristine and neat and new and it is very exciting all together. Hopefully, I won't have to be here too much, but it's great.

(Brian O'Riordan, I.H.S. member)

Fantastic, it is absolutely brilliant. It is badly needed.

(**Angela Lee, I.H.S. member)**

It's fantastic, just fantastic, because the staff were borrowing spaces before and you would have to ring and they would have to see if they could get a spot to fit you in. I think the fact that it is a dedicated centre is superb and the fact that there is a separate entrance is brilliant. I look forward to coming to the clinics.

(Joan Buckley-Keniry, I.H.S. member)

It's fabulous; its great that there is parking outside and that there is a separate entrance.

(Jackie O'Dea, I.H.S. member)

It's great, much bigger than I thought it was going to be.

(Vicky Murphy, I.H.S. member)

Clockwise from top:
* A treatment room in the new Haemophilia Treatment Centre, CUH.
* HNS Helen Browne with members at the open day.
* Members admiring the New Treatment Centre.
* HNS Norma Collins chats to members at the open day.

I know a lot of work has gone into getting the centre open, how do you feel now that it is nearly complete?

I am absolutely thrilled, I am in the job eleven years and we have been working from a very, very small office. Fortunately for children we had very good facilities here, because the children's day unit was wonderful. But it was just to get space to see adults we found difficult. It is just wonderful to have everything at our fingertips, because only having an office not having a treatment area, we had to go around to different wards to collect needles, syringes, dressings and factor. All these things we had to basically beg, steal or borrow. Whereas now everything is going to be at our fingertips and I think it is just wonderful and I think it will encourage patients to turn up to all their clinic appointments, because there are going to be smaller clinics and there is going to be a good bit of time given to them. Up to now when they were sitting in outpatients, you are still sitting with other people who are attending other clinics so you could be sitting with forty people and it can be a bit overwhelming especially for people with severe haemophilia in the 20s, 30s or older who would have hip or joint problems and they are sitting down for quite a while waiting for their appointments. We are hoping that they will be in and out and seen at the appropriate time. It is just wonderful, it will be great for us to be able to give better patient care and treatment.

(Helen Browne, Haemophilia Nurse Specialist, CUH)

It's a fantastic asset for the services here in CUH, delivering care not only for patients with haemophilia, but for patients with bleeding disorders across the board. I came back in 2006 and the seeds for this (the Centre) were sewn even before that, but it will be a fantastic asset. I think we can consolidate our services and provide a comprehensive service as we have been trying to do, we have all the bodies here, willing and able, but previously we were scattered throughout the hospital so this will allow us to bring our services together a lot more consistently. This will be a great asset.

(Dr. Clodagh Ryan, Consultant Haematologist, CUH)

How will the centre improve CUH's ability to treat people with haemophilia & other bleeding disorders?

We will be able to have dedicated clinics more often and with small numbers attending so the patients won't be waiting. Previously parents had to come in on a Friday afternoon and they could be seeing twenty to thirty patients on a Friday afternoon, which is very difficult. It is very hard to get through those numbers so patients did have to wait. We didn't have a drop in centre before, we didn't have any place that was designated as our own so patients would, if they had an acute problem when they weren't scheduled to come to clinic, contact us and then we would have to find a space, somewhere within the hospital to see them. On occasion, this was A&E, and if there was not a space it could have been just a chair in a corridor. Now we have four designated treatment rooms so if a patient calls us with a query or a problem, we can tell them to come in straight away that we have a room for which to see them.

(Dr. Susan O'Shea, Consultant Haematologist, CUH)

Well once we move in it will improve and once we get up and running with clinics and a place where patients can come in to if they have a bleed, which we didn't have before, and they can have their treatment easily. It will be great when we get all the other various services involved here at the new centre. We will have dental hygienists for the children and physiotherapists who will be able to come here to our clinics which wasn't always available before. We will have consultants nearby all the time and plenty of space, which is the thing we were always missing, we had to go and find somewhere in the hospital so now we can tell them to come in here. This should be a huge improvement.

(Norma Collins, Haemophilia Nurse Specialist, CUH)

It should transform haemophilia services in Cork. Up to now, despite the fact that this has been designated a Comprehensive Care Centre they have not had an actual physical building. They now have the physical building and this will allow them to do outpatient clinics, drop in services, deal with walk ins and it will allow them to provide a comprehensive service which they haven't been able to do up until now because of the lack of infrastructure. This is the culmination of several years of work by the team here at CUH, by the National Haemophilia Council and by the Irish Haemophilia Society. The work has paid off and the new centre is the result.

(Brian O'Mahony, CEO, I.H.S.)

Leaving a Legacy to the I.H.S

You will be aware that the Irish Haemophilia Society has broadly increased the support and services which we provide to members over recent years, to include additional conferences, educational meetings and publications.

The Irish Haemophilia Society funding comes primarily from funding granted on an annual basis by the HSE. Almost 80% of our annual funding comes from this source. We are reliant on donations and fundraising to raise the additional funds required to run the organisation. As members of the Society you have been and continue to be generous. We hope that this generosity will now extend to a positive consideration of naming the Society as one of the beneficiaries in your will.

We have launched an appeal to members and friends of the organisation to leave a donation to the Society in their will. A strong, active and effective Haemophilia Society is essential and will continue to be essential in the future if we are to optimise the quality of life for people with bleeding disorders in this country.

A legacy is when you leave a sum of money in your will to a charitable cause. Some people leave their entire estates, but most leave a modest sum. However much you choose to leave, is up to you. But rest assured... that every legacy counts, no matter how large or small. Either way, many people find that leaving a legacy to benefit others after they've gone, is one of the most wonderfully, rewarding experiences of their lives.

Only 40% of people in Ireland make a will as the whole idea of a will can make us feel very uncomfortable, however it is something all of us should do at an early age to ease the burden of the love ones we leave behind. A legacy donation to support your favorite charity or a cause close to your heart will make a difference.

Leaving a legacy is something that everyone can do regardless of their income. My Legacy was established in 2003 by a small group of Irish charities who wished to spread the word about charitable bequests. Since then My Legacy has grown and now it represents nearly 50 leading Irish charities and not-for-profit organisations.

MyLegacy.ie provides unbiased, useful information to individuals, charities and solicitors about leaving legacies to charities. MyLegacy.ie work to promote legacy giving and give donors, solicitors and charities the information they need to make it happen.

Why not check out our website www.haemophilia.ie For futher information and links please see www.mylegacy.ie

We hope that you will support our endeavours by positively considering leaving a present for the future and leaving a legacy to the Society.

Leave a present for the future, leave a legacy!

Debbie Greene
Administrator

IRISH HAEMOPHILIA SOCIETY

Leave a present for the future,
Leave a Legacy.

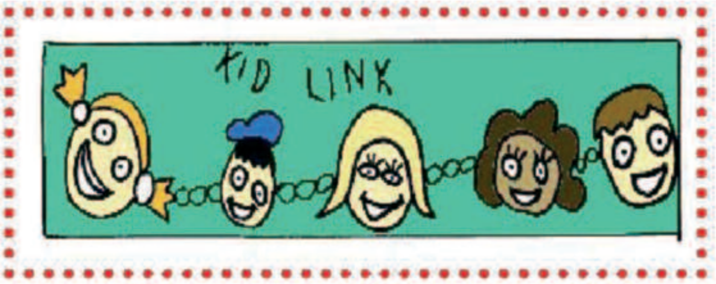
The Irish Haemophilia Society provides services and support to persons with haemophilia, von Willebrands disease and related bleeding disorders. Our activities include advocacy for optimal care and services for people with haemophilia and related bleeding disorders. They also include educational publications, medical and patient conferences and financial support to members and their families.

The Society is a professional charity with a committed volunteer board and professional staff who deal with the challenges ahead with energy, compassion and empathy.

Life is a wonderful gift and just one of its many joys is being able to pass that gift on to people and causes that are important to you. So if you would like to be remembered for a lasting act of kindness, support the Irish Haemophilia Society in your will. For further information please see www.haemophilia.ie

www.haemophilia.ie

Kidlink Club

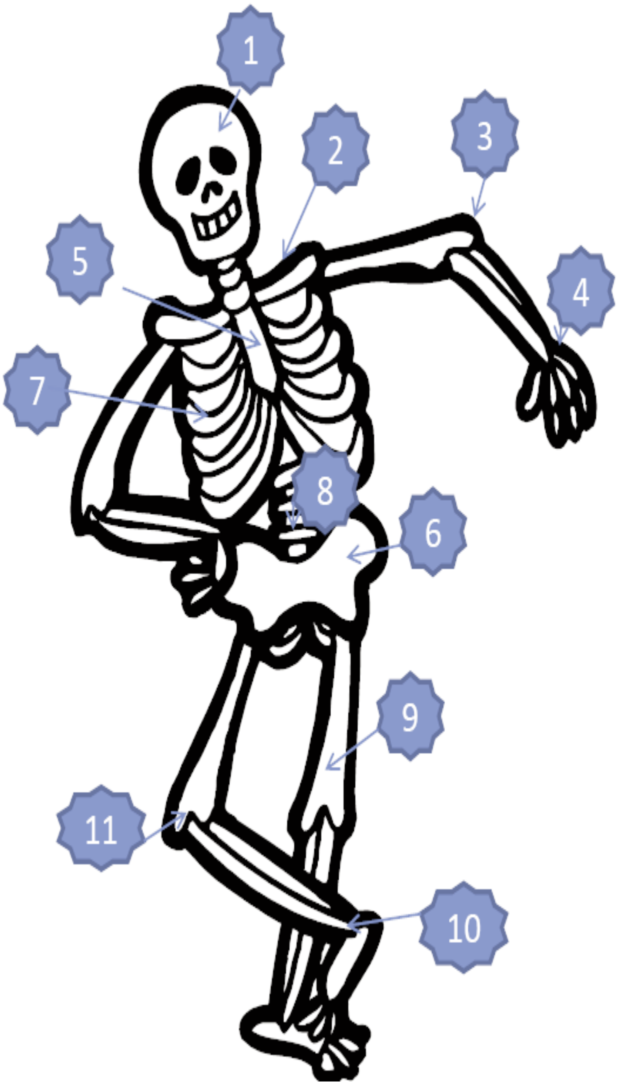


Hello and welcome to the Kidlink and Youth Group pages, where it is strictly - **NO ADULTS ALLOWED!** We hope everyone enjoyed the AGM. Don't worry if you were not able to attend there is the Parents Weekend in May and the Members Weekend in October to still look forward to!

We hope you like the information and games included in this issue, if you have any jokes or stories that you would like included in the newsletter just send them into us and we will be happy to use them!

Have fun!

Congratulations to Kidlink member Niall Jackson, aged 10, who won the Fundraiser of the Year Award for 2010 along with his Parents and Aunt and Uncle for a Garda Band Concert they organised in October 2010. Here's Niall being presented with the award at the 2011 AGM.



I HAVE A BONE TO PICK WITH YOU!

Can you identify the numbered parts on the skeleton? Write the number beside the bone / joint listed below.

Wrist __ Pelvis ___ Sternum ___

Knee __ Clavicle ___ Cranium __

Elbow __ Femur __ Rib Cage __

Ankle ___ Vertebrae ___

Answers on the bottom of page 13.

HAEMOPHILIA IN FOCUS

Q. Should I tell my friends that I have haemophilia?

A. That is something you might want to talk to your parents about, but it is your choice. Sometimes the best explanation is for you to tell them, but you could also ask the nurse from your Treatment Centre or Anne Duffy from the Irish Haemophilia Society to talk to your teachers and/or the children in your class.

Why did the banana go to the hospital?

Because it wasn't peeling well!

Why do cows have bells?

Because their horns don't work!

What do you get when you put a witch in the fridge?

A Cold Spell!

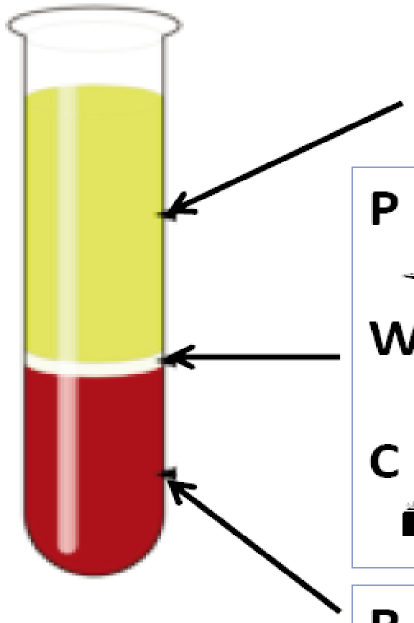
Why should you not tell an Easter Egg a joke?

In case you crack it up!

A Bloody Mess!

Blood is more than red liquid, it is made up of many parts. Using the key at the bottom of the page, can you identify the different parts that make up blood?

Answers at the bottom of the page



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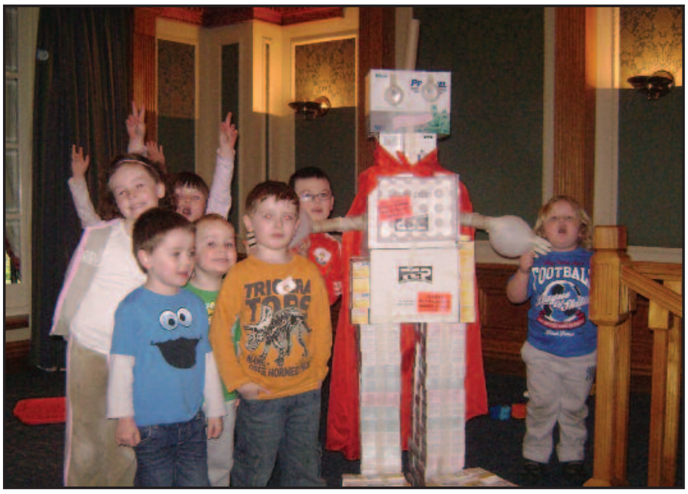
Answers: I have a bone to pick with you: (1) Cranium, (2) Clavicle, (3) Elbow, (4) Wrist, (5) Sternum, (6) Pelvis, (7) Rib Cage, (8) Vertebrae, (9) Femur, (10) Ankle

A Bloody Mess: Plasma, White Blood Cells, Red Blood Cells.

AGM 2011 - A Member's Memory

Having heard great things about the Slieve Russell Hotel in Cavan, the venue of this years AGM, we were not disappointed. Upon arrival on Friday evening we were most impressed with the beautiful hotel and grounds. The bedrooms were a very good size - in our case, holding two doubles and one single, and still having room to walk about! The kids were very excited to meet up with everyone and headed off to the Wii champsionship.

Saturday morning, after a lovely breakfast buffet, the kids were dropped off to their clubs. The younger two, Jessica and Adam to the crèche where Carmel, Clare, Aoife, Erika and Liz were waiting with art, toys and dvds. This year the crèche was held in a very large room which gave the older kids plenty of room to run around, although I'm sure this meant more running around for the ladies too. Anne Duffy gave a talk complete with puppets, about haemophilia. I think this is a very good idea at this age, not just for the boys but also their siblings. Jessica and Adam particularly enjoyed making their giant robot from empty factor boxes. He was christened Freddie X Factor and they were delighted to see him on stage at dinner that evening.



The children from the Creche with their robot creation Freddie X Factor

Hannah took part in the Kidlink programme. She was delighted to head off away from Mam and Dad and thoroughly enjoyed the day. She particularly loved the swimming and animation workshop. The workshop was a great idea and gave them a chance to learn something new, and she was thrilled to have everyone view their movie at dinner that evening.

While the kids were being entertained, we attended the AGM where this year a new governing body was elected. The meeting gave us a chance to hear the events of the past year, notably the successful opening of the Cork Centre, review the financial position of the Society and hear about the plans for the coming year. The Society has set up a fundraising committee headed up by Debbie and Nina. In the current climate, fundraising will be vitally important. Already the men are being recruited, or maybe coerced, into growing their moustaches for Movember.

Attendance at this year's AGM was higher than in previous years

Following lunch, I attended a most interesting session, Update from Comprehensive Care Centres. Doctors from Crumlin and St James's Hospitals as well as representatives from physiotherapy, dentistry and the nursing staff were present. Dr. Beatrice Nolan, OLCHC, confirmed the appointment of a new community nurse, who will travel the country to assist families and advise schools or playschools where required. This is a great addition to the OLCHC team. Even though OLCHC has the most relevance to me at the moment, it was interesting to keep up to date with all developments across haemophilia care worldwide. The advances made in the use of hand-held devices for members to log their factor usage is excellent. The hospital is hopeful that everyone wishing to use this method, rather than the pink sheets, will be provided with a device within the next year.

Professor John Bonnar chaired the session: Update from Comprehensive Care Centres

The Gala dinner on Saturday evening was very enjoyable. Following the delicious meal, there were the presentations to this years scholarship winners and a special presentation to Alison Daly who is stepping down after many years running the Young Adults & Kidlink programme. Paul Dunne and Caitriona Moriarty will now take over the reins. The B Sharps then took to the stage to entertain us into the early hours.

A family affair: From left to right Jessica Byrne, Jim Dunne, Ken, Hannah, Joan & Adam Byrne and Margaret Dunne at the Gala Dinner

Sunday morning brought kids clubs again for the girls, golf on the hotels golf course for Adam and his dad and I attended a talk on the Twinning Programme with Vietnam. Brian and Michael visited Vietnam last year and brought back lots of pictures including many of young children with lots of severe bleeds with no treatment available. Having a young son myself and knowing I can head to Crumlin Hospital as and when I need to, made me realise how difficult it must be for the families in many parts of the world who struggle to get treatment. Brian spoke of the action plan in place for twinning with Vietnam over the next couple of years.

After working with the IHS for 10 years, Alison Daly stepped down as Kidlink and Youth Group Co-ordinator at the AGM..

Following the morning session, it was on to lunch before heading home with very tired children. We all thoroughly enjoyed our weekend. The hotel was lovely and the food and service excellent, a great choice of venue. A big thanks to all the Society staff and all the leaders for a great weekend. Looking forward to the next one.

Joan Byrne

WHAT A WEEKEND!

This year the AGM was held in Slieve Russell Hotel, in Cavan. When we arrived, the hotel was lit up beautifully. When we went inside we found the inside was as pretty as the outside. After we had checked into our room, I went to the Kidlink Wii championship. I had a great time. After that, I had to go to bed to get ready for a busy weekend.

On Saturday, after a really nice breakfast, I went to the Kidlink group. We first wrote a memory or a good luck message for Alison, the former Kidlink leader and organiser, to put in a scrapbook which was presented to her at dinner that evening. Then we went swimming. The pool was gorgeous and lovely and warm. We had great fun with Paul throwing us all into the water. We spent a long time in there and didn't want to get out!

Left: *Kidlink Members Dara Dowling and Brandon Griffiths presenting Alison Daly with a "Book of Memories" created by the Kidlink and Youth Groups at the AGM.*

After lunch, we headed back to our kidlink base and played team games. These were great fun but I'm glad I didn't win the smelliest shoe competition! After that, we made an animation movie, called the Story of Brian's Life. It was about a boy with haemophilia who didn't want to take his factor. We worked really well together and had lots of fun. Lucia took some group photos before we finished up for the day. We headed back to our rooms to get ready for dinner.

The food at dinner was lovely. After the meal, there were some presentations and awards and our movie was shown. Thanks to Lucia and Declan for getting it ready in time. It was great to see all our hard work pay off. The band, the B Sharps, were great.

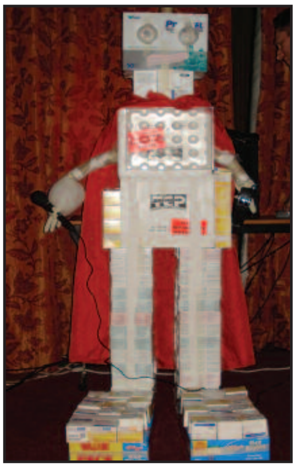
On Sunday morning, everyone was tired but the leaders got us all warmed up with games and took some more photos because we are all so pretty! We went swimming again and then it was lunchtime. I was sad to go home because the weekend had gone too quickly. It was a great weekend and I think everyone had an absolutely great time. Thank you to all the leaders for all the fun.

Hannah Byrne, Age 10

AGM 2011 - Behind the Scenes

Given that it was my first year running the Crèche, Kidlink and Youth groups for the weekend; let's just say I was a little bit anxious. Alison Daly has left an amazing programme for us to work with so without her I was considering it a big challenge. On Friday night as registration kicked off, I was relieved to see the excited and eager faces of the children coming through the door. I was equally excited about seeing the friendly and enthusiastic faces of our volunteers.

The Crèche group probably had the busiest time of all, with 20 kids booked in for the weekend! The activities ranged from a puppet show, making sock puppets, arts 'n' crafts and finally making a 'Super Freddie X Factor Robot' which took pride of place at the Gala dinner – if rumours are to be believed he even had a dance later in the evening! Créche leader Aoife Downey tells us more about the weekend in the Créche:



The newest IHS Member, Freddie X Factor

The AGM was a fun packed non-stop weekend full of games, laughter and excitement for the children in the Crèche. The fun started with the making of our robot, "Freddie X-Factor". With the inspiration of Sara, the children built him by using their collection of factor boxes, toilet rolls, yoghurt pots, rubber gloves and of course sellotape to stick him altogether! Once "Freddie X-Factor" was brought to life the children then played a little bit of football. After a little bite to eat, we were all off again!! Anne Duffy entered the room with a little red chair and a black bag which made the children wonder what Anne had up her sleeve. They settled down comfily on a duvet and watched a great puppet show all about "Super Factor Turtle". The puppets explained that when boys got bleeds, they might be feeling slow like a turtle and not wanting to do anything. However when they take their factor they will turn into "Super Factor turtle" being able to do all the activities they want to! The children were told that not every boy has a Freddie and some have to inject into their veins, however the factor helps to boot them up in the same way allowing them to be the "Super factor Turtle" whizzing along without a care in the world! Every now and again we got a few adult heads peeping in through the door to see if the children were all ok but they went un-noticed as the children were too busy making their Sock puppets and their colourful, sticker and picture filled place mats for the table!! When the place mats were done all the children raided the dress up box and turned into army men and women, doctors and nurses and many more. As a little thank you for the I.H.S office the children put "our family" of hand prints onto a canvas. By Sunday, we were all worn out from all the excitement and activities, but we are looking forward to the next weekend when the excitement will start all over again!

Aoife

With over 20 kids registered, the creche was a hive of activity over the weekend.

With over 30 kids registered with the Kidlink and Youth Groups, the leaders were very busy, but luckily we had a jam packed programme to keep everyone entertained. Here Kidlink and Youth Group Head Leaders, Catriona Moriarty and Paul Dunne tell us how they felt the weekend went with their groups. Saturday morning brought a full day of fun and adventure for the kidlink and youth groups.

When thinking back on this year's AGM one of the things that stand out is the number of kids that attended, between the crèche, the kidlink and the youth group there were over 50 children. That has got to be some sort of record! I never would have imagined all those years ago, when I was one of three staff members' kids who just tagged along with our parents to the AGM, that the involvement of the kids at these weekends would become so big. It was back in those early years, must be 12 years ago now, that I first got to know Alison Daly, as she was the *one who used to keep us three entertained; bringing us bowling, swimming or to the cinema. If I'm honest I thought she was a bit mad. If I'm really honest I still do. Over the years, our little group expanded and an official programme was put in place including activities, like day trips to castles, farms and caves or horse riding, circus school, samba drumming and the once legendary Saturday night disco.*

For the last seven years or so I've been volunteering at the I.H.S. conferences and so too have a number of those who used to come to the conferences as kids just like me. This year Alison stepped down as Kidlink coordinator and as she couldn't possibly be replace by just one person, I was asked to share the responsibility of leading the programmes with Catriona Moriarty which would be coordinated by Fiona Brennan. For this year's activities we started on Friday with a not-so successful Wii Championship. It seems on certain occasions even a Wii can't compete with a box full of toys, which were for use in the crèche for the following day. So although there was some Wii playing, most of the time on Friday evening was spent playing with train sets, sponge footballs and indoor Frisbees. ***Paul***

On Saturday morning, we started off with arts and crafts. As Paul mentioned, Alison Daly stepped down this year as Kidlink Coordinator after ten years and we wanted to make something special for her to show our appreciation for all her hard work. It was decided that the kids would help make a keepsake scrapbook that would be presented at the Gala dinner later that night. All the kids enthusiastically made pictures and wrote thank you letters to put in a scrapbook. They discussed their favourite memories and reminisced on their favourite activities and adventures that they enjoyed and took part in over the last few years. It was clear from their enthusiasm and dedication in producing this scrapbook, Alison was going to be missed by everyone.

Following that we went swimming, which is a favourite among many if not all of the kids. They took to swimming like a duck to water and even used some of the leaders as surf boards! Everyone enjoyed the swimming and as always they didn't want to get out of the pool. God help use if we ever go to a hotel with no pool, as swimming has certainly become an obligatory part of any weekend.

The Kidlink group made an animated movie called "The Life of Brian".

After lunch, the kidlink group took part in a movie animation workshop. This workshop made an educational movie about a ten year old boy named "Brian", who had haemophilia. The group split into three smaller groups and each were given a different scene to portray. Everyone took part in making the scenery for the animation, and they were very enthusiastic using different materials for special effects. As you can imagine, a lot of effort went into creating each scene for the animation, but I know everyone enjoyed this activity. ***Catriona***

The youth group work together to get out of a tricky situation in their Team Building Workshop

For the podcasts, the young adults were give three topics to make their recordings on. They were needlephobia, joint replacement and living with Haemophilia 40 years ago. Three members came in to talk about the topics which related to them and I for one found this really interesting. The group then split into three groups and were given one of the topics to research and make their podcast about. All the podcasts turned out great. ***Paul***

After such a busy day, it was time for our annual Gala dinner. The room looked spectacular and the food was even better. I can safely say that all 180 guests enjoyed it, and I think it was the best gala dinner yet! Luckily, Lucia worked extremely hard and finished editing the movie animation "The life of Brian" just in time and we all got to see the video after dinner. The feedback from the parents and other guests was very *positive, and they were very impressed with all of the hard work the kidlink group put in. The scrapbook was presented to Alison by Dara Dowling and Brandon Griffiths, and the kids were very pleased with the end result. Overall a great night was had by all.*

Catriona

On Sunday the youth group took part in some team building activities, while the kidlink group played games such as "cat and mouse" which turned out to be extremely entertaining for both the kids and the leaders. Afterwards it was another session of swimming before our final lunch. Everyone was sad that this year's AGM was over, but we have the Parents Weekend and the Members Conference to look forward to. We really hope all the kids had a good time and are looking forward to the next weekend. We know we are!

Paul & Catriona

All in all, the weekend went off without a hitch and the volunteers and I enjoyed it as much as the kids. I would like to thank all of the volunteers for making it a weekend that the kids both enjoyed and will remember!!

Until May,

Fiona Brennan

To view the kidlink group's animation movie, to listen to the youth group's podcasts, or to read the full reports from the AGM, check out our website, www.haemophilia.ie

Clockwise from top left:

* Kidlink leader Ciaran Dowling accepting the Maureen Downey Educational Grant from IHS Board Member Pat Downey

* Hilary O'Sullivan presents Susan & Philip Clarke, Edel & Vincent Jackson and Kidlink Member Niall Jackson with the Bill O'Sullivan Fundraiser of the year award for 2010

* IHS Chairman Michael Davenport presents Sarah Gilgunn with the Margaret King Educational Scholarship

* The Kidlink group strike a pose in their movie animation workshop

In Focus: von Willebrands Disease

Haemophilia.ie spoke to a woman with von Willebrands Disease and the parents of a boy with von Willebrands Disease. Here they tell us their stories and the impact von Willebrands has had on their lives.

Story 1: Woman with von Willebrands Disease

Growing up with von Willebrands in the 1960's was a lot different than it is now. When it was discovered that I was a "bleeder", my mother was confused as to where this all came from. We didn't know that there was a medical name for it for a number of years. On the advice of the district nurse, I was encouraged to use ice packs for the bruising and put pressure on the cut or graze to stem the bleeding. None of my brothers or sisters had any problems with bruising or bleeding so therefore my mother was unsure what to do when a crisis arose. With my unusual bleeding condition, all care was taken to ensure that I didn't get into too much mischief to worry my parents. But that wasn't always the case. I remember on one occasion I was out helping my brothers and sisters do some chores on the farm and of course I was the one who took a tumble and ended up with a huge gash on my forehead. My mother was frantic and I was placed on the couch beside the fire, holding a towel to my head and under strict orders not to move for the rest of the evening. I did bleed for some time and I remember it being a day or two before the wound started to heal. The reality now is that I should have been quickly brought off to hospital and had the wound stitched, but when you live in rural Ireland and are not close to a train station or didn't have access to a bus route the home remedies are first to hand and were quickly put into action.

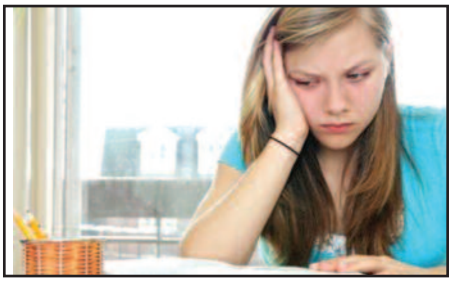
When things were going good the bleeding condition was put to the back of our minds, but not forgotten about. However, a routine visit to the dentist, when I was about eleven years old, brought it all tumbling back into our lives again and made us rush into "bleeding" mode again. The dentist said there was a lot of overcrowding and I would need some extractions.

So, more expert advice and care was needed. My parents were not taking any chances as they knew that this wouldn't be straight forward and I remember being brought to the Children's Hospital in Crumlin. This was a huge adventure for me because I was getting to go to Dublin for the day. But the day turned into another day and another day. I think I was kept in for about a week and I was so homesick I thought I would never see my family again, but with the teeth taken care of I was glad to be re-united with my family again.

There was another occasion when I was looking forward to going on a school trip and I had to bring my bus money into school a few days before the trip and I was so excited I was running all the way there, when I literally hit the ground running and cut both knees. I had to turn around and go back home to have both knees bandaged. Later, I headed back to school with the money safely in my school bag. Luckily the trip wasn't for a few days and I had time to make a good recovery. It turned out to be a great school trip with no adventures or mishaps to worry my mother.

When I started having my periods it was another very anxious time for everyone. I was in hospital for a few days at a time and it was around that time that there was a name put on my bleeding problem. Von Willebrands had made its debut into my life and unfortunately was here to stay. At least we knew what was going on and we were advised what to do if and when I had any major problems. I felt that I was a bit of a freak among family and friends, because no-one else had this problem with the weird name. So therefore it was hard for my friends to understand the severity of this condition and the impact it was having on my life.

Naturally, with all the disruptions my school work and attendance suffered and I ended up having to repeat a year and I wasn't too happy about that. It is hard to explain to your friends that you have something going on in your body and you have absolutely no control over and have to do your best to live with it. But thankfully as we all got older and wiser we were able to talk about it and understand the meaning of all these hospital visits and check-ups and the important role they played in my life.



During my adult life I had many eventful times and prolonged hospital visits, some of them too difficult to talk about and resulting in many different health issues. Thankfully, there have been many wonderful advances in the treatment of people with bleeding disorders and we know that the care we get is second to none. In the 1990's I was going through a bad time and I was privileged to be put in touch with the Irish Haemophilia Society who were a brilliant support and helped me through.

Story 2: Parents of a boy with von Willebrands Disease

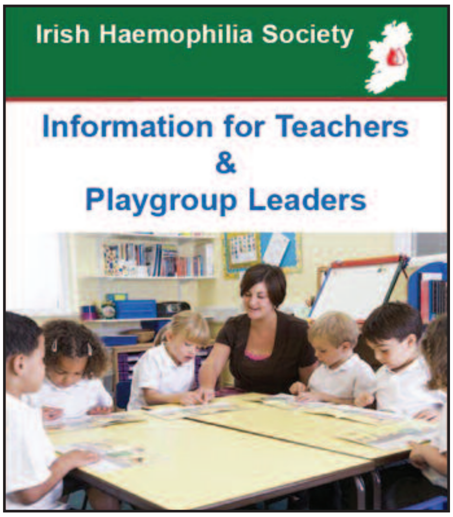
We are the parents of a boy who is five years and 10 months old (apparently the 10months is very important and I mustn't forget it!) He's in Senior Infants and is very bright, he has great fun playing with his friends and doing all of the things that five year old boys do. The only difference is he has von Willebrands Disease and is non DDAVP responsive. It has been quite a steep learning curve, but fortunately we have known about it since he was six months old. I had never heard of it before I met my husband; he has 5 siblings, but is the only one with the condition. He wasn't diagnosed until he was 10 years old and I am sure that he caused his mum many sleepless nights both before they knew and after! Thankfully medical advances have meant that we can be proactive with both of their care.

When our son was younger, having von Willebrand's Disease was less of an issue, his environment was more controlled, and he was either with me or in the crèche where they were fully aware of his condition. Although most of his bleeds have happened before he started school, we have been quite lucky really in that he has only been hospitalised a few times. His first bleed was when he was only about 18months old; he was in crèche, who had been looking after him since he was six months old. He was going outside to the play area, when he fell against the metal railings and hit his face. Fortunately the treatment he received in the hospital stopped the bleeding and he didn't need any stitches.

I think the hardest part of him having a bleed is making sure that the people around him don't panic. As parents we are used to seeing that amount of blood, and he takes it all in his stride. However it is easy to forget how upsetting it can be for caregivers to see it. So far we have been lucky, but I do think that a lot of it is how you deal with it yourself. I always take great care to play down a minor bleed, although to those not used to children with a bleeding disorder they never look minor!

It was a totally different situation when he started school though, I felt like I was totally out of the loop. After all it was such a controlled environment in the crèche but not so much in schools, especially with all the bigger children around. So I was a little panicky to start with and it took me a while to adjust. We thought long and hard about which primary school to send him to, we were in the fortunate position of being able to choose between several. The school we chose is a rural school with around 200 pupils. All of the teachers, including the head teacher know each pupil and I felt he would be looked after there without being micro-managed or worse being just a face in the crowd.

The first thing I did was to inform his class teacher of his condition and what it actually meant on a day to day basis, which fortunately is very little. The literature available from the Haemophilia Society for schools was brilliant; it explained everything simply and without causing panic. He hasn't yet had a bleed at school and I do worry about that in case the staff panic, or don't recognise an internal bleed. The only comfort I can take is that I have provided them with all the information available, I know that this has been distributed through to the relevant people and places. This combined with the fact that I have prepared our son with as much information about recognising a bleed and what he should do, gives me some peace.



Irish Haemophilia Society

Information for Teachers
&
Playgroup Leaders

The only really scary bleed he had was when his tonsils began bleeding when they became infected. At the time we didn't realise he had such a bad sore throat, and until we spoke to Dr Nolan, his consultant in Crumlin, we weren't aware of how potentially dangerous it could be. We were transferred to Dublin by ambulance and to his disgust my son slept the whole way and missed the sirens and flashing lights! Now he only has to mention his throat is sore and we are straight off to the doctors to get it checked out! Although we have been very lucky and he seems to avoid picking up most bugs going round the school.

What we didn't realise, or rather what didn't sink in, was the amount of preventative work we have to do for him. For example he has to see a dentist every six months as we have to try and avoid any unnecessary work being done. I have to be extra vigilant about him getting flu vaccines and his standard vaccines because of the way they have to be given. I need to make sure that I am with him when these are being administered to ensure they are given correctly. It is added stress on top of being a parent and can become overwhelming sometimes. It can also lead to being questioned by doctors and nurses about the condition and they can sometimes question your intentions, so it is very important to be knowledgeable about the condition and also to have confidence in that knowledge.

However, to be honest, most of the time, I don't really think about it. We make sure that he wears a medical bracelet with his details on it when he is away from home, with or without us. Thankfully there are so many different types now, including ones specially designed for children, which makes it easier to get them to wear them. I am more aware that as he is getting older, the chance of a serious bleed is more likely, he's a very active boy and tends to be quite impetuous and tends to act before he thinks. He would rugby tackle his 14 year old cousin not a problem!

Although I've said that I don't think about it too often, subconsciously I am quite protective of him, and rarely leave him, except obviously when he is at school. He has started attending birthday parties and I mostly stay with him, unless I am confident that the parents know all about his condition and are responsible enough to deal with any potential accidents. I feel that it is quite a big responsibility to hand over to someone who may not really be that interested in the welfare of your child.

Having said all of that I do look at the fact that each bleed or new experience that happens increases our knowledge and this in turn helps us to cope with any new situations that may happen. It also gives me more confidence in dealing with the medical profession. I think that as parents of a child with a bleeding disorder you have to remind yourselves that you are the experts in this situation and you know what's is best for your child. This can be quite difficult, especially when you meet those who 'always know best'.

I do think that one of the hardest parts of having a child with von Willebrands is that there are no obvious signs that there is anything wrong with them. This has lead to strange looks when swimming due to the amount of bruises he has, to being questioned by locum doctors about how he gets bruised. Thankfully I have developed quite a thick skin and no longer mind it.

We do find it difficult sometimes though, because we don't know anyone else with von Willebrands. It would be nice to be able to share experiences, whether it is how to handle explaining that they aren't able to play contact sports or just being able to talk about day to day life.

I do worry about how he will deal with having von Willebrand's Disease as he gets older. His dad rebelled against not being allowed to do anything physical, so I am more conscious of not stopping him doing everything he wants to do. I just either place conditions on what he is doing, or watch him like a hawk. Even now I worry about him being caught up in fights at school or something as simple as being pushed. He has already had many close calls at school, and seems to come home with new bruises each day. As it is now, I can check him over myself without it being too obvious at the moment. I can only hope that by educating him on his condition, making him aware of what a bleed will feel like, that he can take responsibility for himself.

It is hard not being near a hospital with specialised facilities, Our Lady's Children's Hospital in Crumlin is over 2 hours away and Cork would be over an hour away. I would have no problem in travelling to either of these, but the stress of there being an active bleed would not make it a very safe journey. It would be nice to see some kind of specialised training at the larger regional hospitals. I guess only with sharing our own experiences and being proactive with medical care, we can improve the level of care our families receive. I just take comfort in the fact that there have been medical advances and this will continue thanks to the hard work of organisations such as the Haemophilia Society.

Every Little Helps....

In these difficult times every little helps, no matter how big or how small, when it comes to fundraising it all adds up, we really need your support, so if you think you can help raise funds in aid of the Society, maybe a pub quiz, cake sale, coffee morning, fun run, denim day, whatever. Let us know what fundraiser you have in mind and we will be more than happy to help you in any way we can, such as organising tickets, sponsorship cards, posters and IHS t-shirts.

The Women's Mini Marathon is a great fundraiser and we hope this year will be better than ever, if you would like to walk, jog or run the race this year on behalf of the Society, (please see the details below), if however you cannot take part in the race, but would like to contribute you can always support the Society by sponsoring a participant.

Another fundraiser that is really starting to take off all around the country is 'Movember', the month of November when men grow a moustache to raise funds for charities. 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.

The Society also has a planned giving campaign, which allows you donate a set amount on a monthly basis, any amount you wish for all long as you like. Monthly amounts of €21 or more received by the Society are eligible for charitable tax relief, so at the end of year we make an application to the Revenue for this fund, after all every little helps.

We would like to take this opportunity to thank everyone who raised funds in 2010; we really appreciate all your hard work and support and hope that 2011 will be an even better year.

For more information on planned giving or help with a fundraiser, please contact Nina or Debbie on 01-6759900 or email us on nina@haemophilia.ie or debbie@haemophilia.ie

Women's Mini Marathon

The Women's Mini Marathon is a great fundraiser, this year the race will take place on Monday 6th June 2011 at 3.00pm starting from Fitzwilliam Square and finishing in St. Stephen's Green. Application forms are available in the Evening Herald every Wednesday and Saturday from the 2nd March or you can register on line at www.florawomensminimarathon.ie. The closing date for entries is Wednesday 27th April or sooner if the number of participants is reached.

Refreshments and T-Shirts will be provided on the day in Buswell's Hotel on Molesworth Street, sponsorship cards are available from the office, just contact me on 01-6579900 or email nina@haemophilia.ie. Don't forget if you cannot take part in the race, you can still sponsor a participant.

Nina Storey

Calendar of Events

APRIL

Women with Bleeding Disorders Information Days

Date: Saturday 16th April 2011
Venue: The Rochestown Park Hotel, Co. Cork

Date: Sunday 17th April 2011
Venue: The Hilton Kilmainham, Dublin

MAY

Parents Weekend

Dates: 20th to 22nd May 2011
Venue: Fitzpatrick's Hotel, Killiney, Co. Dublin

Please see page 2 for further information

JUNE

Mini Marathon

Date: Monday June 6th 2011
Venue: Buswells Hotel, St. Stephen's Green

SEPTEMBER

HIS I.H.S.

Conference for men up to 30 years of age

Dates: 10th & 11th September 2011

Venue: Clarion Hotel, Dublin

OCTOBER

Members Weekend

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

NOVEMBER

Relatives Day

Date: Friday 18th November 2011
Venue: Cork

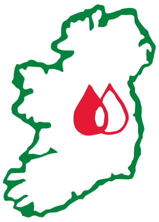
Date: Saturday 19th November 2011
Venue: The I.H.S Office, Dublin 8

Regional Meetings

Date: Mon. 21st Nov. 2011
Venue: Galway

Date: Tues. 22nd Nov. 2011
Venue: Sligo

Date: Wednesday 23rd Nov. 2011
Venue: Letterkenny



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