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Magazine of the Irish Haemophilia Society



December 2010

Announcing AGM & Conference 2011

Venue: Slieve Russell, Co. Cavan

Dates: 4th – 6th March, 2011



We wish to announce that our Annual General Meeting and Conference will take place next year from 4th to 6th March in the Slieve Russell Hotel, Co. Cavan. Below you will find a taste of the adult, kidlink and youth programmes which we are in the process of planning.

ADULTS PROGRAMME		KIDLINK & YOUNG ADULTS PROGRAMME	
<u>Saturday 5th March</u>		<u>Friday 4th March</u>	
10.00am – 1.00pm	Annual General Meeting	7.00pm - 8.00pm	Wii Championship
1.00pm – 2.00pm	Lunch	<u>Saturday 5th March</u>	
2.00pm – 3.30pm	Haemophilia Teams from: NCHCD (St James's) OLCHC (Crumlin) CUH (Cork)	10.00am– 11.30am	Arts & Crafts (FULL GROUP)
3.30pm – 4.00pm	Coffee	11.30am – 1.00pm	Swimming (FULL GROUP)
4.00pm – 5.00pm	Prophylaxis	1.00pm – 2.00pm	Lunch (FULL GROUP)
<u>Sunday 6th March</u>		KIDLINK	
10.00am – 10.30am	I.H.S. Twinning Programme	2.00pm – 5.00pm	Slideshow Movie (Educational)
10.30am – 11.30am	Ageing	YOUTH GROUP	
	Or	2.00pm - 4.00pm	Talk from member about their experience of haemophilia
	von Willebrands Disease	4.00pm -5.00pm	Podcasts
11.30am – 12.15pm	New Therapies for Haemophilia and von Willebrands Disease	<u>Sunday 6th March</u>	
12.15pm – 1.00pm	Open Forum Discussion	KIDLINK	
1.00pm	Lunch	10.00am – 11.30am	Games
		11.30am – 1.00pm	Swimming
		YOUTH GROUP	
		10.00am – 11.30am	Team Building
		11.30am – 1.00pm	Games
		1.00pm	Lunch (FULL GROUP)

Booking forms and AGM packs will be sent out in the post to members in early January 2011. You will also be able to book to attend this event online on www.haemophilia.ie in early January.

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CEO'S Report



Irish Haemophilia Society Strategic Plan 2011 - 2014

We are facing difficult and challenging times as a nation and as an economy. We have made major strides in improving treatment and care for persons with haemophilia, von Willebrands Disease, and related bleeding disorders over the past number of years. We are determined to work to ensure that these vital improvements are not reversed, damaged or destroyed by the current and future economic environment. We are also anxious to ensure that the Irish Haemophilia Society carries out our full mission of providing support, services and advocacy not only for persons with haemophilia, but for those with von Willebrands Disease, related bleeding disorders and their families. Coming to the end of 2010 we are also completing our current Strategic Plan which has run from the time period, 2006 to 2010 inclusive. In our analysis and audit of the current Strategic Plan we were delighted to see that we have achieved some 87% of the objectives and strategies which we had set out to achieve four years ago.

While we may take a brief moment to pause and reflect with some satisfaction on this achievement it must be just a brief moment, we must move on. We must strive to meet the ever changing needs and requirements of our community whether those challenges be economic, treatment related, demographic or broadening the community. We are currently finalising a new Strategic Plan, which will take the Society forward into the period to the end of 2014. This plan will again have four major goals, these are:

- 1) Provision of optimal support and services for all persons with haemophilia and other related bleeding disorders and their families.**
- 2) Representing the interests of people with haemophilia**

with all external bodies and agencies.

3) Ensuring the viability and development of the organisation in the future.

4) Ensuring the Society plays a full and active role in the development of haemophilia care globally.

The new Strategic Plan, which we are finalising, will have some 35 objectives and over 130 specific strategies. We will work to ensure that we provide the right support and services to, and advocacy for, all of our members on an ongoing basis. We will work to ensure that our commitment to those with von Willebrands Disease, and rare bleeding disorders is known by those individuals and their families and that they avail on a more comprehensive basis of the services available from the Society.

We will work to ensure that women with bleeding disorders are fully catered for in the organisation. We will produce an ambitious list of specific publications on areas including: von Willebrands Disease, Ageing and Mild Haemophilia in the coming years. We will seek to harness the enthusiasm, energy and motivation of our volunteers by providing them with more training and support. We will work closely with the Haemophilia Comprehensive Care Treatment Centres in St. James's, Our Lady's Childrens Hospital Crumlin and Cork University Hospital to assist them in the development of the optimum level of haemophilia care and treatment which those with bleeding disorders deserve.



The staff and board of the I.H.S. during the Strategic Plan brainstorming session

We will continue to work proactively with the external bodies including the National Haemophilia Council, the Haemophilia Product Selection Monitoring and Advisory Board and the Hepatitis C Consultative Council to ensure that the interests of people with haemophilia are paramount and protected. We will work constructively with the HSE and the Department of Health and Children to advance the treatment and care of persons with haemophilia. We will not neglect our commitment to persons with haemophilia who do not have access to the same level of treatment and care which we enjoy in Ireland. We will work to pursue an active and vigorous twinning programme with the haemophilia organisation in Vietnam and we will continue to play a role in supporting the World Federation of Hemophilia through programme work and through assisting them with donations of factor concentrates being shipped through our headquarters to developing and emerging countries around the world.

The coming years will be challenging, but we are ready to face the challenge. We will fulfil our mission of maintaining and improving services and support for persons with bleeding disorders by advocacy, by information and educational activities including conferences and publications. You can all play your part by maintaining the strength and unity of purpose of this organisation which is such an essential part of our existence.

Research funded by the Irish Haemophilia Society

The Society will be funding a research project over the coming year in relation to a genetic determinant which may prove to be a very useful predictor of success or lack of success with Hepatitis C treatment. In the last year, a specific configuration at a particular gene (known as the IL28B gene) has been shown to demonstrate potential for being able to predict the level of responsiveness to Hepatitis C treatment for those who are infected with Hepatitis C. Each individual has one of three possible configurations at this gene and a simple blood test will identify what their genetic type is.

Working in conjunction with Dr. Colm Bergin from St. James's Hospital and Dr. Claire Gardiner from Trinity College, the I.H.S. are funding research which will allow each person with haemophilia who has been infected with Hepatitis C to have a simple blood test done at their treatment centre or hepatology clinic. The results of this test may well offer them more information in relation to the possibility of any future Hepatitis C treatment being successful for them. It is important that each person with haemophilia who has Hepatitis C should be tested for this gene. This is the case even if you have already

undergone treatment successfully and do not require future treatment as it is important to check the predictive value of the gene also among those who have had treatment and who have succeeded or failed in relation to achieving a sustained response.

Brian O'Mahony

Thank You

A special thank you goes to everyone who volunteered at various events and activities during 2010. We very much appreciate it.

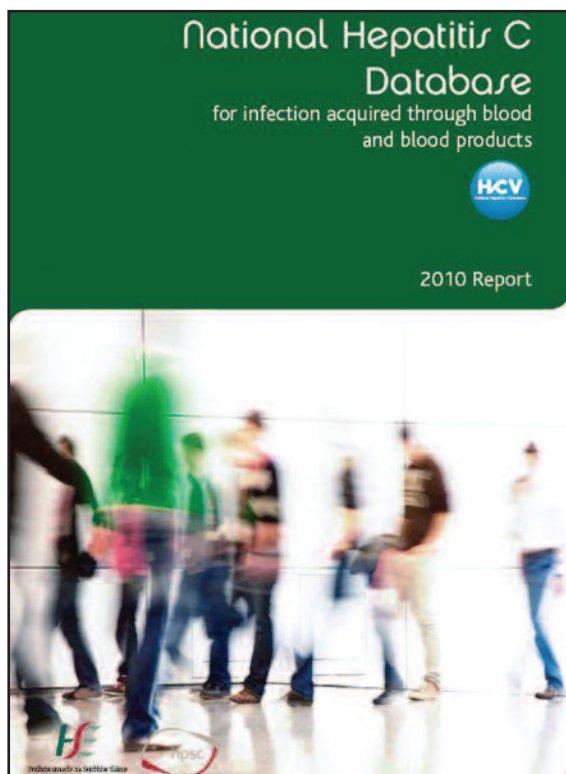
We would also like to thank all those who did some fantastic fundraising for the Society this year.

A thank you also goes to all those who sent in donations. Again it is very much appreciated.

Wishing you all a very Merry Christmas and a Peaceful New Year.

From the board and staff of the Irish Haemophilia Society.

Hepatitis C Database Report Issued



The latest annual Hepatitis C Database Report from the Health Protection Surveillance Centre (HPSC) has just been published. This report, which is updated annually, gathers information from medical charts of persons who were infected with Hepatitis C via blood or blood products supplied by the state. The report includes data from persons who contracted Hepatitis C from Blood transfusion, anti D, renal dialysis in addition to treatment for Haemophilia. The report is an excellent resource as it charts the progression of Hepatitis C in these diverse groups and also assists us in planning the support and services we will deliver to our members affected by Hepatitis C.

Some 73% of persons with Haemophilia who have Hepatitis C have given permission to their Hepatology centres for their data to be included. We would strongly encourage those who have not yet given permission to positively consider doing so by contacting your Hepatology clinic and giving them permission to include your details in the database.

In the group of persons with haemophilia covered by the database report, 31% were characterised as having severe liver disease with 14% classified as having cirrhosis. A significant proportion (42%) were co-infected with HIV, and the rate of severe

liver disease was twice as high in this group (33%) compared to those without co-infection (16%). Of the 161 people with Haemophilia covered by the database, 72 are currently chronically infected with Hepatitis C, 27 had cleared the virus, 34 have liver disease and 67 were deceased (the majority of whom were co-infected with HIV).

In relation to progression of liver disease, the factors which increase progression are age (higher progression in those over 50, and again older than 65), male gender, Genotype 3, alcohol use and number of years infected with Hepatitis C. Obviously, you can not impact your age, gender, or duration of infection or genotype.

However, it is clear from the current report that the single greatest risk factor for progression of liver disease is excessive alcohol consumption. Some 17% of people with Haemophilia consumed alcohol in amounts in excess of 40 units per week and a further 18% consumed between 21 and 40 units per week. (The maximum recommended alcohol intake per week for an adult male without Hepatitis is 21 units). The relative risk of developing severe liver disease is increased 5 fold by drinking excessively.

There are a number of clear messages we can take from the report. For those with Hepatitis C, alcohol should be avoided and if not avoided, consumption should be minimised. I am aware that some people with Haemophilia have used alcohol as a painkiller due to swelling and arthropathy in the past but I believe they need to re-evaluate this. Members with Hepatitis C should try to maintain a healthy weight and body mass index. These are areas where you can assume control of your Hepatitis C and your life. It is also important that you attend your Hepatology centre and have them routinely monitor your Hepatitis C.

Brian O'Mahony

The Haemophilia Success Story

A Canadian colleague has referred to the topic of ageing and haemophilia as 'a success story' and, while this is true, it is one which will present many challenges for people with haemophilia and their health care professionals in the future.

This article gives us the opportunity to look at some of the expert knowledge and experience from the different aspects of ageing and haemophilia care. In addition, it is an opportunity to start an important dialogue on the future needs of the physical, psychological, medical, financial and social needs of ageing people with haemophilia. Most importantly, it may be an opportunity to give a voice to the concerns and fears of senior people with haemophilia.

The article is based on the sessions 'Ageing with Hemophilia' and on the 'Emerging Co-Morbidities in the Ageing Hemophilia Population' presented during the World Federation of Hemophilia Congress in Buenos Aires July 2010. The session 'Ageing with Hemophilia' focused on:

- * The medical, psychological and social implications of aging with haemophilia.
- * The potential effects of early retirement through illness or disability from haemophilia.
- * Recognition that many people over the age of 50 who did not have factor concentrate available to them for bleeding episodes when they were young, have developed severe arthropathy which has left them with severe mobility difficulties.
- * The experience of a person with haemophilia living in a developed country.
- * Lobbying for services to improve quality of life.

Dr. Alison Street, an Australian Haematologist spoke on the medical aspects of ageing, ranging from mobility issues to the age-related problems of kidney, heart and prostatic disorders, including osteoporosis, diabetes and cancer. In addition, Alison talked about 'Wellness Checks' and how important it is to watch weight, blood glucose, cholesterol, and to monitor blood pressure. The importance of keeping connected with family and friends, health professionals, your haemophilia treatment centre, and the haemophilia community were also highlighted.



The questions which emerged from this session were:

Renal disease – is there an increased incidence with haemophilia?
Cardiovascular disorders – is there a decreased incidence with haemophilia?

Zygmunt Gruszka is a member of the Swedish Hemophilia Society. Zygmunt spoke on the need of his organisation to formulate their future strategies based on the expressed needs of their senior members and to lobby for their future service needs. These will prove challenging for National Member Organizations and Haemophilia Treatment Centres.

Surveys from Sweden and Denmark indicate that people with haemophilia who work until retirement are well educated, are used to living with limitation, pain and disability, and that Senior Citizens consider that their 'health is good'. This senior generation are worried that they may not be able to manage to inject themselves.

How will they manage other diseases and increased pain? There is a fear of becoming weaker and being unable to manage everyday tasks, plus financial insecurity and the reality of liver cancer caused by Hepatitis C.

Future challenges for National Haemophilia Societies worldwide include, developing strategies and lobbying to meet the expectations of senior members; the need to collect updated data about the social, financial and health status of senior members, and gather information on future needs, concerns and possible threats.

The Swedish Society has Advisory Councils which meet with clinicians. This has resulted in the introduction of regular PSA (blood test) for prostate cancer. Zygmunt highlighted the need for mutual understanding between the Haemophilia Treatment Centres and the needs of senior members.

Mike Carnahan from New Zealand has been an active member of the Haemophilia Foundation of New Zealand, and is now a campaigner for the care of older people with haemophilia.

Mike shared his personal experience of living with haemophilia and of taking early retirement in a developed country. Mike took early retirement to have restorative surgery over a 5 year period. He recommended that all people with haemophilia have an annual review with their Haematologist to establish a written health plan, using prophylaxis and



intensive physiotherapy to retain function. Other considerations include taking care of the veins, good dental care, pain relief, rest periods – 30 minute activities followed by rest, staying in contact with people, and the use of public health screening programmes. These actions are all part of the individual accepting responsibility for his health.

Another area of concern is avoiding falls and making life easier through identifying and managing the risks in the home, having purpose built accommodation where possible, use of non-slip flooring with easy access, without steps, and low maintenance. Making the appropriate bathroom changes e.g. walk-in shower with seat, and high toilet with handrail. Having your home as automated as possible - use of remote control for radio and TV, heating and cooling.

Angela Forsyth, an American Physiotherapist spoke about the benefits of exercise and physical activity, and the use of adaptive equipment to improve overall health and functional mobility, which can positively affect a person's quality of life. Exercise can have a positive role in minimising osteoarthritis, prevention of falls, and osteoporosis. In order to maximise functional ability and independence, Angela recommended the appropriate use of splints and braces,

and assistive devices around the home. For the best advice, it is important that a person have an individual assessment by his Haemophilia Physiotherapist and an Occupational Therapist.

Techniques suggested were, pacing oneself, balancing rest and activity, use of the biggest joint for the job (using joints wisely), keep moving – avoid prolonged positions to minimise stiffness, the use of assistive devices to help with daily tasks and to maintain independence with damaged or painful joints.

Angela ended her session with a quote from Hippocrates - "That which is used develops, and that which is not used wastes away."

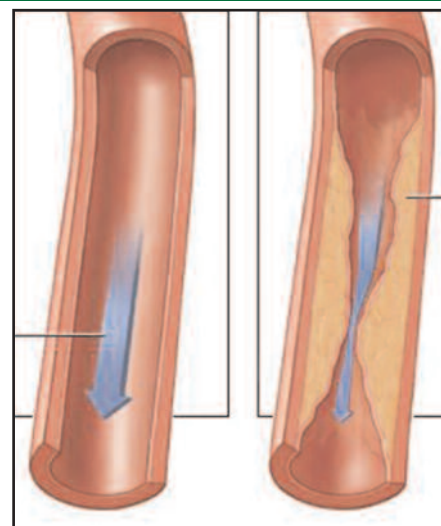
Professor Craig Kessler, Director of Hemophilia & Thrombophilia Comprehensive Care Centre in Georgetown, USA spoke about the need to modify the standard approaches to diagnosis, treatment and prevention of these conditions in those with hereditary bleeding disorders. In the absence of data, the medical profession has assumed that the management of cardiovascular diseases should be similar to that given to patients without haemophilia, provided that factor concentrate treatment is given when required. This however, may prove to be a naïve approach.

Currently, there are many unanswered questions:

What is the optimal clotting factor level needed to minimize bleeding in the haemophilia patient on Warfarin?

How does the doctor calculate the bleeding risk in the haemophilia patient with severe joint disease who is at risk of falling?

What are the critical drug interactions in the haemophilia patient on Warfarin who



who is on anti-retrovirals for HIV or, in those with compromised liver function due to chronic Hepatitis C?

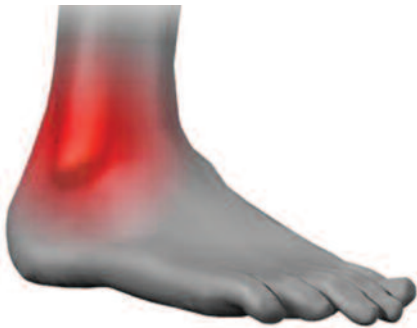
Evidence based research is required to begin to answer these questions. Perhaps, the best approach to the treatment of ischaemic heart diseases is to prevent them with good diet and exercise which can help to reverse risk factors:- Good nutrition, stop smoking, loose weight and exercise, prevent diabetes. Basically it is about modifying our behaviour patterns and living standards.

Dr. Gerry Dolan, Consultant Haematologist in Nottingham, UK spoke about the availability of safe, effective factor concentrates, comprehensive care centres and prophylaxis, and how life expectancy for people with haemophilia has significantly improved.

However, there is little evidence based data of age-related medical problems to guide their management. Estimates suggest that 77% of the general population over the age of 65 years, have two or more chronic illnesses. It is likely that the management of older people with haemophilia will become more complex. Non-cardiovascular, age-related conditions include cancer, kidney disease and musculoskeletal disorders. In the general male population, the rate of new cancer

diagnoses increases sharply from ages 45 to 54, with prostate, lung and colorectal cancer being the more common.

For people with haemophilia, there is an increase in hepatocellular carcinoma in those with Hepatitis C, and in non-Hodgkin's lymphoma for those with HIV. This may provide challenges for medical care, as there may be a bleeding risk with biopsy procedures, and a risk of venous thromboembolism in older people with haemophilia on replacement therapy for cancer treatment.



While chronic renal disease is an age related condition, there is evidence to suggest that the risk may be increased in haemophilia, especially in those with HIV, hypertension, and a history of haematuria (blood in urine). Quality evidence based studies are needed to assess the risk, together with appropriate screening and intervention being available to all.

Despite resources currently used to prevent arthropathy, this will not protect the ageing person with haemophilia from degenerative arthropathy. These patients may require a significant amount of joint surgery, raising the issue of appropriate analgesia. The assessment and management of geriatric musculoskeletal issues such as osteoporosis, balance, and movement problems may need to become part of comprehensive care.

Because people with haemophilia have come to rely on Haemophilia Treatment Centres for all of their medical care, this may have resulted in many patients being excluded from preventative medical programmes for cardiovascular disease, diabetes, hypertension, and cancer prevention screening. This highlights the need for a formal review of comprehensive care for older individuals.

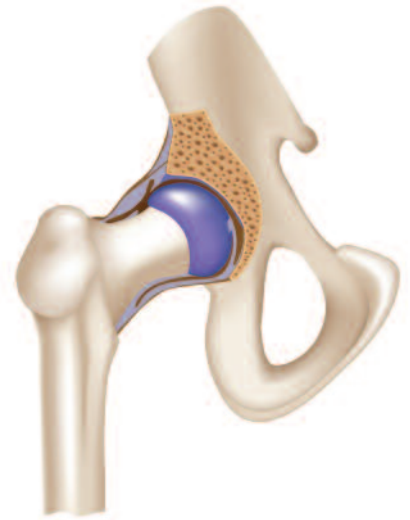
What the individual can do:

- Stop smoking
- Loose weight
- Eat a healthy diet
- Avoid alcohol
- Look after your teeth and bowel
- Pace yourself - balance rest and activity
- Use joints wisely
- Exercise (check with your doctor first)
- Use splints / braces and adaptive equipment (check with your physiotherapist first)
- Maintain social activities, keep connected with friends and family.

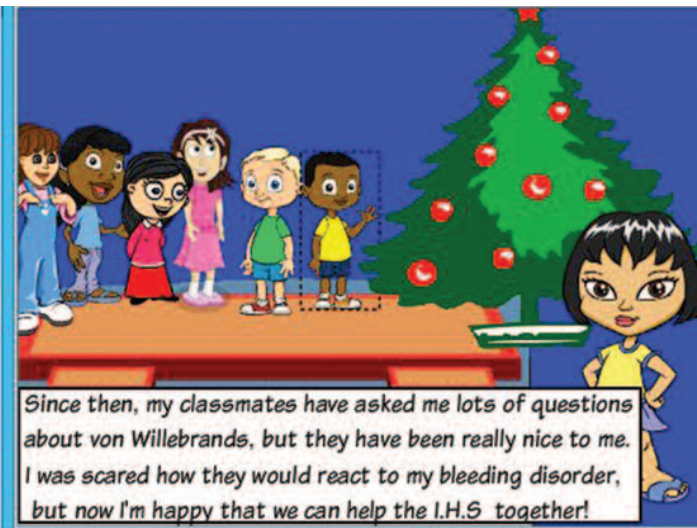
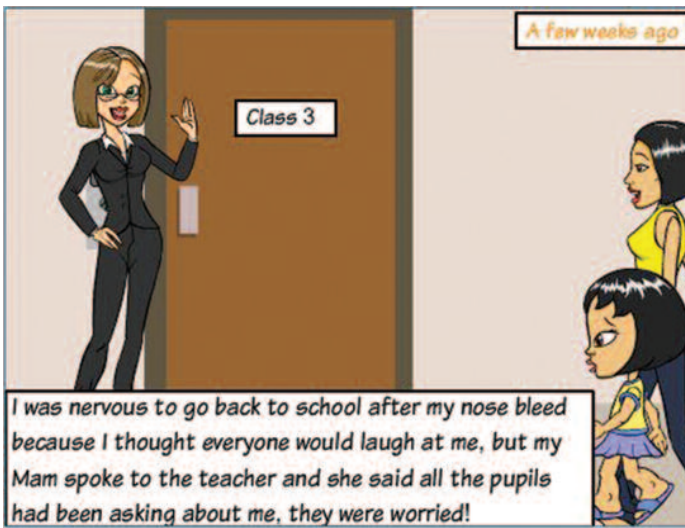
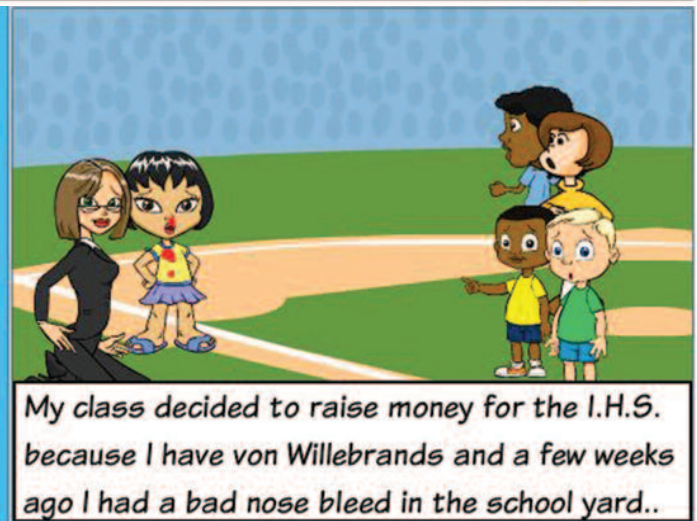
What the Haemophilia Treatment Centres hopefully may monitor in the future:

- Body Weight
- Blood Pressure
- Blood Glucose and Cholesterol
- PSA levels.

Anne Duffy



MEET THE KIDLINK CLUB MEMBERS



www.haemophilia.ie

On the twelfth day of Christmas, my true love sent to me Twelve drummers drumming, Eleven pipers piping, Ten lords a-leaping Nine ladies dancing, Eight maids a-milking, Seven swans a-swimming Six geese a-laying, Five golden rings, Four calling birds, Three french hens, Two turtle doves, And a partridge in a pear tree!

1 = f, 2 = h, 3 = d, 4 = e, 5 = b, 6 = g, 7 = a, 8 = i, 9 = j, 10 = c

1. santa claus, 2. rudolph decorations, 4. reindeer 5. snowman, 6. presents 7. mistletoe, 8. snowflake 9. turkey, 10. north pole



Adam's Arrows

Draw an arrow from the word on the left to its correct meaning on the right, please see the example.

1. Haemophilia
2. Factor
3. Treatment Centre
4. Clot
5. Bruise
6. RICE
7. Vein
8. Joint
9. Infusion
10. Irish Haemophilia Society

- a) Treatment is injected into these tubes
- b) Mark you sometimes get on your skin when you hurt yourself
- c) The Organisation for people with haemophilia and other related bleeding disorders
- d) Place you go to meet your nurses and doctors that deal with haemophilia all the time
- e) The plug that is made when someone hurts themselves to stop a blood leak
- f) Disorder where someone takes longer than normal to stop bleeding
- g) When you get a bleed, you should rest, put ice on it, compress the area and elevate
- h) Something in your blood that helps to make a strong plug over a leak
- i) Part of your body where your bones are joined
- j) Injection of treatment when there is a blood leak

HAPPY CHRISTMAS EVERYONE



www.toondoo.com

Wendy's word jumble

Can you rearrange the words below to find the words associated with christmas

1. casualants
2. hodpurl
3. iscartooned
4. reedrine
5. wonanms
6. netpress
7. itsomelet
8. falseknow
9. keyrut
10. hornetlop



Connor's Christmas Carol

Can you fill in the missing words from this well known Christmas carol?

On the twelfth day of Christmas,
 my true love sent to me
 Twelve _____, (7, 8)
 Eleven _____, (6, 6)
 Ten _____, (4, 1-7)
 Nine _____, (6, 7)
 Eight _____, (5, 1-7)
 Seven _____, (5, 1-8)
 Six _____, (5, 1-6)
 Five golden rings,
 Four _____, (7, 5)
 Three _____, (6, 4)
 Two _____, (6, 5)
 And a partridge in a pear tree!



- | | |
|-------------------|-----------------|
| swans a-swimming | ladies dancing |
| calling birds | pipers piping |
| turtle doves | maids a-milking |
| drummers drumming | geese a-laying |
| French hens | lords a-leaping |

www.haemophilia.ie

Members Weekend 2010

We were mentally booked into this weekend ever before we got there! Eoghan, Jack (who has severe haemophilia) Joanna and I, had been looking forward to the weekend for our own particular reasons.

Eoghan who is now 14, had missed the Spring Irish Haemophilia Society weekend and was looking forward to his first Young Adults weekend, away from his parents and siblings, at the mercy of Alison and her team at the Jamaica Hostel and the University of Limerick Activity Centre. Jack aged 12 had been to the Parents Weekend and after watching the self-treatment demonstration by Gary Butler and Mary Kavanagh (Haemophilia Clinical Nurse Specialist – OLCHC) had begun treating himself during the summer holidays before he went to Barretstown. At Barretstown, Jack had met his buddies Conor, Adam, Gary and Fergal who were all around his own age and who all have haemophilia. On the day he got back from Barretstown he said, “Can we go to Limerick for the next weekend?” so he could meet the lads. Joanna who is 9 years of age was looking forward to meeting some friends, swimming, and bowling. The highlight for her would be staying up late for the Quiz after dinner on Saturday night.

I was looking forward to the weekend as well. It's great to chat to other parents of children with haemophilia, meet old friends from the IHS and to get to know some new members. The great thing about the IHS is that at almost all of the weekends away for members some educational talks are included in the programme. I like this aspect of the weekends because it gives you a chance to address different issues related to living with haemophilia that might not come up in the usual day-to-day experiences with our own family.

One of the talks I attended was called “Positive Living with a Bleeding Disorder” which was given by Owen Hegarty, Psychotherapist. Owen has a unique style of addressing the audience. He energetically paced over and back in front of us like a caged tiger, assessing our mood. He had our attention. He then tried to set the scene in the context of what he was about to say, in his best Cork accent. So far, so good! He then told us that because he has no personal experience of living with a bleeding disorder, he is not able to make any presumptions about what it might feel like to live positively or otherwise with a bleeding disorder. He's lost me now! Owen talked about being positive in terms of being positive is “feeling based”, not “thinking based”; can we control our feelings? No, we can ‘manage’ our feelings but not ‘control’ them; feelings are more powerful than thoughts, etc. This psychotherapy theory is all very well, and it's interesting to listen to but I wonder would Owen have held the audience better if he tried to apply the ‘positive’ theory more directly to ‘living with a bleed-

ing disorder’, as he seems to have some knowledge of this topic. Some lively banter ensued between Owen and the audience at question time. Perhaps I wasn't the only one lost after all, as a member of the audience asked, “What's wrong with being pessimistic?” Touché Owen!

The highlight of the afternoon was the ‘serious’ debate chaired by Brian O'Mahony on “Guiding the child with a bleeding disorder, who does it better, the mother or the father?” Susan Clarke outlined the case for the mothers eloquently and almost had us convinced of a landslide victory for every mother in the room. We were almost out of our chairs ready to take a bow in the name of motherhood, when ...Sean O'Sullivan took to the floor. He first began to tell us of the hands-on approach that the fathers of today take in guiding their children. We had heard all the clichés before but we weren't prepared for what came next. Sean convincingly outlined that naturally a child needs the efforts of both parents to guide them, be there for them and to fill in for each other when needs be. Well, we were all left speechless! Whose side was he on anyway? There were no winners of that debate, except of course, the children. Nice one Sean!

Anne Duffy facilitated the Mothers' Workshop. Several issues were discussed and opinions given by both new mothers and more experienced mothers and unfortunately time ran out very quickly. Next door the Fathers' workshop was in progress and I noticed lots of laughter coming from there. What were they discussing? Who knows? At least they enjoyed it.

Later in the afternoon the I.H.S. staff outlined the services and support offered by the IHS. I realised that although I would have been familiar with most of the services that are available, that the IHS is continually evolving to meet the needs of the members, for example: the communication opportunities that are now available through the IHS social media developments on Facebook etc. I'm sure this will have great appeal. Well done to the IHS.

I met some old friends and some parents who are new to haemophilia and the Society. Other peoples' experiences help me look at the bigger picture and put my own experience of haemophilia in context. I am grateful that the IHS is always there to offer support if needed.

Well, the kids had the usual fantastic craic thanks to Alison, Paul and all the leaders. All the kids in turn paid tribute to the leaders and their helpers who give each of them great attention. However, Joanna kept asking on Sunday when would she

be seeing Alison? Alison, you have made a lasting impression! The kids always enjoy the social aspect of the weekends immensely and it puts haemophilia in a very positive framework for those affected, their siblings and parents.

Thank you to all who made our weekend so enjoyable. Roll on the next one!

Joan Buckley Keniry



Barretstown Gang Camp



'Make friends, make films, sing, fish, dance, ride horses, whatever you want, because at Barretstown anything is possible and everything is fun!' (Barretstown 2010)

As you are probably aware Barretstown is a specially designed camp that provides programmes of activities, adventure and fun for children with haemophilia and related bleeding disorders and other various conditions. Barretstown run a variety of camps including:

Camps for Families which run in the Spring and Autumn, lasting for two days. These camps take place at weekends. Family camps, gives parents and children some time out together to have fun and relax in a safe and caring environment.

Camps designed for children with haemophilia and related bleeding disorders are on at various stages throughout the summer months for a duration of 7 to 10 days. The children take part in a range of activities including archery, fishing, high ropes and movie making amongst others!

Camps designed specifically for the siblings of children with haemophilia and related bleeding disorder. These camps are also run throughout the summer and last for 10 days. This is a fantastic camp for brothers or sisters of children with haemophilia and related bleeding disorders.

The comments from the children who attended the camps in the past are always extremely positive. The Irish Haemophilia Society secured places with Barretstown this year and we have since been offered places for the 2011 camps. We would therefore like to encourage members and their children to take advantage of this fantastic opportunity.

We are currently compiling a register of those interested in attending camps next year. If you think your child / children may be interested in attending next year, or for information on the various camps please contact Fiona in the office on 01 657 9900.

Fiona Brennan

A quiz about you



1. What age group are you in?

- a) 18 – 24
- b) 25 – 30
- c) 30 – 40
- d) 40 - 50
- e) Over 50

2. Which three words best describe you?

- a) Fun, outgoing, bubbly
- b) Quiet, friendly, kind
- c) Creative, energetic, thoughtful
- d) Caring, sensitive, sensible
- e) Adventurous, confident, supportive

3. How are you associated with the Irish Haemophilia Society?

- a) Person with a bleeding disorder
- b) Sibling or relative of a person with a bleeding disorder
- c) Child of a person with a bleeding disorder
- d) Partner of a person with a bleeding disorder
- e) Parent of a child with a bleeding disorder

4. What was/is your favourite subject in school?

- a) Maths
- b) English
- c) History
- d) Geography
- e) Irish

5. Do you attend any Irish Haemophilia Society events or conferences?

- a) No never
- b) I did attend a meeting some years ago
- c) I only attend the AGM
- d) I attend as many as possible
- e) I attend all events and conferences

6. If you wanted to relax after a day at work or school which of the following would you do?

- a) Read a book
- b) Listen to music
- c) Watch television
- d) Go for a walk
- e) Talk

7. Have you ever volunteered for the Irish Haemophilia Society?

- a) No never
- b) I did some years ago
- c) I regularly volunteer
- d) I don't but may be interested in volunteering in the near future
- e) I have done volunteer work but not for the I.H.S.

Are you mostly As, Bs, Cs, Ds or Es – find out what you would be good at on the next page..



Congratulations you would be good at **VOLUNTEERING**



volunteers. We hope that this database will help us to identify members who have expertise or even an interest in a particular area, and hopefully we could utilise their skills. With the establishment of this new database, it will allow us to introduce a rotation system with our volunteers, with regards to events, conferences, and publications.

Anyone who signs up to the volunteer programme will receive training from the Irish Haemophilia Society, so although previous experience would be an advantage, it is not a necessity. Volunteering is a great way to become involved, to learn new skills, to meet new people, to add to your C.V., and for anyone interested in helping out with our children's programmes they will receive a recognised certificate in Child Protection Training.

And remember you could volunteer from the comfort of your own home. Could you write an article on your life living with haemophilia or related bleeding disorder? You may not think this is volunteering but it is. Are you good at arts and crafts? Are you a good photographer? Do you have a hobby or a skill that you could teach to others?

If you think you could contribute or volunteer in some small way, we would be delighted to hear from you. Contact any of us in the office on 01 6579900.

Nuala McAuley



The Irish Haemophilia Society are looking for volunteers! What are the requirements you ask? There is only one, you must be 18 years or over.

The Irish Haemophilia Society could not function without volunteers. For example:

- *The governing body of the Society is made up of nine volunteers who attend monthly board meetings.*
- *The magazines, website and other publications rely on input from members.*
- *Indeed our weekend conferences would not be possible without our volunteers, as they are responsible for the organisation, supervising and running of the various children's programmes.*

Excluding the board, currently the Society have a co-hort of eight to ten volunteers that we rely on to help out at each weekend, and a pool of ten to twelve members who write articles for the magazines and the website.

Currently, the Society organise a minimum of three weekend conferences a year, and we organise a full weekend of programmes for the various groups. This means that at our weekend conferences there are four programmes running simultaneously - Creche, Kidlink, Young Adults and of course the Adult programme.

The idea of the volunteer programme is to create a database of

Hospital Christmas Opening Hours

National Centre for Hereditary Coagulation Disorders St. James's Hospital, Dublin



December 2010

Friday 24th December	Closed
Saturday 25th December	Closed
Sunday 26th December	Closed
Monday 27th December	Closed Bank Holiday
Tuesday 28th December	Closed Bank Holiday
Wednesday 29th December	Opening: 08.30 – 17.00
Thursday 30th December	Opening: 08.30 – 17.00
Friday 31st December	Closed

January 2011

Saturday 1st January	Closed
Sunday 2nd January	Closed
Monday 3rd January	Closed Bank Holiday
Tuesday 4th January	Re-opening: 08.30 – 17.00

When the NCHCD is closed, patients with a bleeding disorder, who have a bleed, should present themselves to the Walter Stevenson Ward.

Our Lady's Children's Hospital Crumlin



December 2010

Friday 24th	08.30 – 17.00
Saturday 25th	Closed
Sunday 26th	Closed
Monday 27th	Closed Bank Holiday
Tuesday 28th	Closed Bank Holiday
Wednesday 29th	08.30 – 17.00
Thursday 30th	08.30 – 17.00
Friday 31st	08.30 – 17.00

January 2011

Saturday 1st	Closed
Sunday 2nd	Closed
Monday 3rd	Closed Bank Holiday
Tuesday 4th	08.30 – 17.00

A registrar haematologist will be on call at all times and will be available for any emergencies throughout the holiday period.

Cork University Hospital



December 2010

Monday 27th	Bank Holiday (Haematology team on call 24hrs)
Tuesday 28th	Bank Holiday (Haematology team on call 24hrs)
Wednesday 29th	Mobile cover + Haematology team on call 24hrs
Thursday 30th	Mobile cover + Haematology team on call 24hrs
Friday 31st	Mobile cover + Haematology team on call 24hrs

January 2011

Monday 3rd	Bank Holiday (Haematology team on call 24hrs)
Tuesday 4th	Normal duty resumes

Noticeboard



The staff and board of the Irish Haemophilia Society would like to wish members a very Happy Christmas and Peaceful New Year.

Christmas Office Opening Hours



We would like to inform you that the offices of the Irish Haemophilia Society will close for Christmas on Thursday 23rd December and will re-open on Tuesday 4th January. In case of an emergency please contact Anne Duffy on 087 2320255.

Mini Marathon



A special thanks goes to everyone who took part in the Mini Marathon in June of this year. We really appreciate the continuing support of members and friends who enjoy this event by taking part, or by sponsoring a participant. Just a reminder for those of you who have not yet sent in sponsorship, we would ask that you do so at your earliest convenience. Don't forget a draw will take place early in the New Year for all fundraisers who raise over €150.

www.haemophilia.ie



Irish Haemophilia Society Discussion Forum

Don't forget to log on to the Irish Haemophilia Society Discussion Forum on www.haemophilia.ie/forum

This is a private members forum for people with haemophilia and related bleeding disorders and their families to share their experiences, and to discuss any issues.

Also don't forget to check out the Irish Haemophilia Society website: www.haemophilia.ie

Calendar of Events

MARCH

AGM & CONFERENCE

Dates: 4th - 6th March

Venue: Slieve Russell Hotel, Ballyconnell, Co. Cavan

Further information is on page 2.



MAY

PARENTS WEEKEND

Dates: 20th - 22nd May

Venue: Fitzpatrick's Castle Hotel, Killiney, Co. Dublin

We are in the process of planning this weekend.
Further information will be available in the New Year.



SEPTEMBER

HIS IHS

Dates: 10th - 11th September

Venue: Clarion Hotel Liffey Valley, Dublin 22

An information meeting for young men with haemophilia and related bleeding disorders aged 18 - 30 will take place in September 2011.

Topics that will be discussed at the weekend include:

- Travelling
- College or Work Life
- Sport
- When haemophilia becomes part of your relationship

Further information on this weekend will be available in the New Year.



OCTOBER

MEMBERS CONFERENCE

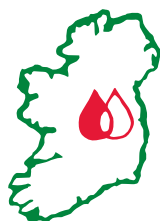
Dates: 14th - 16th October

Venue: Carlton Shearwater Hotel, Ballinasloe, Co. Galway

We are hoping that this popular weekend will be a great success again in 2011.



KEEP CHECKING THE WEBSITE FOR FURTHER UPDATES www.haemophilia.ie



IRISH HAEMOPHILIA SOCIETY

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