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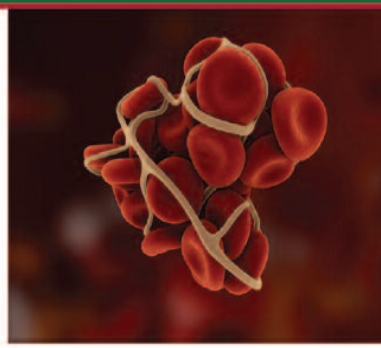
Magazine of the Irish Haemophilia Society

Women and Bleeding Disorders

IRISH HAEMOPHILIA SOCIETY

Rare Bleeding Disorders



IRISH HAEMOPHILIA SOCIETY

Irish Haemophilia Society

A Guide to Benefits & Allowances for Adults with Haemophilia

Irish Haemophilia Society

A Guide to Benefits & Allowances for Parents of a Child with Haemophilia

Irish Haemophilia Society

A Guide to Benefits & Allowances for Carers

October 2010

It's good to talk....

Irish Haemophilia Society Discussion Forum

Log on to www.haemophilia.ie/forum and check out the new Irish Haemophilia Society Discussion Forum, a private forum for people with haemophilia and related bleeding disorders and their families to share their experiences and any issues that they may have.

www.haemophilia.ie/forum

Support is only a click away!

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Contents

I.H.S. Policy on vCJD Screening

Delegates from Ireland, UK, Canada, France and USA attended a conference on vCJD screening in Dunboyne Castle in June 2010

In 2004 and 2009, the Irish Haemophilia Society communicated with our members in relation to vCJD, and potential risk of past use of plasma-derived products manufactured from UK plasma. Some of you may recall that in 2004 a risk assessment was published in the UK due to the fact that a number of persons who had developed vCJD in the UK were blood donors and some of their plasma went into pools for the manufacture of plasma-derived factor concentrates in the UK. Measures were taken in relation to use of endoscopes, informing surgeons in the case of particular types of surgery and informing their GP's and dentists. In Ireland at that time this information was looked at very carefully. There were a number of people with Haemophilia in Ireland who had used UK plasma-derived factor concentrates for rare bleeding disorders or indeed had been treated while living, working or visiting the UK. Each of these individuals were specifically informed about the situation by the National Centre for Hereditary Coagulation Disorders. A clear policy based on practical evaluation of the risks was put in place in relation to ensuring that procedures were put in place for dealing with endoscopy's and particular types of surgery involving lymphoid tissue. However, it was not deemed necessary for people with Haemophilia, who had been exposed to these products to inform their GP or their dentist. This is still the case.

In 2009, it emerged that a man with haemophilia in the UK in his 70's who had died of other causes was found on autopsy to have Prions in his spleen. Prions are the abnormal proteins which are thought to cause vCJD. Again as in 2004, a communication strategy was put in place by the IHS in conjunction with the National Centre for Hereditary Coagulation Disorders. Members were informed by letter, a special phone line was set up, meetings were held and background information was given to the media. There is no new risk or there has not been a new case which necessitates this article at this point in time. However, one of the problems in relation to vCJD is that there is no test for vCJD. There is no screening test, there is no confirmatory test and it is not possible currently to say if somebody has Prions in their tissues without doing a biopsy of those tissues. A number of companies are actively working on developing a screening test for vCJD. It is now very unlikely that there will be a screening test available for vCJD in the next year. However, the IHS wanted to be proactive in developing a policy setting out our views on such a test when and if it becomes available. It may seem logical to state that if a screening test is available then people with Haemophilia should immediately be offered or avail of this test but on closer examination this simplistic view would have to be challenged for a number of reasons.

Firstly, the ability of any screening test to determine a real positive from a false positive would have to be examined (and indeed the ability of the test to detect real positives as opposed to giving false negative results). Having a screening test in the absence of a confirmatory test may give an individual misleading information and it is to be hoped that a confirmatory test would be available prior to or at the same time as a screening test. If a person tests positive for HIV or Hepatitis C antibodies, there are confirmatory tests which can detect the virus and prevent the individual from having to deal with a false positive result or indeed the uncertainty of not knowing if the antibody test result is accurate. For this reason, it is our considered view that people with Haemophilia should not undergo a screening test for vCJD if and when such a test becomes available until there is an accurate confirmatory test also available.

Secondly, it must be remembered that there is no treatment for vCJD, no cure and no steps which can be taken to prevent the person from developing vCJD even if they have a positive screening test. Onward transmission risk would be limited primarily to the use of endoscopes or specific types of surgery and this risk can be prevented by the existing policies on quarantine of endoscopes used by those persons who were treated with UK Plasma derived products in the past and by the existing policy on notification in the event of specific types of surgery.

Thirdly, it was the experience in the UK that access to optimal health care was compromised for some people with haemophilia in the UK following their being informed that they were on the at risk register. Thankfully, this did not occur in Ireland but the IHS is strongly of the view that persons with Haemophilia should not consent to any screening and /or confirmatory test for vCJD until they received reassurance that their future access to and quality of health care would not be damaged or compromised by any result of such a test.

Finally, it is our view that, in the event of a

screening test becoming available in the absence of a confirmatory test, such a test would have value in screening of blood donors in preventing onward transmission by blood or blood products. This policy was the result of an expert meeting we convened in June of this year attended by experts from Ireland, Canada, the USA and France, Haemophilia clinicians from Ireland and the UK and Haemophilia Society representatives from France and the UK. I believe that this policy, which has been endorsed by all those in attendance, prepares us as a community to respond to the future challenge to be faced if and when a screening and hopefully a confirmatory test become available for vCJD. The policy will be kept under review and amended when necessary in the light of scientific developments. Any amendments will be published in the I.H.S. newsletter and on the website. Below you will find a copy of this policy.

Brian O'Mahony
CEO

I.H.S. Policy on: vCJD Screening of Persons with Haemophilia and Related Bleeding Disorders

July 2010

Based on the currently available information:

• Whereas vCJD is a terminal illness known to be transmitted by blood; and

• Whereas vCJD is known to have a long incubation period, lasting possibly many decades; and

• Whereas there is currently no therapy for this disease; and

• Whereas a hemophilia patient has been reported to have been infected with vCJD, almost certainly through plasma-derived factor VIII in the United Kingdom

• Whereas a vCJD screening test may be available in the future;

• Whereas we understand that a positive test will have psychosocial implications for patients and families

• Whereas we understand that a positive test would necessitate specialized handling of surgical/dental instruments used on that person; and

• Whereas we acknowledge that testing people exposed to vCJD and quarantine of said surgical/dental instruments may reduce risk to uninfected persons; The Governing body of the Irish Haemophilia Society is of the view that the following principles must apply:

Principles:

• Screening tests should only be offered to those who received plasma-derived products or labile blood components.

• The use of a screening test in persons with Haemophilia should not be countenanced until an accurate complementary confirmatory test is also available

• Full informed consent must be obtained from each person before they are tested.

• Pre- and post-test counseling must be provided.

• Persons tested must be informed of the test results .The following points should also be noted:

• Transmission of vCJD is by contaminated meat, blood transfusion or blood product. Sexual, respiratory or faecal transmission has never being documented. Therefore there is no risk of onward transmission from a vCJD infected individual apart from the minimal risk from sharing of endoscopes. Quarantine of endoscopes is available to prevent onward transmission. This puts in perspective the limited benefits of application of a screening test for persons with haemophilia.

• Research studies can be carried out using a validated vCJD assay to determine the prevalence of vCJD infection, on an anonymised basis, in the general population and specified risk groups such as persons with haemophilia. These could be done without a confirmatory test. These would serve to give an indication of the relative incidence and prevalence in the Haemophilia population compared to the general population prior to considering individual screening tests.

• Assurance would be required that persons with Haemophilia who test positive in the screening and / or confirmatory vCJD tests would not have their access to adequate health care compromised or damaged. Persons with Haemophilia should not consider being tested in the absence of such an assurance.

• The right of persons with Haemophilia to confidentiality in relation to all aspects of their medical condition must not be unduly jeopardised.

The following points should be noted in relation to the application of a vCJD screening test on Blood and Plasma Donors:

• The purpose of blood and plasma donor screening is to make the products safer for recipients

• For the purposes of improving the safety of the product, introducing a vCJD screening test for donors does not require a confirmatory test. (If a donor tested positive with a screening test, and negative for a confirmatory test, their donation would not be used and they would be deferred).

• A confirmatory test does not add to the safety of the blood product- it does allow better and more complete information for dealing with the donors.

• Concern has to be expressed that implementing a screening test in the absence of a confirmatory test would lead to a large number of donors being given a false positive test result and there would obviously be difficulties in dealing with these individuals.

• Although a screening test must attain high specificity and very high sensitivity, the predictive value required for a diagnostic test do not need to be met for a donor screening test.

• It is essential that the vCJD confirmatory assay is formatted to complement the vCJD screening assay with appropriate sensitivity and specificity to enable discrimination between a true positive and a false positive result.

Ideally, a confirmatory test will become available before a screening test. Health authorities should take steps to proactively encourage the development of such a confirmatory test.

My Sizzlin' Summer Holidays

Thursday July 8th

I woke up really excited. I'd never been outside of Europe before and I wasn't looking forward to the flight. We left for Dublin at 8:30am and arrived in Buenos Aires at 9:00am. I've just spent 28 hours travelling and I'm excited at the prospect of spending a week in Argentina. The flight wasn't so bad but the food wasn't the best and I wouldn't recommend it.

Friday July 9th

Our hotel is cool. It is quite small and breakfast is in the same room as the reception but I like it. It is in the city centre and near a load of shops and the area is really cool. The name of the street is Suipacha and it really has everything here so we aren't going to get bored anytime soon!

Saturday July 10th

We did an open-top bus tour today and it was mince. It was quite cold because it is winter here but we went through all the city, passing places including Boca Juniors stadium and I liked it. Later in the day we went to the opening ceremony and I don't think I've ever been in a conference centre so big (in fact, I've never even been in a conference centre!) and filled with so many different nationalities. There were a few different speeches and then there was tango and ballet, which was terrible.

Sunday July 11th

I went to the San Telmo market today and bought two Argentina jerseys. There were loads of people there and the atmosphere was electric. Later in the day I went to a bar to watch the World Cup Final and my sister, Niamh was bored sick. It wasn't the best of games but I'm glad Spain won it.

Monday July 12th

We went on an accompanying person's tour today and visited the grave of Eva Peron. The graveyard was cool. It's much different to a graveyard in Ireland because it has endless passageways and you could easily get lost. Later in the day we went to the cultural night and I had four burgers! There was tango there, but as I've already said, I don't like tango.

Tuesday July 13th

I went to Boca Juniors football ground today. It was pretty good and we got the stadium tour. On it we got to go into the away dressing room (the home one was under construction), we went into the stands and we got to go into the museum. So I enjoyed it all and I've got quite a liking for Boca Juniors now.

Wednesday July 14th

It was the Gala dinner this evening. There was opera singing but it wasn't the best. It had good music then and I really didn't want to leave when we did. So I really enjoyed the congress and I hope to go the next one in Paris in 2012.

Thursday July 15th

Flew to Rio de Janeiro. It was pretty hot when we arrived. I am impressed with our hotel so far and I hope the breakfast will be nice. The hotel is near a square so we will probably be eating there. So far, I like it here.

Friday July 16th

Today we went to Brazil's football ground. It's called the Maracana and it is the biggest sports ground in the world. It has 200,000 seats! I also got the stadium tour and it was ace! We went into the dressing room and the stands. We also went into the V.I.P. lounge and a platform at the side of the pitch! Also there were impressions of past and present players' footprints and it even had Pele! So now I can say I've been to the World Cup 2014 final stadium!

Sunday July 18th

We went to the statue of Christ the Redeemer today. I had previously seen pictures of it but it was so big I was gobsmacked. We got up there in a tram. At the top there were shops and, of course, the statue. There was a brilliant view and you could see almost everything. When we came back we went to the Ipanema beach. It was a bit bumpy but it was huge. I liked it. Afterwards I tried a coconut and I loved the milk!

Monday July 19th

Today we went to Sugarloaf Mountain. We got up to both levels by Cable Car and it was pretty cool. The views were good but not as good as those from Christ the Redeemer. There were a few animals like monkeys there.

Tuesday July 20th
Today we spent all day on the Ipanema beach. It was different to Irish beaches because it was permanently hot. Also it was different because everyone was either playing football or volleyball. Then in the evening we (everyone from the I.H.S.) all went out to a restaurant.

Wednesday July 21st
Today we left to go home. I didn't want to leave but I wasn't too sad getting on the plane to fly back to Madrid. I definitely enjoyed my South America journey and would recommend it to anyone.

Wednesday July 28th
Today we went to the 3 Irish Open Pro-Am. I got ten signatures! I also got a few photos of me with Harrington and McDowell. We saw loads of well known golfers. We even met Rory McIlroy!

Wednesday August 4th
I went to Barretstown today. I am staying here for a week. I have been here once before but I can't really remember it that well. So I was looking forward to it. When I first saw it I was impressed with it. We stay in cottages and there were ten in my cottage. I was staying with three Irish people and six Spanish. The first activities I did were fishing and archery. I have an exciting week ahead of me!

Thursday August 5th
I was really looking forward to today. We found out that the other people in our group were Greek. The first activity we did today (apart from breakfast) was archery. I was pretty good at it and I enjoyed it. Then we went to arts and crafts but I can't remember what I made. Then we went to lunch. Afterwards it was rest hour. I read during rest hour. Then we went to 'high ropes'. I somehow managed to get to the top. 'High ropes' was like climbing up logs and stuff. There were plays then we all went to bed.

Friday August 6th
Today before breakfast we had an early bird activity and I chose giant Cluedo. It was pretty good. Then after breakfast we went to music. I didn't really like it. Then we went canoeing but it started raining. I was really looking forward to it as well. After lunch and rest hour we went to photography. One of the shots we had to do was fit into a telephone booth (seven of us)! So squashy! After that we went straight to baking. We made Greek cakes. Then after dinner we went to archery (again!).

Saturday August 7th
When we were done with breakfast today we went to the theatre. Everyone had to dance like their characters on stage and we had pirates so we danced like pirates. Then after lunch and rest hour we went to music. After music we went to arts and crafts. After dinner we got to drive in very old vintage cars!

Sunday August 8th
Today we did movie making. It was terrible. After that we went fishing which wasn't the best. After lunch and rest hour we went horse riding and I loved it! Then after dinner we did a cabaret on stage.

Monday August 9th
Today we did discovery in Barretstown's secret garden. It was cool. Then after lunch and rest hour we got to dress up our caras (leaders) in wigs and costumes. Then we came back and packed our bags. I really didn't want to leave but we had to.

Tuesday August 10th
We had to leave today. Some people had already left early in the morning but I was one of the last to leave. I know I'm going to miss Barretstown but hopefully I can go there again. I've had such a summer holiday, and I really don't won't it to end, but all things do.

Conor Birkett

Ain't No Mountain High Enough

For anyone who does not know me, my name is Daryl Butler. I am a 23 year old final year college student with severe haemophilia, and this summer I climbed Kilimanjaro.

This story begins at the start of June when 3 friends and myself, travelled out to Tanzania to work in a hospital for four weeks. After our time there and watching almost every World Cup match going we set out to travel around Africa for 3 weeks. Our first adventure took us on a four day Safari tour across the Serengeti to take in all of the magnificent wildlife that Africa had to offer. Next on our travels was Mount Kilimanjaro, the 5895m tall, highest free-standing mountain in the world. In total nine of us set out to climb the mountain including myself, six from my class and two friends of a friend.

This was a personal goal which I had set for myself to achieve and if nothing else a target to push and see how far my joints could go. To climb the Marangu route (commonly called the 'Coke Cola' route) takes three days to reach the summit and two days to descend. As well as trying to gain a comfortable equilibrium in number of layers of clothing you wear the main concern is the rising altitude. As more people die of altitude sickness than from falls it's important to climb slowly and avoid the complications.

I will say that it is a tough task to undertake however, the reward of taking on such a challenge is hugely gratifying. As you ascent you pass through five different climates of cultivation, rain forest, heather and moorland, alpine desert and finally glacial terrain. Thus the view is ever adapting and once you get above the clouds at about 3500metres the immense size of the mountain really strikes you. At this point you just know that you have to achieve your goal.

Our final night came around and we prepared to ascent the last 1200metres to the summit, a journey which we would begin at midnight and would take us seven hours to complete. The final push is certainly the toughest as you aim to climb the aptly named 'wall' up the eastern face of Kilimanjaro along paths of shifting scree with only your head-torch to guide you. At this point we had already lost one member of our group to altitude sickness but fortunately he did not suffer too badly and had decided to stay at the nearest base camp. The one thing I would mention from a Haemophilia point of view is that at the summit the temperatures drop to minus 15 degrees, so if you are carrying factor with you as I needed to then it's important to be aware that these temperatures will inactivate your factor so it's essential to either find a way to keep it warm or else cross your fingers that one of your climbing party need to stay back due to altitude sickness. When we reached the half way point of about 5300metres another of our group fell prey to the altitude and became disorientated and so needed to turn back. The remaining seven of us forged on through the climb and most all of us succumbed to some form of dizziness, confusion, shakes, headaches, and nausea.

But at 7am in the morning and with the rising sun on our backs we reached the top of Mt. Kilimanjaro and were greeted by awe inspiring glaciers and the breath-taking inside of the mountain crater. This truly is a fantastic feeling, although, once you get there all you want to do is take a photo of it and get off the top as fast as possible because you really feel the effects of the altitude most when up there!

The climb down is a lot tougher on the joints and a few days of rest are definitely deserved but all in all it is a great experience and I would advise anyone who is able to make it a goal for themselves.

Daryl Butler

Grants and Scholarships

We are delighted to announce that after hours of scrutiny and adjudicating the recipients of the grants and scholarships for 2010/2011 have been chosen. In total 21 applications were received which were mainly received online which is very encouraging. Once the closing date arrived the applications were collated following which a sub group of three board members (which cannot include anyone with a family member applying for the grants) met to consider the applications, to score each application and finally to decide on recipients.

I am now pleased to announce first, second and third place recipients for both awards:

Educational Grant in memory of Maureen Downey

This grant is made available to a person with haemophilia or related bleeding disorder, who has been accepted on a post second level educational course.

First Place:	Ciaran Dowling	€4,000
Second Place:	Daryl Butler	€2,000
Third Place:	Irene Clarke	€2,000

Educational Scholarship in memory of Margaret King

This grant is made available to an immediate family member of a person with haemophilia or related bleeding disorder, who has been accepted on a post second level educational course.

First Place:	Sarah Gilgunn	€2,000
Second Place:	Catriona Moriarty	€1,500
Third Place:	Richard Butler	€1,000

We were delighted also, to be able to make further payments to a number of applicants, and we are pleased to announce that the Irish Haemophilia Society made payments totalling €23,000 in relation to Grants & Scholarships this year.

So as you can see it is well worthwhile applying for these grants and scholarships. They really do help a lot and we would like to encourage you to apply. And don't forget even if you are a recipient of a payment this year, you can still apply again next year.

I will leave you with some words from some of the recipients of 2009/2010.

"I would like to thank the Irish Haemophilia Society for the very generous grant of €1,000. I am currently in my 3rd year of a 4 year degree course in GMIT. The money has enabled me to buy a computer, its very useful as I have a lot of project work. The money also helped with my accommodation and travel costs. Once again thanks very much for the award". Lorcan Friel – Donegal

"I was the grateful recipient of the Margaret King Educational Scholarship. I am currently in my first year of Applied Psychology at UCC, and this award has truly helped me make my first year at university enjoyable and enriching". Christina O'Sullivan – Cork

"I am writing to thank the Society for the award. I am well settled into my first year of Business Studies at Magee College in Derry. I stay in student accommodation during the week and travel home at the weekend, and this award enables me travel home to see my family". Fergus Friel – Donegal

"I write this letter to extend my upmost gratitude to everyone at the Irish Haemophilia Society for the Educational Grant which I received. This grant has made a very positive impact on my university life. With the aid of this grant I have been able to purchase the essential text books necessary for my course work. For these things, and many others I would like to thank you again". Daryl Butler.

Debbie Greene

Growing up with Haemophilia in the 1960s

Waking up in the early morning with the coppery taste of blood in your mouth, with a sick feeling in your stomach and with your face crusted with dried blood from yet another nosebleed. The dark hours before dawn, lying awake with a cold compress, dipped in a basin of water which had earlier been reassuringly cold but now was at best tepid, wrapped around an ankle, knee or elbow. Waiting, waiting, waiting for the house to rouse, for the distraction of conversation or company. This was the reality of growing up with severe Haemophilia in the 1960's in Ireland. A time before factor concentrates were available. A time when Haemophilia treatment consisted of cold water, ice and little else. A time before comprehensive care. Growing up with Haemophilia then was difficult and challenging more often I think for the parents than for the person with Haemophilia. I know that parents then felt a sense of helplessness, of isolation; often of near despair. Haemophilia was a cruel burden on the whole family.

This grim picture may read like an excerpt from Angela's ashes that was not my intention. The burden was Haemophilia with no availability of treatment. It was not accompanied by cruelty or neglect, deprivation or despair. The opposite was the case.

Despite the inevitability of bleeds on an almost weekly basis, life went on in as near normal a fashion as possible. In my own case, my parents, and particularly my mother (well, this is an Irish family in the 1960's we are talking about) was excellent. She gave me all the care and attention you could wish for and she was very sympathetic and helped in every way possible when I was coping with regular bleeds. At the same time, she strongly encouraged me to get on with my normal schoolwork and activities when I did not have a bleed. I was encouraged to get the best education I could manage. When I had recovered from a bleed, I would return to school as soon as possible. During a bleeding episode, I would, when possible, have homework sent to me so that I would not fall too far behind. I was encouraged to participate in sports such as running, swimming. I was not rebuked too strongly when I played soccer except for one occasion when I played Gaelic football.

As I grew up, I was encouraged to get a summer job which I did from the age of 13 and I went away for weekends with the scouts and the youth club. At age 15, I hitch hiked around a large part of the country with 7 friends. It is worth remembering that I did not have any

reassuring factor in my rucksack, no mobile phone and no comprehensive care centre to go to in the event of a bleed. At age 17, I moved to Dublin to go to college. Despite the inevitable shock on discovering that shirts do not self iron, I was ready to cope with independence. At about that time factor concentrates became available on something like a regular basis and they confirmed my sense of freedom with life stretching out before me as an endless kaleidoscope of possibility and promise.

Why am I rambling on like this? Perhaps this story will not seem relevant for parents of young children with haemophilia. Your children are fortunate. They have access to state of the art treatment and prophylaxis using recombinant products. The experiences that I and those of my generation went through should seem as remote to them as ancient history. They have access to comprehensive care and home treatment. For children with haemophilia now in Ireland, life is full of promise and possibility. Their treatment, if complied with, should ensure that they do not get joint damage. Their quality of life and life expectancy will be normal. There should be no obstacles to their getting an excellent education, employment (providing the economy eventually recovers!) and have a healthy, happy and fulfilled life.

The obstacles may come, not from their Haemophilia, but from how they cope with their Haemophilia. Even with excellent treatment, haemophilia remains a challenge. Children do not like to be different to their peers and they may at times feel that their Haemophilia sets them apart. They may feel that regular injections place a burden on them. They may resent the few things they can not do (such as boxing, rugby) rather than appreciating the very many sports and activities they can participate in. At some point in childhood or adolescence, they may rebel and refuse to take their treatment. This can happen, ironically, because the treatment has meant that they do not get bleeding episodes. They may not realise that stopping the treatment will lead to bleeding episodes and perhaps risk damaging their joints which will have been so carefully nurtured by prophylactic treatment up to that point.

These are challenges which may confront you as parents. How you deal with them will, I believe, greatly influence and mould your child's ability to cope positively with his Haemophilia for the rest of his life .It may influence your daughters view of her brothers Haemophilia and if she is a carrier may influence her decisions about having children in the future. These are potentially onerous challenges but, from personal experience, I am going to take the liberty of suggesting some strategies and actions which you might like to consider:

Your child has Haemophilia. He will have this for the rest of his life. The sooner you can help him to deal with this in a positive way, the better for his future. For a child with haemophilia, this is his reality always has been and always will be. I believe sincerely that it is often worse for the parents who can feel helpless resentful or even guilty. Don't. Haemophilia, especially with modern treatment is a light burden for a boy to grow up with providing his parents are supportive and his life is not unnecessarily constrained. Resenting the Haemophilia or feeling guilty are destructive and unnecessary feelings.

Talk to your comprehensive care centre team and teach your child about Haemophilia giving him age appropriate information as he grows up.

Of course this means learning a reasonable amount about Haemophilia yourself. Learn. Know how to recognise a bleed. Understand the differences between treatment products. Absorb information from reliable sources such as your treatment centre or the Irish haemophilia Society. (Beware of limiting your information to what you can Google there is a lot of nonsense amid the real information).

Encourage your child to miss as little school as possible. Education is very important to the person with haemophilia. You want your son to get an education which will give him the option of a career where he will work with his intellect and as an educated and mature adult you will also have assisted him to cope with haemophilia into the future.

Encourage your son to participate in appropriate sports. If you would like your child to swim, play tennis, play golf, encourage this. Why not play these sports with him.

Give your son the love and affection he will need. Be sympathetic and comforting if and when he has a bleed (In my childhood, this also included extra treats such as extra comic books or large bottles of fanta orange). However, take care not to smother him, to overprotect him or to treat him differently from his siblings. (If he gets a treat, so should his brothers and sisters). This is a job for both parents- not just the mother. Guilt and resentment are counterproductive and the antidote is constructive and constant involvement in your child's development and life. Fathers should not feel a sense of loss for what their son can not do rather they should feel a sense of pride that their son can deal with this challenge and a sense of fulfilment that they are playing their full part in helping their son to live a full and active life.

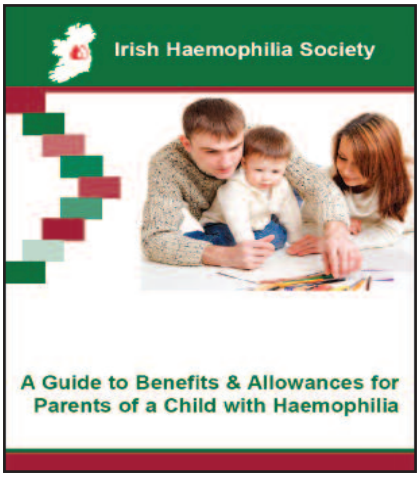
I was fortunate. My mother, despite never having access to any materials on dealing with haemophilia or prior to the availability of any materials on the psychosocial aspects of Haemophilia, did everything right. As a parent, she helped and comforted when that was required but she also encouraged a positive attitude of coping, of not giving in to setbacks, of working hard and focusing on the positive. Above all, her attitude helped to ensure that while Haemophilia was a part of my life, it did not control my life, my education, my ambitions, my choice of career or my self esteem.

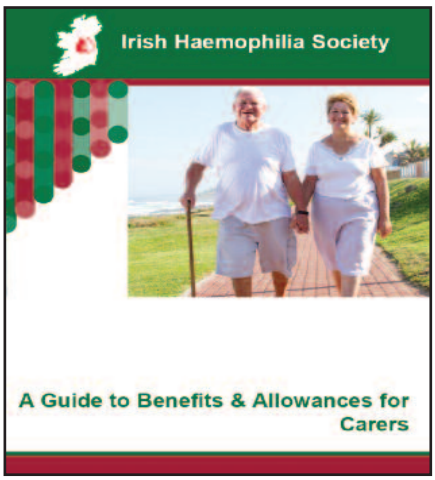
As parents, the greatest gift you can bestow on your child with haemophilia is to work together to give him a normal life. There is no reason why Haemophilia should prevent this. It will be prevented only by your own fears, anxieties or non engagement. For your child, and for you as parents, knowledge and good coping skills will mean that life will come first and Haemophilia second. That is as it should be.

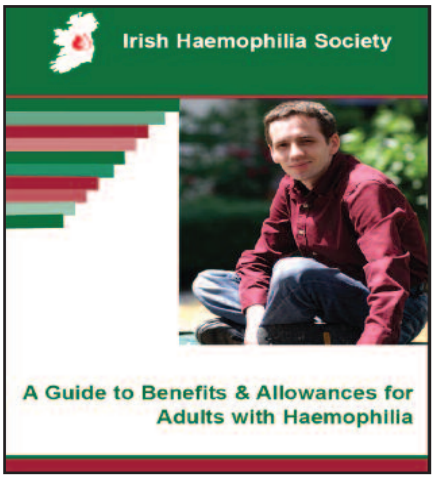
If you would like to share your story about living with haemophilia or a related bleeding disorder please contact Debbie on 01 657 9900 or debbie@haemophilia.ie.

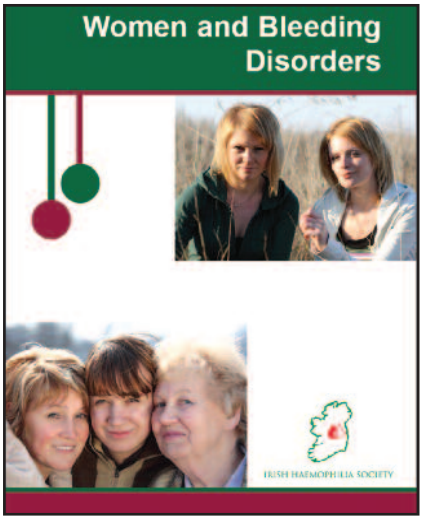
All stories can be printed anonymously.

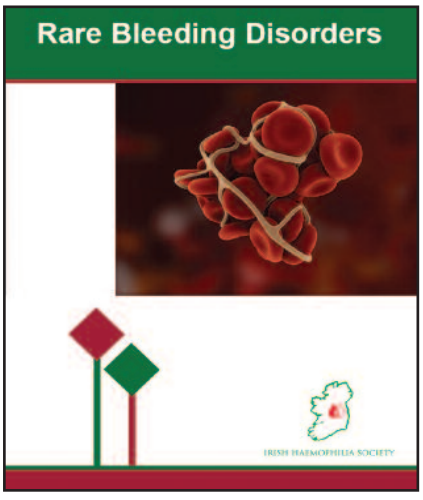
Publications Update











Publications

In recent years we decided to look at revamping publications & to look at doing some new publications. After giving it a lot of thought we now have our own Irish Haemophilia Society template that we use for all our publications including the website. We prepare and design all our publications in house and then send them out for printing.

In 2009 we produced four quarterly magazines, the annual report, a "Travel Card" and a publication on "Haemophilia and Dental Care". 2010 has been an extremely busy year for publications. Along with the quarterly magazines and annual report, so far we have produced publications on "Women and Bleeding Disorders", "Rare Bleeding Disorders", "A Guide to Benefits & Allowances for Adults with Haemophilia", A Guide to Benefits & Allowances for Parents of a child with Haemophilia", "A Guide to Benefits & Allowances for Carers" and by the end of the year we will have two more publications produced which are "A Dental Care leaflet for Children", and an "Information for Teachers & Playgroup Leaders" booklet. In 2011 we are hoping to produce some more publications which we will keep you informed about.

Website

I hope you are all logging on regularly to our website. Although the hits have improved quite a bit, we are still trying to make it as attractive as possible. Nuala in the office updates the website on a regular basis, and we are constantly trying to develop it. Are you all aware that you can register online for all our events and activities? This is very useful and convenient to members, as it's faster and secures your place quicker for our events as they do get pretty full up these days very quickly. More and more members seem to be registering online for events, which is great. You can also download any of our publications from the website, read reports from conferences, read updates on treatment and safety and supply, get tips for travelling, read newspaper articles which are updated daily, apply for the yearly grants and scholarships, read up on any of our services, get good information and join the discussion forum or facebook.

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

Debbie Greene

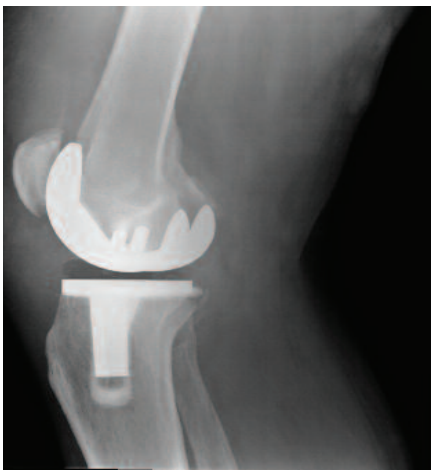
A Joint Venture

Haemophilia.ie looks at an issue that is becoming more common - joint replacement. In this story two men with haemophilia share their stories of life before and after joint replacement.

Story 1:

Having Haemophilia attack my knee joint relentlessly for over forty six years and despite availing of every option offered to keep my target knee functioning within a manageable pain threshold, the day finally came that I had no choice but to go for a total knee replacement. I was very apprehensive about the prospects of surgery, considering my medical complications and the general poor condition of my knee joint, but having built up over the years a strong working relationship with the team in St. James's Hospital, I felt confident about their reassurances that they had the expertise and experience to deal with any complications that may arise.

Total knee replacement is major surgery even if you do not have Haemophilia, preparations included intensive physiotherapy and regular visits to the orthopaedic surgeon in an attempt to build up my knee as much as possible for the operation. This involved a great deal of commitment on my part, but this attempt to ensure that there was little difference for my surgery and recovery as you would expect for an average person undergoing the procedure was certainly worth it.



I spent approximately five weeks in hospital and a week of intensive physiotherapy in an Orthopaedic Hospital. Yes, I have to state that it was a difficult time for me and involved some pain and discomfort, but nothing like the constant pain I had become used to living with my crippled joint. I have nothing but praise for the attention, care and advise given to me at this time by the full team that enabled me to make steady but slow progress towards recovery.

I expected to be up and running within weeks but I soon discovered that it is much more realistic to start slowly and build up an exercise programme that fits in with your physical state and lifestyle over a period of time to ensure that you can sustain your programme into your new and more active future. Remember, if you receive a new knee it will take time to grow strong and stable, it will also have limitations that you will have to learn to cope with over time.

In total I was out of work for four months and my G.P had to be very forceful in making me see the reality that rushing back to work should not be my priority, but instead I should concentrate on working hard at making a full recovery, including making simple lifestyle changes that not alone would greatly improve the stability of my new joint, but would also give me the added bonus of improving my general health now and into the future.

From this process I have learned the lesson that you must listen to your body by making steady and sustainable progress and try to avoid attempting to be constantly pushing your body to the limit, sixteen months later I am enjoying my new joint as I enter a new painless phase of my life.

Story 2:

Its six months today since the surgery and its only now I can finally write something about it. This is partly due to the brain haze created by my painkillers but mostly due to the fact that it's only now I'm starting to fully realise what it actually means.

Before I explain the difference I'll skip back a bit to give a quick synopsis of the background as to why a hip replacement was needed. I had always been active and reasonably fit. There have been numerous bleeds in ankles and the occasional knee or back bleed over the years that have left their aches but nothing significant. Then in 2003, I started to feel a bit of an ache in my right hip but compared to the other joints it didn't really get rated as an issue. I really only felt any ache after a lot of exercise such as day walking or a few hours in the gym and after short rest it was fine and I was good to go. It never prevented me from doing any daily activities or going anywhere.

Gradually it started to become more prominent and by 2006 it was starting to be a bit uncomfortable. I was starting to arrange days in such a way that I was getting everything done a bit more efficiently. Like instead of randomly meeting up with friends during the week I would meet two or three of them at the weekend. I was still able to keep reasonably fit but I switched from cycling to swimming. Minor adjustments but it was the start of a slippery slope. In 2007, it continued to deteriorate and by the end of the year, especially going into the winter, it was really starting to cause problems on a day to day basis. It had gotten a lot sorer and walking to even the shops was difficult. On the up side when I wanted some chocolate, the effort to get to and

back from the shop wasn't worth it so I ate better and less which has to be good for me. By January 2008, I had to get a car to get round as getting to bus or train stations was too much of a struggle. After a fairly intense few weeks of physiotherapy I gained back some movement in the joint and I was walking with some soreness but I was walking again. On a side note, if you have to go to a new physiotherapist get an idea of what your in for by asking who she treats, if county footballers and Provencal rugby players are on the list, prepare yourself properly as it will most likely feel great after but it hurt during the session. Although I was walking, it was still restricted. Anything over 40 minutes left my back and left leg sore from compensating for my right hip and the right hop would be sore and weak and become extremely stiff afterwards. At the start of March it had reached the point where I needed it checked out properly and I went to see the orthopaedic surgeon and I was informed it was gone and it needed to be replaced. My response was "Ok, when will that happen? Will I get to 45 or 50?". Up to this point in life I had bargained for my car, for rent, for clothes on a market and now I was trying to bargain as many years as possible out of the consultant. Best I could get was 30 so obviously bargain skills need some work, 3 more years, that wasn't that far away.

By July 2009, it had become clearly apparent that it was a lot further away than I thought. I had to change my car to something higher just to be able to get in and out and drive safely. I wasn't sleeping through the night and walking was getting more difficult and shots of pain would shot from my hip and I'd drop to the floor faster than Irish bank shares. Again with the concept of making it to the 30 mark, I was prescribed strong painkillers and anti-inflammatories for when I needed them, for the days that it was sore. They worked at the start but at the start of 2010, when ever I needed them became every day and the small amount quadrupled (not because I was fast becoming a drug addict).

In April of this year I got my new hip and the morning after surgery the physiotherapist arrived to get me out of bed and on my feet for the first time. Top tip for after surgery if you have a morphine pump as I did, press it as many times as you can when you see them coming. You will be a lot more mobile and it won't hurt as much afterwards. That is a joke but there is some truth in it as the more you do, the sooner you do it up to a point, and the quicker things get better. After a week I was let home. The adjustments had been made to the flat and there were no steps which made it easier. Another great tip, try not to drop the pick up stick on the floor, pretty frustrating. After two weeks, I could already do stuff I had not been able to do in a year such as stretching to the side without pain and my personal favourite sleeping. After two months I could walk further than I had in a year and everyday it got stronger.

It's now 6 months and looking back I have no idea why I was bargaining to try and keep it longer. It was like banging your head against and brick wall and wondering why you had a headache. The improvement thankfully up until now is unbelievable. I can walk with out pain, (some muscle soreness but that's nothing), I can drive, I can stand long enough to iron a load of clothing (so its not all good news) and most importantly I can plan. I can plan to meet friends and not have to cancel, I can plan holidays. One of the other things I now realise is how much energy goes into your day when trying to just get through and maintain what you have. Fighting to stand still is so much more difficult than fighting to move forward. In the last month I feel full of energy that I haven't felt in so long.

When it comes down to it I wasn't left with any real choice to get it done. Quality of life is so much more important and there wasn't any quality before the replacement. If you need a replacement of any type and your unsure about it, sit down and list the top 5 or 10 things that are most important to you whether it is going to the cinema, walks with the family. Think about what you could do before any pain and now (within reason if your 50 and the last time you could do it was when you were 16) and the answer will come to you pretty quickly.

Top tips for hip replacements

Before:
List the things that are most important to you and if you can't do any of them it really isn't a choice. Maybe its time to stop holding on and start moving forward.

After:
You will probably be on painkillers, try to get them before the physiotherapists appear. They are fantastic and help immensely but can be tough.

Don't worry about your dignity in the few days after surgery. You will have lost it with the blood in the operation. It will build back up but may take a while.

Listen to the doctors and physiotherapists. I know generally we have a habit of doing the bits we like but the rules are there for a reason.

Before you go into hospital get your home sorted with high chairs, bed raisers, shower chairs etc. If this is done before you go in it means you can get out of the hospital as quickly as possible.

Pick-up sticks are great but don't drop it on the floor. Very frustrating!!!

Fundraising

It has been a busy few months with regards to fundraising, in particular September and October were very busy. Not that we are complaining though, quite the contrary, it is great to see so many people organising and taking part in fundraisers for the Irish Haemophilia Society, particularly in the current economic climate.

During the week of September 5th - 12th, John Fitzgerald took part in the "Col du Tourmalet Cycle Challenge" in the Pyrenees in France. Speaking to John after the week long cycle, which is a route in Tour de France, he said it was a great personal acheivement and he was lookig forward to a well deserved rest. Congratulations to John and his fellow cyclists on completing the challenge.

From France to Cork, where Andrea Hickey had organised a table quiz in aid of the Irish Haemophilia Society as well as getting a group of her friends to join her and take part in the Cork City Mini Marathon. I.H.S. Board Member, Eoin Moriarty attended the table quiz on behalf of the I.H.S. and said it was a great success. Andrea too felt that the table quiz had gone well, but there was no rest for her as just three days later on Sunday September 26th Andrea and her friends took part in the Cork City Mini Marathon. The weather for the Cork Mini Marathon was much better than it had been for the Dublin Mini Marathon in June and the girls completed the course in 1 hour 13 minutes. A huge thank you to Andrea for organsing and taking part in two wonderful fundraisers.

Next it was on to Monaghan, where a group of members had organised a Garda Band Fundraiser. The concert, which took place in the Glen Cairn Hotel in Castleblaney on Thursday October 7th was attended by over 300 people and raised over €5,000. The I.H.S. was well represented on the night with Brian O'Mahony, CEO, Debbie Greene, Administrator and myself attending. A great night was had by all and a massive well done and thank you to all involved in the organisation - Susan & Philip Clarke, Vincent & Edel Jackson and our youngest fundraiser, Niall Jackson, 11.

Then it was to Limerick, where the Members Conference took place in the Castletroy Park Hotel. This hotel would be the venue for the final weigh in for the "Operation Transformation: Pound for Pound Weightloss Challenge". For those of you not aware of the challenge, I will bring you up to date. At the AGM in March, six staff members challenged six members to a weightloss challenge. In six months, both teams had to start a healthy eating and exercise plan and whichever team lost the most weight at the end of the six months would be delcared, "Society Slimmers of the Year". As a competitive person, I was hoping that the staff would come out victorious, but alas it was not to be. With an amazing total group weightloss of 5 stone 13 lbs the members team claimed the title and beat the staff who finished with a weightloss of 2 stone 11lbs. A huge well done to all who took part and for all the hard work they put in over the six months. The results were fantastic and hopefully all the participants are now both much happier and healthier.

Nuala Mc Auley

Clockwise from top:

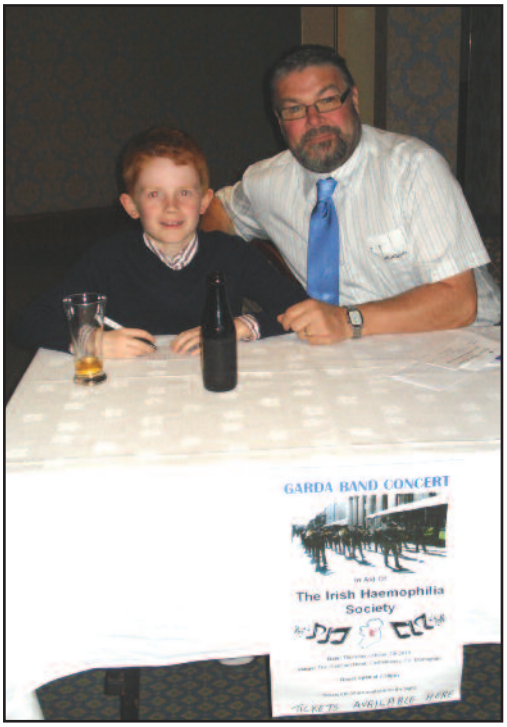
** John Fitzgerald having completed the Col du Tourmalet Cycle Challenge,*

** (L-R) Orla O Sullivan, Laura O Donovan, Emma Corbett, Andrea Hickey and Kate St Leger having completed the Cork Mini Marathon,*

** The youngest fundraiser of the I.H.S., Niall Jackson and his uncle Philip Clarke act as doormen at the Garda Band Concert in aid of the I.H.S.*

** The Garda Band perform at a concert in aid of the I.H.S.*

** The slimmed down staff at the final weigh in of the Operation Transformation Pound for Pound Weightloss Challenge.*



Noticeboard

As you are all probably aware Barretstown is a specially designed camp that provides programmes of activities, adventure and fun for children with Bleeding Disorders and other various conditions.

Due to the popularity of the Camps last year with young members of the Society, we would like to encourage people to take advantage of the opportunity to attend these camps.

If you think your child / children may be interested in attending next year, or for information on the various camps in 2011 please contact Fiona in the office on 01 657 9900 or fiona@haemophilia.ie

KEEP UP TO DATE WITH THE I.H.S.

The Irish Haemophilia Society are now mobile! Get updates on all I.H.S. events and activities by signing up to the I.H.S. text service. To sign up to this free service simply log on to www.haemophilia.ie and register online or email nuala@haemophilia.ie

The I.H.S. website is updated regularly with news and information. We hope you are all logging on regularly!

Don't forget you can now follow the Irish Haemophilia Society on facebook. We have nearly 100 followers so far, so why not join that list if you ***like*** what we do!!

SHAW GRAHAM – AN APPRECIATION

Shaw Graham who passed away in May was a longtime stalwart member and key leader of the Northern Ireland Haemophilia Group. Shaw joined the Northern Ireland Haemophilia group in the late 1970's.

Very shortly after joining he became Secretary and later became Northern Ireland Co-ordinator, a position he held for around 25 years. He was a key person in establishing the Northern Ireland office & drop-in centre in Belfast. I first met Shaw in the 1980's and we had many memorable meetings characterised by a mixture of serious discussion, personal banter, warmth and real friendship. Shaw was a lovely man who bore the burden of having inhibitors with fortitude and courage. He was greatly helped by his wife Esther and it was always a real pleasure to meet up with them. I regret the fact that this happened all too rarely. His life and his work have left an enduring legacy of good memories for many people. He will be greatly missed.

Brian O'Mahony

A SPECIAL BIRTHDAY MESSAGE

Mrs. Rita Hoey recently celebrated her 101st birthday. We would like to wish Rita a belated Happy Birthday. Rita is the oldest member of the Irish Haemophilia Society and looks forward to reading her copy of the magazine, so that she can keep up to date with what's going on in the Society. Some of you might remember Rita from way back when she got involved by supporting her sister and brother in-law Maureen & Jack Downey through fundraising at events such as bottle stalls and the famous knit in. Many congratulations Rita!

IMPORTANT MESSAGE

To enhance our magazines and website, we use photographs that have been taken at our events and activities. If you would prefer not to have your photograph included in our publications, please contact Debbie Greene in the office on 01 657 9900.

Calendar of Events

DECEMBER

PARENT COFFEE MORNING IN OUR LADY'S CHILDRENS HOSPITAL, CRUMLIN

Date: Thursday December 2nd

Venue: Children's Medical Foundation, Our Lady's Children's Hospital Crumlin

Time: 10.00am

The Haemophilia Multidisciplinary team would be delighted if parents of children with haemophilia could joint hem for a parent's coffee morning. This is a great opportunity to meet other parents and the Haemophilia Multidisciplinary team for a chat.

Light refreshments will be provided. Children welcome to attend, with parent's supervision. Please book your place with Emma Murphy at 01 409 6913.

DECEMBER

MEMORIAL SERVICE

Date: Sunday 12th December

Venue: The Irish Haemophilia Society Office, 1st Floor, Cathedral Court, New Street, Dublin 8

2011 Events

MARCH

AGM & CONFERENCE

Dates: 4th - 6th March

Venue: Slieve Russell Hotel, Ballyconnell, Co. Cavan

MAY

PARENTS WEEKEND

Dates: 20th - 22nd May

Venue: Fitzpatricks Castle Hotel, Killiney, Co. Dublin

SEPTEMBER

HIS I.H.S.

Dates: 10th - 11th September

Venue: Clarion Hotel Liffey Valley, Dublin 22

An information meeting for men with haemophilia and related bleeding disorders aged 18 - 30. Learn more about how haemophilia will impact on various relationships and scenarios in your life.

Topics that will be discussed at the weekend include:

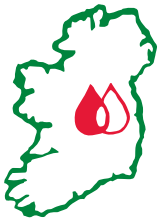
- Travelling and haemophilia
- College or Work Life
- Sport
- Joint Care
- When haemophilia becomes part of your relation ship

OCTOBER

MEMBERS CONFERENCE

Dates: 14th - 16th October

Venue: Carlton Shearwater Hotel, Ballinasloe, Co. Galway



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