

# haemophilia.ie

**Magazine of the Irish Haemophilia Society**



**40 Years And Still Growing....**

**Edition: Spring 2008**

## Our Loyal Fundraisers...



## Women's Mini Marathon Monday 2nd June, 2008

The 2008 Flora Women's Mini Marathon takes place on Bank Holiday Monday, 2nd June at 3.00pm. This event is the biggest all women's event in the world and continues to grow each year. Women of all ages from all parts of the country take part in this great fundraising event.

We are hoping this year to significantly increase our numbers. As well as raising funds, the Mini Marathon helps us to raise awareness of haemophilia, which is a very important aspect of our work.

This year the race starts in Fitzwilliam Square and finishes in St. Stephen's Green. Entry forms are available in the Evening Herald every Thursday. The fee is €15.00 and the closing date for entries is 22nd April.

Members, it is worth noting that the organisers are insisting that the event is strictly **FEMALE ONLY - MALES ARE NOT ALLOWED** to participate in the event at all this year.

We will be providing changing facilities for those taking part on the day in Buswells Hotel in Molesworth Street. We will also be providing a free T/Shirt, refreshments before and after the run, and a commemorative scroll.

Anyone who takes part and raises over €150 will be entered into a draw for a weekend away for two, which will take place later on in the year.

Most of you should have received sponsorship cards in the post, however if you require additional sponsorship cards, please do not hesitate to contact us.

We would also like to announce that the winner of our Mini Marathon Draw 2007 is Ms. Sheila Fitzgerald from Cork. Sheila's prize is a weekend away for two in any of the Carlton Group of Hotels in Ireland.

Congratulations Sheila, and many thanks for all your hard work fundraising.

**Debbie Greene**



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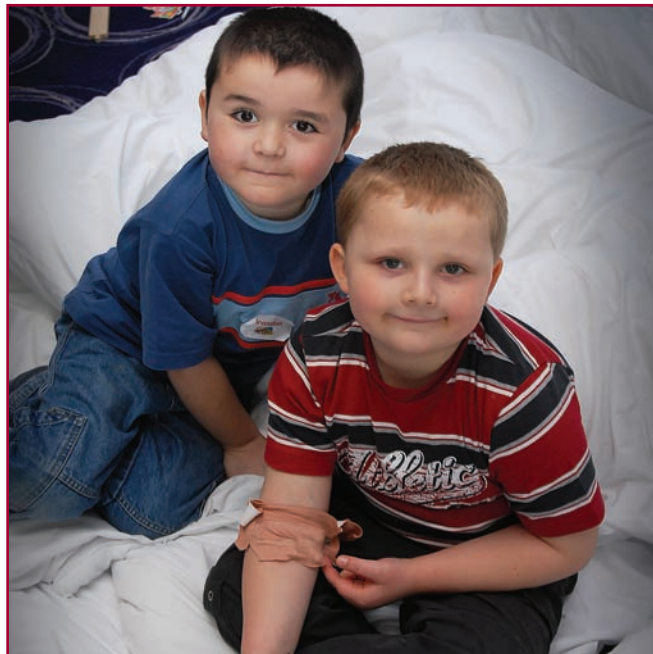
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The Annual General Meeting and Conference took place in the Park Plaza Hotel in Tyrrelstown Dublin over the weekend of 29th February to 2nd March. Being the 40th anniversary of the Society it was a challenge to put together a programme which gave an accurate sense of where we have come from and the challenges we as a Society have faced over the past forty years, while at the same time looking forward with a sense of hope and determination to the future. With that in mind we decided the theme of the Conference should be 'Past Present and Future'.

I searched through the old photos and files and put together a slide show covering some of the people and events of the past 40 years. The slide show ran in the conference foyer over the course of the weekend and proved to be a popular talking point. There were over 200 images in the slide show. I had some difficulty in keeping it to that,

in fact we could have included twice that number. On Saturday morning the Chairman Michael Davenport opened the business meeting. Reports were presented by the Secretary Kevin Birkett and Treasurer Ger O'Reilly. Their reports outlined all of the activities and the audited accounts for 2007. In the Chairman's Address Michael Davenport recorded his appreciation to the Board members and the staff for their commitment to the Society. He thanked Pat Devlin, in his absence, for the major contribution he made to the Society and its members over his 16 years on the executive.

Since there were no new nominations received the current members of the Board who were willing to go forward again were deemed to be elected. The Board members are as follows:

Michael Davenport  
Traci Dowling

Kevin Birkett  
Ger O'Reilly  
Michael Butler  
Declan Noone  
Pat Downey  
Barbara Guilfoyle

The CEO Brian O'Mahony then presented his report. This report included a summary of the major activities during 2007. The report also included an update on the progress and implementation of the three year Strategic Plan and an outline of the activities planned for 2008.

The Chairman opened the meeting to the floor and the delegates contributed to a lively discussion before the AGM was officially closed.

In the afternoon there was a large attendance for the official opening of the Conference which was performed by the Minister for Health and Children Mary Harney.



The Minister then went on to see the Kidlink programme and visited the crèche.

Dr. Paul Giangrande from the Oxford Haemophilia Centre who is also Vice Chair Medical of the WFH chaired the afternoon programme. On the theme of "Past Present and Future" Brian O'Mahony presented a history of the Society over the past 40 years. Again Brian trawled through the archives for old photos and documents and his well thought out presentation, I think, gave a clear picture of the very rocky road we have travelled. From the small group who responded to a need for support and started up the Society in 1968 which ran from people's homes, to the professional organisation we now have, it was clear that what has remained the same throughout the last forty years is the ethos and compassion which inspired those founding members. The Society is, and always has been, the sum of its members and their families who with their courage, selflessness, humour and determination have always, and continue, to support each other.

Claudia Black's presentation looked at the current developing world programmes of the WFH. Claudia is the Executive Director of the WFH. There are still so many people with bleeding disorders around the world who receive little or no treatment and indeed her presentation brought it home to me that Ireland could have been included in a similar presentation in the 1960's and 1970's. It was also clear that while we must never become complacent about the treatment and services here in Ireland we have a very real duty to

do whatever we can for those less fortunate than us by sharing our expertise and experience whenever we can.

The last presentation of the afternoon was from Dr. Barry White who spoke about the future of haemophilia treatment and services in Ireland. Again this presentation brought home to me the important role the Society must continue to play in the improvement of services throughout the country. Our presence and full participation on the National Haemophilia Council and the Product Selection Group is vital if we are to continue to have a meaningful role in the future development of services for all people with bleeding disorders in Ireland.

The afternoon concluded with a question and answer session for the panel which was chaired by Dr. Paul Giangrande.

On Saturday evening we were delighted to welcome many old friends as guests at our Gala Dinner. The tables decked with balloons and flowers and with chocolates for everyone made it a real celebration.

Following the dinner there was the presentation of awards. The Bill O'Sullivan Fundraiser of the Year Award this year went to Michael Walsh who organised a fun run last September and raised over €1700. Michael is the father of a young boy with haemophilia and we are very grateful for his support. The award was presented by Grace O'Sullivan. Irene Clarke was presented with the Maureen Downey Scholarship by Pat Downey. Irene, who has severe vWD, is studying in the Ballyfermot College of Further Education and is at the beginning of her journey towards becoming an Art Teacher. We wish Irene every success in her chosen career.



**Our fantastic Creche Supervisors**

The Margaret King Education Scholarship for a family member of someone with haemophilia was awarded this year to Laura Egan. Laura has two brothers with haemophilia. Michael Davenport presented the award to Laura who is studying Applied Social Science in Galway.

Just before some excellent musical entertainment from Liam O'Sullivan and Frank O'Connor, otherwise known as the B Sharps we were treated to a very special performance from the Kidlink group who had attended Clown School in the afternoon. This was a real treat and showed clearly the enthusiasm the young members bring to everything they do in the Kidlink programme. The B Sharps music encouraged lots of people to take to the dance floor for the rest of the evening.

Despite the late night there was an excellent turnout for the presentations on Sunday morning. Dr. Paul Giangrande's session for women with bleeding disorders was an excellent informal session and I think those attending were very glad to have the opportunity to have their questions answered.

Michele Tait, National Hepatitis C Liaison Officer, gave a very comprehensive outline of HAA Card entitlements and was happy to answer individual questions. A new up to date information booklet on all services and entitlements available to HAA Card holders was also available.

The conference ended with an open forum where members could address specific issues with members of the comprehensive care teams from St. James' and Our

Lady's and our thanks must go to all the team members for their time and expertise at this important session.

We would like to record our thanks to all speakers and to the members for your attendance at all the presentations. In preparing the programme we try to have something of relevance for everyone and we rely on your feedback to help in putting together future programmes. The evaluation forms which you have been requested to complete give us a much clearer picture of what topics you would like to see included in our programmes and this in turn forms the basis on which we plan for future events.

**Margaret Dunne**



Dr. Barry White, Director, NCHCD at AGM 2008



Raymond Bradley presenting Michael Davenport with Waterford Crystal marking the 40th Anniversary of the IHS



The boys....



I.H.S. members at AGM 2008



## AGM Photo Gallery.....



Kidlink Girl Power



Irene Clarke recipient of the 'Maureen Downey Scholarship' with Pat Downey



Mary Harney, Minister for Health & Children at our AGM



Michael Walsh, Fundraiser of the Year being presented with his plaque by Grace O'Sullivan



Claudia Black, CEO (WFH), Brian O'Mahony, CEO (IHS) & Dr. Barry White, Director (NCHCD)



Michael Davenport presenting Laura Egan with the Margaret King Educational Scholarship Award



The Celtic Tiger



That piece goes there...

# Consultative Council on Hepatitis C: Information Day

The Annual Information Day organised by the Consultative Council on Hepatitis C was held in Croke Park on Saturday February 16th. The Plenary Lecture on the Hepatitis C Database (which was covered in our last newsletter) was followed by a number of workshops. The workshop on family matters raised a number of issues including communicating with adults and children regarding Hepatitis C, communications between parents and children, and coping with resentment from children due to the parent not being able to participate fully in their lives because of the debilitating effects of Hepatitis C.

An interesting workshop was held on the subject of using the Fibroscan machine as a possible alternative to liver biopsy. The Fibroscan is an ultrasound based technology which measures liver stiffness. The greater the degree of fibrosis in the liver, the greater the degree of stiffness in the liver tissue.

The Fibroscan is a non invasive technique and involves sending a mechanical wave through the liver, followed by an ultrasound wave which measures the outcome and speed of the mechanical wave. The procedure has the advantages of being non invasive, can access a large sample across the liver, you can take multiple regions from the liver, and the results are immediate. The technique was said to be useful at excluding cirrhosis and useful in staging fibrosis in combination with blood tests.

**"It certainly appears from the workshop that the availability of Fibroscan machines would be a very useful addition to diagnostic testing techniques for persons with Hepatitis C."**

A Fibroscan will also appear to have a greater degree of accuracy at higher levels of fibrosis than at lower levels of fibrosis. It certainly appears from the workshop that the availability of Fibroscan machines would be a very useful addition to diagnostic testing techniques for persons with Hepatitis C. We are currently waiting on the purchase of a Fibroscan machine for St. James's Hospital.

The Information Day was as usual a very good opportunity for members to update themselves with regards to many aspects of Hepatitis C. There were 8 people with haemophilia in attendance, and we would strongly encourage all members with Hepatitis C to actively consider attending this Annual Information Day in the future.

**Brian O'Mahony**





# A guide to the Health Amendment Act Card

## What does it entitle me to?



Michele Tait, Hepatitis C  
National Co-ordinator

**A**s most of you may be aware, the Health Amendment Act of 1996 set out the legal framework for a range of healthcare services to be established and provided to all men, women and children who had been infected with Hepatitis C as a result of administration within the State of contaminated blood and blood products. All men, women and children infected with Hepatitis C via contaminated blood and blood products are entitled to a Health Amendment Act (HAA) card which gives them access on a statutory basis to a wide range of primary care and hospital based services. For those of you who may be unsure whether or not you are entitled to a card, you can contact me in private on 01 6201750 to discuss your eligibility.

The HAA card is one of the most important cards awarded by the HSE as it gives entitlement to a range of services for the lifetime of the cardholder. It is completely separate to the medical card, GP visit card and Drug Payment

Scheme (DPS) card; however, we do advise our HAA cardholders to retain any of the above health cards they might have, as these may be useful for other family members in certain circumstances. If HAA cardholders already have private health insurance they may wish to retain this also as hospital services covered with the HAA card are within the public hospital setting only.

Once you are awarded the HAA card, you will also be assigned a Hepatitis C Liaison Officer within the HSE area where you live. Their role is to ensure you can access all of the health services to which you are entitled to and also to provide you with information, advice and assistance in relation to service providers.

For example your Liaison Officer can assist you in locating a dentist, physiotherapist or chiropractor in your area and will make arrangements for them to be paid for providing you with care. If you wish to have your entitlements administered by a Hepatitis C Liaison Officer outside of the area where you live, that can be arranged for you. Likewise, if you prefer for us not to correspond with you or have information sent to an alternative postal address, we would be very happy to facilitate this. It is very important that you keep in contact with your Liaison Officer in relation to any queries

or concerns that you might have, they are there to support and assist you and above all, any information discussed or exchanged between you remains completely confidential, I can assure you of this.

During the latter part of 2007, new look HAA cards were sent to all existing cardholders to replace the old blue card, which had been in circulation since 1996. The new card is modern in design and definitely more discrete as it is the size of a credit/bank card and can be very easily stored and kept secure.

The new HAA card is bright orange with the Consultative Council sunflower logo. If you still have not been sent your new HAA card, please let your Liaison Officer know (telephone numbers below) and they will make arrangements to have one sent to you.

### So what exactly does the HAA card entitle me to?

The Consultative Council on Hepatitis C recently published an updated guide to services, which explains in great detail each part of the HAA scheme and goes through each of the entitlements individually. This guide was launched at the annual Information Day on Hepatitis C which some of you may have attended in Croke Park. The Hepatitis C Liaison Officers will soon be making arrangements to have the new guide issued to all HAA cardholders as well as a range of the service providers whom we work with.

**Within the community setting, i.e. outside of hospital, as a HAA cardholder you are entitled to the following:**

GP services, all prescribed drugs, medications, aids and appliances. Dental services, optical and aural services, physiotherapy, counselling, chiropody, home support, home nursing and complementary therapies. You will need to produce your card when accessing services in some cases, particularly if you have not attended the service before, however, the best advice is to keep your card with you at all times in case you are asked to produce it. Your HAA card has a unique 6-digit number beginning with the letter R e.g. R98765. This number is used by the HSE in order for us to re-imburse the service providers providing you with care:-

- In the case of GP services, you are entitled to attend any GP of your choosing free of charge, the GP can then claim re-imbursement from the HSE.
- All prescribed drugs and medications once on a prescription are provided to you free of charge. Again the pharmacist claims re-imbursement from the HSE. We do not wish for any HAA cardholder to be prevented from receiving any prescribed drugs and medications which they are entitled to receive and we certainly do not wish for a HAA cardholder to be placed in a situation where they are explaining their entitlements to any service provider so what we are advising all HAA cardholders to do for any service area where they run into difficulties is to contact their Liaison Officer in the first instance or alternatively let the service provider deal with the Liaison Officer directly.
- Chiropody services are provided free of charge, you do not need a referral and can attend whenever you need to do so. Your Hepatitis C Liaison Officer can provide you with details on Chiropodists in your area or alternatively you can attend a chiropodist of your choice once you have given us copies of their qualifications as they need to be accredited to one of the accrediting bodies for Chiropodists. Further details can be found in the guide to services.
- Counselling services are provided without charge to all HAA cardholders and also their immediate relatives. The Hepatitis C Liaison Officer in your area will provide you with details of counsellors in your area or alternatively you can attend a counsellor of your choice. We do require the counsellor of your choice to be accredited to certain professional bodies and further details on this can be found in the guide to services or by speaking to your Liaison Officer.
- All routine and emergency dental treatments are covered without charge with the HAA card and we try to encourage cardholders to attend dentists already on contract to the HSE via the DTSS (Dental Treatment Services Scheme) however, if you have been attending a dentist not on contract to the HSE and wish to continue doing so, you should talk to your Liaison Officer who will be happy to assist you in continuing care with your dentist. Cosmetic type dental treatments are generally not covered, however, full details on dental entitlements are covered in the guide to services and any questions you have should be referred to your Liaison Officer.
- Physiotherapy services provided by chartered physiotherapists are covered by the HAA card, your Liaison Officer will give you details of physiotherapists in your area and further details on physiotherapy services are outlined in the guide to services book.
- Aids and appliances are covered by the HAA card and these must be prescribed by your GP, Consultant, Occupational Therapist or Public Health Nurse/Clinical Nurse Co-ordinator. There are many different aids and appliances used nowadays by people to assist them inside and outside their home with mobility, movement etc. These include walking sticks and frames, wheelchairs, grab rails, shower seats, bath and bed hoists etc. Depending on your need, the GP/Consultant/ Occupational Therapist will decide what suits you best. Further information on what is covered by the HAA card and how to access aids and appliances is available from your Liaison Officer.
- Complementary therapies currently covered under the HAA card are reflexology, aromatherapy, massage, acupuncture and hydrotherapy. HAA cardholders need to be referred by their GP/Consultant in order to avail of this service and the Hepatitis C Liaison Officer will either arrange to pay the therapist directly on your behalf or else will re-imburse you on production of receipts etc. Only complementary therapists who are already registered general practitioners (i.e. RGN's, GP's, Chartered Physiotherapists or for reflexology, Chiropodists) can work with HAA cardholders, you may attend a therapist however who is not qualified in one of these professions if you wish, but your card will not cover you.





In any case or if you are unsure about whether or not your therapist of choice can be used you should speak with your Liaison Officer. The use of complementary therapies as an area of healthcare continues to become more in demand by the HAA cardholders

- Optical services are provided to all HAA cardholders and cover any optical services, which are clinically necessary, including the cost of your eye examination and whatever lenses you are prescribed. As a HAA cardholder, you are entitled to choose frames up to a value of €90 and anything above that cost you will be liable for yourself.

Whatever lenses you require are covered also, if you wear bifocals or varifocals there is a maximum grant of €250 (including frames) which you are allowed per pair and if the cost is more than this as a result of the lenses being more expensive, you will have to pay the balance to the optician and seek re-imbursement from the Liaison Officer. The grant of €250 should be sufficient to cover the full cost of a pair of varifocals. You are entitled to 2 pairs of glasses every 2 years; however, if your prescription changes within the 2 years you are

entitled to new glasses. Contact lenses are also fully covered if there is a clinical reason why you need to wear them, however, if you wear them by choice you will only get an initial supply every 2 years. For further details on this and all aspects of the optical services covered, please refer to the guide to services and of course speak with your Liaison Officer.

- Access to a home support service is available to all HAA cardholders who require assistance in carrying out their normal household duties and this can mean many different things depending on the needs of each individual person. Basically there are 2 options, which can be discussed with your Hepatitis C Liaison Officer. One is where the HSE provide you with a home support worker who remains the employee of the HSE and the other is where you can choose someone yourself to assist you around the home and the HSE pay you a cheque based on a recommendation from your GP/Consultant outlining the number of hours required per week. Further information on how home support may be accessed is available from your Liaison Officer and described in detail in the guide to services booklet.

- Home Nursing is available to all HAA cardholders who require nursing care at home as a result of any condition and not just those related to Hepatitis C. A Clinical Nurse Co-ordinator has been appointed within the HSE whose role is to co-ordinate and develop the home nursing service. Further details are available from your Liaison Officer or from Maria Breton, Clinical Nurse Co-ordinator Hepatitis C tel 01 6201803.

### What about hospital services?

Hospital services are available to HAA cardholders through the 8 designated units, which have been set up especially to look after hospital-based care for individuals infected with Hepatitis C.

There are very specific entitlements attached to your hospital care including a designated hepatology clinic, which takes place on days set aside for HAA cardholders only. The entitlements within the hospital setting in summary are as follows:

- Open access to hospital facilities for Hepatitis C or any related condition, including the right to a public hospital bed without charge.
- HAA cardholders should not have to wait more than two weeks for an appointment with their liver specialist and also for the first referral to another specialty, this is generally referred to as the "two week rule" Once a patient is referred by the Liver Consultant to another Consultant in a public hospital for the testing, investigation or treatment of any condition, they have to be given a first appointment within a 2 week period.

Delays with this should be explained to you and should you have any queries regarding the timeframe in which your appointment is being arranged you should speak to the hepatology nurse in your hepatology unit or you may contact me in the HSE at 01 6201750.

Further details on hospital entitlements are described in the information guide to services or by contacting me on 01 6201750. I hope this gives you a clear picture on exactly what the HAA card entitles you to. There are some important points, which should be remembered by you for the future.

**1.** Know who your Hepatitis C Liaison Officer is for your area.

**2.** Any queries or concerns you have regarding your entitlements should be discussed with your Liaison Officer who is there to help and assist you.

**3.** Any information discussed with Liaison Officers remains completely confidential.

**4.** Your HAA card is awarded for your lifetime and is a very valuable card.

**5.** If you lose your HAA card or if you move address, it is important that you inform your Liaison Officer immediately as your R number will be cancelled and you will be issued with a new one.

**6.** You should not have to resolve any difficulties yourself or explain your entitlements to any health-care professional and the HSE will make every effort to ensure that all HAA cardholders are afforded this courtesy.

Finally, I would like to add that the range of services available to you are there for you to access as often as you need them. The HAA scheme was set up to ensure you are provided with as many health care services as possible and the Liaison Officers work very closely with each service provider to ensure you are looked after. I am very grateful to the Irish Haemophilia Society for allowing me an opportunity to describe your entitlements in detail and also to tell you a little about what we do. I am also very happy to acknowledge the excellent work your organisation does on your behalf in monitoring all of the services we provide and in giving us your feedback and concerns. I think I have met quite a lot of you in my time as Liaison Officer and for those of you I haven't met personally yet, I look forward to that. My contact details are: **01 6201750 / 087 9061878** or you can email me at **michele.tait@hse.ie**.

**Michele Tait,  
Hepatitis C National Co-ordinator,  
Health Service Executive**

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## An Update from our Chief Executive

The AGM and Conference was held in Dublin this year in the new Park Plaza Hotel, in Tyrrelstown. It was a special event this year, given that it was the 40th Anniversary of the Irish Haemophilia Society. Full reports and coverage of the AGM can be found elsewhere in this newsletter, but I want to give some personal impressions of the meeting.

The hotel was new, modern and somewhat isolated, which in fact is often an advantage as it engenders a sense of togetherness over a weekend. (In other words there are less opportunities for people to escape to go shopping!) The hotel perhaps is in contrast with the Society which is 40 years old, although I believe we are modern and are not isolated from the community of people we represent, or from the broader issues in Society with which we have to contend. The symposium on Saturday afternoon was opened by the Minister for Health and Children, Mary Harney. The Minister in her remarks made it clear that the building of the proposed National In-Patient Unit in St. James's Hospital Dublin, which would be an in-patient facility for people with haemophilia from all parts of the country, would be a priority for 2008. This was important.



Mary Harney, Minister for Health & Children with Brian O'Mahony and Michael Davenport at our recent AGM

**"If building  
is initiated  
this year,  
it should  
be opened  
in early  
2010."**

The unit was first proposed in 2003 and was accepted by the Department of Health and subsequently by the Health Service Executive. In 2006 when we met with the Minister for Health & Children she confirmed that the building would proceed directly from design and planning stages to being built. The building is at design stage and is now going to planning stage. We want to ensure that the building work is started in 2008. The fact that the building is in the HSE budget for capital projects for 2008 does not necessarily mean it will go ahead this year. We want to do everything possible to ensure that in fact this is the case.

If building is initiated this year, it should be opened in early 2010. We are very excited about the prospect for this new In-Patient Centre which will provide 6 specific beds for persons with haemophilia and related bleeding disorders, and an additional 8 beds for hepatology. The design and fit out of the unit would be to a much higher specification and standard than previously seen in St. James's Hospital. A very good explanation of the requirement for this new In-Patient Unit was delivered by Dr. Barry White in his lecture on Saturday afternoon on the 'Future of treatment in Ireland'.



Young members at the AGM



What a weekend!

The symposium on Saturday afternoon which had the theme of 'Past, Present and Future' delivered an afternoon of contrasts. As I spoke about the history of the Society over the 40 years and showed several photographs of activities over those years, and of members who had been involved in those activities, I could see that a number of those present were moved by seeing pictures of friends and of family who had passed away. My presentation finished with a video clip of the speech delivered by President McAleese at the opening of the I.H.S. office in June of last year. She conveyed perfectly the sense of continuity and the sense of history which has brought us to this point, and which has made the Society the organisation it is today. This was followed by a lecture from Claudia Black, the Chief Executive of the World Federation of Haemophilia on the situation in the developing and emerging countries. In a sense this is intertwined with history as I have often felt that the situation currently in many emerging or developing countries is similar to the situation we faced in Ireland back in the 1960's or 1970's.

Dr. Barry White spoke with enthusiasm about his hopes for the future of treatment in Ireland and we are working closely with Dr. White and with the clinicians from Crumlin

and Cork through the National Haemophilia Council to make sure that resources are in place over the coming years, to enable the comprehensive care centres in St. James's, Our Lady's Hospital in Crumlin, and Cork University Hospital provide an optimum service to people with haemophilia.

While the adults were engaged in this symposium the children and teenagers were having great fun at the 'Clown School'. (Perhaps next year we can have lectures for the children and teenagers and the adults can have a fun activity such as 'Clown School' - wishful thinking?)

On Sunday morning Dr. Paul Giangrande gave an excellent presentation on issues for carriers and women with von Willebrands Disease, and Michele Tait the Chief Hepatitis C Liaison Officer from the HSE gave an excellent update and explanation of the benefits available to relevant members from the HAA Card.

Several of the evaluations we received from last years meeting from members stated that they wanted more interaction at the AGM with the Health Care Workers from the centres and an opportunity to ask questions about the services and treatment available.

To this end the last session on Sunday morning was an 'Open Forum' discussion with several members of the comprehensive care teams from St. James's Hospital and Our Lady's Children's Hospital in Crumlin. The panel members were from St. James: Olwyn Halvey (Social Worker), Alison Dougall (Dentist), Emma Sherlock (Physiotherapist), Sarah Jamieson (Psychologist), and Ann O'Sullivan (Haemophilia Nurse Specialist), and from Our Lady's Children's Hospital were: Dr. Beatrice Nolan (Consultant Haematologist), Mary Kavanagh (Haemophilia Nurse Specialist), Imelda Kelly (Haemophilia Nurse Specialist) and Diarmuid O'Riain (Physiotherapist). Each of the panel briefly introduced themselves and then fielded a number of questions from members in relation to services and treatment of care. I believe this was an excellent session which gave many of the members an opportunity to raise issues either in person or anonymously by questions submitted in writing. The session gave the Health Care Workers an opportunity to introduce themselves to members who had not met them and it gave them an opportunity to see the kind of issues which are exercising the minds of members at this point in time.

The highlight of the weekend was the Gala Dinner on Saturday night. This was attended by over 200 members and their families. For the first time the adults and children all dined together and this was a great success. The vast majority of members who filled out the evaluation forms viewed the majority of the sessions as excellent or very good. Roll on the Members Conference in October!

The Insurance Scheme for members with Hepatitis C and or HIV started on September 12th 2007. Some 146 members are eligible to take out Life Insurance, Mortgage



Insurance, Re-mortgage Insurance and Travel Insurance under this Scheme. At the time of writing approximately 35 - 40 members have taken out insurance under this Scheme. Up to recently only one Insurance Company - Eagle Star, was an approved insurer under this Scheme offering Life Insurance, Mortgage Insurance and Re-mortgage Insurance. They have now been joined by a second insurance company Bank of Ireland. Members who wish to avail of insurance under this Scheme can contact Eagle Star directly or through a broker, or can contact Bank of Ireland directly. Bank of Ireland will not deal with brokers for this Scheme.

We were unhappy with the fact that Bank of Ireland would not deal with brokers as to date the majority of

our members who have taken out Life Insurance under this Scheme have done so utilising a firm of brokers who have specific knowledge of this Scheme. However we are working with the Bank of Ireland to ensure that members who wish to approach them in relation to a quote for insurance may if they wish deal with one of only four designated individuals in the country (in Dublin, Cork, Limerick and Galway). We will assist and facilitate our members in setting up these appointments where they require our assistance. We wish to ensure that all members who are eligible to avail of insurance under the Scheme are fully aware of the Scheme and have an opportunity to at least consider taking out Insurance under this Scheme in the first year of operation of this Scheme.

(The benefits available under this Scheme are optimised if insurance is taken out before September 11th 2008). To this end we will be organising further specific meetings on insurance during the months of April and we will be contacting members by mail in relation to these meetings.

In the meantime any member who wishes to find out more about the Scheme or who would like to make an appointment to avail of a specific consultation in relation to this Scheme can contact Anne Duffy at the I.H.S. office.

**Brian O'Mahony**

## A word of thanks.....



I am so grateful to the Irish Haemophilia Society for the amazing contribution I received in October 2007, when I was selected as the recipient of the Maureen Downey Memorial Grant for 2007/2008. When I first applied for the grant I never expected to be the recipient of this prestigious award. I can't begin to explain how much this grant has helped me in my first year in college.

I am studying Art in Ballyfermot College of Further Education, with a view to going on to do Art Teaching.

I have recently submitted my Art portfolio to the National College of Art and Design (NCAD) where I would like to be accepted so I can pursue my dream of becoming a Secondary School Art Teacher. I am very passionate about Art and I love my course in Ballyfermot. It is a very costly course as art materials are very expensive. The grant has allowed me to purchase whatever supplies I need without being dependant on my parents all the time.

Not only have I dealt with having von Willebrands Disease, but I have battled with dyslexia throughout my school years. I found school very tough going, but I was very lucky to have the support of the Dyslexia Association, who helped me through it. I have worked hard and will continue to do so to achieve my dream. And thanks again to the I.H.S. for giving me this substantial grant which has helped me and will continue to do so until I have completed my studies.

**Irene Clarke**



**Debbie Greene in conversation with  
Mark Skinner,  
President of the World Federation of Haemophilia  
on his recent visit to Ireland.....**

**Perhaps we can start with your background?**

I grew up in rural Kansas, in a small farming community with a population of about 4,000. I have one older brother. We both have severe haemophilia A. We have a family history of haemophilia. Two great uncles died from haemophilia related complications. I really didn't know anyone else other than my brother with haemophilia until I was in my late teenage years. Essentially I lived alone with haemophilia. I was born in 1960. At that time, the only treatment available was fresh frozen plasma, and whole blood. As a child I had quite a few problems with my joints. By the time I was in the first grade, I was wearing a brace on my leg, using a wheelchair and was told I would never walk again without support. However, life progressed and with the arrival of clotting factor concentrates, and home treatment, things certainly improved. Since then and because of all the joint damage that I had developed during childhood, I have had both knees replaced, both ankles fused, and my elbow rebuilt twice. Then of course there was the cycle of the 1980's. The arrival of treatment that gave me freedom, allowed me to walk again and to be successful, but also brought the complications of HIV and Hepatitis. So that's really my background.

**How and why did you become involved with WFH?**

I am involved because firstly I know life can be better. I have seen both sides - life with and without access to treatment. In addition, with the awful tragedies of the 1980's and 1990's, we can and need to prevent them from repeating around the world. Therefore, it's kind of twin motivation, which really comes from my experiences growing up.

My first involvement began with the National Haemophilia Foundation (NHF). I had graduated from law school and was serving as Chief of Staff for the Speaker of the House of Representative. Towards the end of my legislative work, I got involved with a couple of the doctors, and we enacted a state haemophilia programme for Kansas to provide cover and insurance support for those with a low income. That was my first involvement, which was in 1984. I did go to the occasional NHF Annual Meeting, but I really wasn't involved. Later, the NHF had a call for national elections. NHF was changing from a self-electing board to open elections within the haemophilia community. My mother was reading the NHF newsletter and said to me "you should apply for

that". One of the things they outlined was that they wanted somebody with government or advocacy experience, so my mum reckoned I was a good candidate. At that point I had moved to Texas and my job was in government affairs. I worked for the American Insurance Association and managed government affairs. The NHF elections were public among the haemophilia community, and I really wasn't widely known. Anyway, the ballots went and low and behold I was elected. So I kind of came out of nowhere for many people. In 2000 and 2001 I was elected President of the board. Shortly after I was on the board I became involved in the NHF Advocacy and Blood Safety Committees, both of which I ultimately chaired. Towards the end of my service on the NHF Board, I became involved with the WFH Blood Safety Committee, which evolved into my being asked to join the WFH Executive Committee and later being elected President.

### **Could you elaborate on your vision 'Treatment for All?'**

I think one of the wonderful things about the message 'Treatment for All' is that there is something in it for everybody. One of the things that I stress, in particular in countries who don't have as many economic resources, is that treatment is not just about treatment products. You can do an awful lot if you organise care, provide basic knowledge, and physical therapy support. 'Treatment for all' to me also means comprehensive care. Organisation of care can make great differences in somebody's life. It also means that we take care of everybody in our community. I do believe that one day treatment is going to be available for everyone. The most important thing about our vision is to understand the goal, help people advance along the development continuum, and for them to recognise that treatment improvements will come incrementally. It took us 40 years to get where we are now in the US. The exciting thing today is that around the world a lot of countries are moving at much faster pace. One can look at countries like the US or Ireland or other parts of Western Europe or Australia and say you have it all. However, we know we each took a similar amount of time to get to the level of care we now have as well. We didn't get to this level overnight. Then you look at the speed that some of the other countries are developing and it gives us great hope.

### **How can the I.H.S. help?**

One of the remarkable things about the Irish Society, and I am sure certainly part of it is Brian's involvement here, is that Ireland has a vision of the world. The Irish Society, your members and all those that I

have come to know here in Ireland, have an interest in giving back to the rest of the world, a kinship and feel an obligation to help those less fortunate. It is truly amazing and true leadership. We would love to have other National Organisations do some of the things that Ireland is doing. That's not to mean that others aren't doing a great deal of work, but Ireland is leader. For one, the financial commitment that Ireland has made to provide support for WFH programmes such as the Global Alliance for Progress is greatly appreciated. We want Ireland to be an example. Then we also have the Twinning Programme, the fellowships, and the product donations. I think what a lot of National Organisations don't realise is how much they get back from giving. It's such an enriching experience. It can be very difficult to comprehend for most what treatment was like 40 years ago versus what it is for us today. For someone born and growing up with haemophilia today, someone who has always had treatment available, it is very difficult to appreciate what it really meant to have haemophilia back then, or what it is like in a country today without treatment. The international exchange and collaboration really helps put it all in perspective.

### **Your four year term as President ends this year, do you think your Presidency has been a success?**

Well it's hard to judge yourself. I did set several goals when I was elected President. One was to increase fundraising. The organisation is very sound right now. Our corporate sponsorship and diversified fundraising have grown, and we have multi year commitments from our sponsors. This has allowed us some luxury to plan and build for the future as opposed to constantly chasing dollars. In the last couple of years, we solidified many of the advances that occurred under Brian, and then as part of our new strategic plan guaranteed that the core funding was available for several years to come allowing us to grow. We have consolidated and now are building again on a secure base. We were previously budgeting from year to year.

One of my other interests was finding a way to take WFH closer to the National Organisations to get more people involved, so we have taken a number of steps. For example, the regional training programmes that we have been doing in Europe and now hope to do around the world. The global training is wonderful but we need to continue to find new ways for the WFH to be present locally. The last goal was to develop a strategic plan, and set a course that unifies everyone. I don't take credit for the words 'Treatment for All', they didn't come from me, but I



do think it certainly is becoming a unifying message for the whole community. We have made good progress in those three major areas, but of course the work never ends. There is not a lot of instant gratification. Improvements come slowly, but the good thing is that we do see progress all around the globe. The small victories are what make volunteering rewarding, in that you see you have made a difference. Not me personally but the WFH has made a difference in somebody's life.

Our mission is not to save each individual life: our mission is to improve skills and capacity for sustainable care over a lifetime. When that happens, to me it is a good assessment that we are on the right track. You certainly get gratified when you see people, particularly over a couple of years, and you realise how things are improving.

**Having already been President for several years, if re-elected what new policies or changes would you like to implement, or are you happy to continue in the present direction?**

The call for elections is in the Spring and I anticipate that I will be running again. I think that we have a good strategic plan, and it clearly was not all going to be accomplished over 3 years. I would see that next fall we would up-date the strategic plan. A lot of it will be an extension of what we are doing and where we are trying to go. We have implemented several new programmes that we are really just launching. For example, the way the world communicates, changes all the time and that requires constant evaluation of our work. Everything from Pod Casts to YouTube to all of the other ways that people learn today is different. Technology will guide some of what we do, and it may make it more economical for us to reach more parts of the world.

I am constantly amazed how wired some parts of the world are when you would not perhaps anticipate this. Some are skipping all those intermediate development steps that Ireland and US went through and now have great access. Using new tools to reach our community is important, we must also be mindful that not every country has internet access. Beyond that, I also think that the organisation can do more

**“Our mission is not to save each individual life: our mission is to improve skills and capacity for sustainable care over a lifetime.”**

to encourage or support research. The WFH is not going to be a primary research organisation but we do have a role. I think through our Medical Advisory Board we could set a vision of what some of what some of the critical research questions are that we believe if answered, would significantly advance care globally. Then our task will be to persuade others to tackle the problems. Of course, we want to find a cure, but also there are some other very important questions that haven't been answered.

For example, inhibitors, what's the best way to predict, prevent, manage or overcome an inhibitor? Inhibitors are the greatest treatment risk that a patient with haemophilia faces today. We can take on such messages and highlight their importance. It is worth noting that since we have started talking about rarer disorders there is a lot more interest on the part of companies and government regulators. Patients and those interested in helping them, now feel like they have a home and somebody who is out there supporting them.

I don't think we can underestimate the podium that WFH has to send a message around the world. As our newly reorganised and invigorated Medical Advisory Board advances, I believe we should identify such key issues and lend our support. Overall, I don't see great changes, but I do see us building perhaps a couple of new areas and adding a few new dimensions to our work.

**Thank you Mark, it has been a pleasure talking to you.....**

# Noticeboard

## I.H.S. receives donation from Hospital Saturday Fund

The Irish Haemophilia Society was the beneficiary of a donation from The Hospital Saturday Fund Charitable Trust at an event in the Mansion House recently.

Our CEO Brian O' Mahony received the donation on behalf of the Society from Vice-President of the Fund and The Lord Mayor of Dublin, Cllr Paddy Bourke.

The donation was put towards the Kidlink Programme at the AGM last month. We would like to thank The Hospital Saturday Fund for this very generous donation in the amount of €1,500.00.



The Lord Mayor of Dublin presenting Brian O'Mahony with the cheque for €1,500.

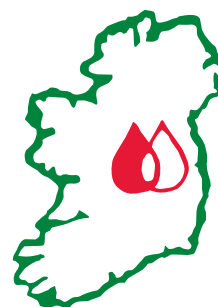
## Introducing...



As most of you know our Kidlink and Youth Group Co-ordinator Alison Daly has been expecting her first child, and we are delighted to announce that Alison gave birth to a beautiful little baby girl on 20th March.

We would like to send many Congratulations to Alison and her partner Steve on Kitty's arrival.

## Membership Fees Reminder



If you have not yet paid your Membership Fee for 2008, we would ask you to do so as soon as possible. The Current Membership Fee is €30 per year, and Life Membership is €650.

You can pay by cheque, or if you wish we can accept laser or credit card payments.

# Safety & Supply Update: News from Home & Abroad

## US Senate votes on HIV Visa Waiver issue

The HIV Visa Waiver Scheme has operated for persons with HIV entering the United States since the 1980's. This has caused difficulties for people with haemophilia and others on many occasions. President Bush promised to take action on this over 2 years ago, but no action has been taken until very recently. In the last few weeks the President's Aids Bill was being enacted by the US Senate. Senator's Kerry (Democrat) and Gordon (Republican) attached an amendment to the Bill proposing that the HIV Visa Waiver provisions would be repealed. This measure was passed by the US Senate. The bill was subsequently passed by the US House of Representatives and we must now wait to see if the amendment as proposed by the Senator's will be implemented.

## New Recombinant Factor VIII licensed in USA

Wyeth has received US FDA approval for a new recombinant Factor VIII concentrate which is manufactured using a completely albumin and plasma free process. Like its predecessor product ReFacto, Wyeth's XYNTHA (pronounced "ZIN-tha") is a B-domain-deleted Factor VIII, and is indicated for control and prevention of bleeding episodes and surgical prophylaxis. Like other recombinant Factor VIII products, it does not contain von Willebrand Factor. XYNTHA had been identified by the working name "ReFactoAF" in earlier communications by the company. According to Wyeth, XYNTHA is the only recombinant Factor VIII product to utilize an entirely synthetic (non-human and non-animal based) purification process in its manufacture.

Additionally, the company has substituted the use of a synthetic peptide ligand for a mouse monoclonal antibody as a means of separating the Factor VIII protein during manufacture; Wyeth invented its new ligand specifically for this purpose. Xyntha is a third generation Recombinant FVIII and is expected to be licensed by the EMEA for use in Europe before the end of 2008, and available in Europe in early 2009.

## EU Commission & Voluntary Unpaid Donors

In February an organisation representing some blood donors - The International Federation of Blood Donor Organisations (IFBDO) - wrote to the European Commission expressing concern that many European Countries are dependent on imported plasma products which are manufactured from the plasma of paid donors from abroad.

This intervention from the IFBDO clearly demonstrates their inability to distinguish between blood products and plasma derived products. Fresh blood products in Europe are primarily sourced from the plasma of voluntary unpaid donors. A majority of plasma derived products which are manufactured, are derived from the plasma of voluntary paid / remunerated donors from abroad. This has been the situation for many years.

Plasma which is collected from voluntary remunerated donors in the USA, Germany and Austria is generally collected under quality plasma programmes, which ensure that the donors are repeat donors and are extensively tested and screened. There are no large numbers of voluntary unpaid or unremunerated plasma donors available in the world. It is entirely unreasonable and unrealistic to suggest that Europe could be supplied with plasma derived factor concentrates, immunoglobulin and other plasma products without utilising the plasma of voluntary remunerated donors.

This proposal from the IFBDO was strongly opposed by the European Haemophilia Consortium, the World Federation of Haemophilia, and the umbrella organisations internationally represented people with primary immune deficiencies and alpha-1 Antitrypsin deficiencies. (These are the other patient organisations whose members rely largely on plasma derived products).

We have been in touch with the European Commission to ensure that when issues like this arise in the future, the organisations representing recipients of the products should be consulted in addition to the organisations representing the donors of the products.



### Blood components reached dangerously low levels in France

As inventories of blood components reached dangerously low levels in France in late 2007, the Etablissement Français du Sang (EFS) launched a series of large scale, nationwide donor recruitment campaigns, making use of all the major media, including the internet. As a result, inventories increased by 66% in the three weeks following the first large-scale campaign in January 2008. Other measures were adopted, such as opening new blood collection sites in more convenient locations for prospective donors, and targeting recruitment messages to students and other young people.

Between 2006 and 2007, blood transfusions increased by about 5% in France: several decades after the AIDS crisis, physicians have become confident in the safety of the domestic blood supply, and more willing to prescribe blood products. At the same time, as the population is aging, the number of patients requiring blood or components has gone up, while new disease conditions requiring blood transfusions have emerged. Blood and components collections have increased accordingly, as reported by the Etablissement Français du Sang (EFS).

### European Conference on Communicating Risks to Patients with Chronic Diseases

A conference organised by the European platform for Patients Organisations Science and Industry (EPPOSI) was organised under the patronage of the European Commission in December 2007. The conference had 2 co-chairs representing patients, science and industry. I co-chaired the conference as the Patient Representative. In the introduction to the conference report (*available on the I.H.S. website [www.haemophilia.ie](http://www.haemophilia.ie)*) I pointed out that the devastation caused to the haemophilia community in the past was greatly exacerbated by lack of understanding of the risks, lack of co-ordination in responding to the threats and poor communication and that lessons have been learned and must be applied. The conference included sessions on, 'Critical elements in informed consent', 'Optimising communication on risks, safety and benefit of therapy'. There was also an examination of case studies which included looking at foreseen risks, unforeseen risks (*the risk of lipodystrophy in HIV*) and theoretical risks which becomes real (*the risk of vCJD transmission from blood transfusion*). The outcome of the conference was a list of recommendations which included:-

- *Properly informed patients should be the final arbiter of acceptable risk.*
- *Patients have a fundamental right to information.*
- *Patients decisions about what risks are acceptable can change over time.*
- *Honest, open and transparent communication is required.*

The conference recommendations also looked at the setting up of various consultation mechanisms with the European Commission to ensure that the view points of patient organisations are listened to and acted on, on a proactive basis. Copies of the conference report are available free of charge from the I.H.S. office.

**Brian O'Mahony**

## Hubert Hartl - An Appreciation



It was with great sadness that we learned, in early January, of the untimely and sudden death of Hubert Hartl, the President of the European Haemophilia Consortium (EHC). Hubert had been a leader of the Austrian Haemophilia Society for many years and latterly was the President of the EHC from 2003. Hubert had great energy and he worked to increase the activities and influence of the EHC. He had a great love of life and I had the pleasure of hosting Hubert in Dublin three months before his untimely death for an EHC steering group meeting. Hubert is survived by his wife Monika and his treasured daughters Arlene, Katharina and Franziska. We will ensure that his contribution to EHC and to the Haemophilia community is appropriately acknowledged when the next EHC Annual Conference takes place in Dublin this September.

**Brian O'Mahony**

# Calendar of Events

## MAY

### Carrier Day

**Saturday 10th May**

**Venue: Offices of the I.H.S.**

We will be writing to members with full details of the programme shortly. Please also check website for further details.

### Benefits Days

**7th May - Dublin**

**21st May - Cork**

Confirmation of venues will be available soon and all members will receive written notification in the post.

## JUNE

### Mini Marathon

**Bank Holiday**

**Monday 2nd June**



Full details of this fantastic fundraising event can be found on page 2 of this magazine. In the meantime if you require any further information, please do not hesitate to contact the office on 01 6579900.

## JUNE

### Insurance Meetings

**20th June - Cork**

**21st June - Dublin**

We wish to ensure that all members who are eligible to avail of insurance under the Insurance Scheme are fully aware of the Scheme. For any member who would like to find out more about the Scheme, please contact Anne Duffy in the office on 01 6579900

Keep checking the website for further updates on these meetings.

## JUNE

### World Federation of Haemophilia

**Congress 2008**

**1st - 5th June, Istanbul, Turkey**

The WFH Congress 2008 takes place in Istanbul, Turkey. The Congress programme will feature internationally recognised experts in treatment and research making it the preeminent meeting for those interested in hemophilia and related bleeding disorders. WFH are expecting to welcome 4,000 health care providers, government officials, patients, and their families to Istanbul from more than 100 countries making it the largest and most comprehensive meeting anywhere. No other event brings together the entire bleeding disorders community. It's a great opportunity to exchange ideas and experiences, to learn more about the latest scientific advances and to support the global efforts of the WFH to close the gap in access and treatment for care around the world. The Congress Programme at a glance includes: Dental, Laboratory, Science, Medical, Multidisciplinary and Musculoskeletal Sessions.

The I.H.S. will be happy to provide information and logistical support to any member who might consider travelling to the Congress. Further information regarding the Congress can be found on: [www.hemophilia2008.org](http://www.hemophilia2008.org)

## JULY

### Tax & Investment Meetings

**10th July - Galway**

**11th July - Cork**

**12th July - Dublin**

We are planning a number of meetings for members in relation to Tax & Investment issues. We will have confirmation of venues available shortly.

## SEPTEMBER

### Insurance Meeting

**6th September - Dublin**

More details will be available soon.

# Calendar of Events

## SEPTEMBER

### **EHC Conference** **12th - 14th September** **Venue:** **Dublin Castle**

#### **Europe comes to Dublin!**

The European Haemophilia Consortium holds its annual conference in a member country. The conference will be held in Dublin from September 12th - 14th 2008. The programme will include lectures on the European Standard of Care, the Irish

Model of Haemophilia Care, Setting National Treatment Goals and Targets, and Reproduction and Haemophilia. The lecturers will include Professor Chris Ludlum from Edinburgh, Dr. Barry White from Dublin, Dr. Paul Giangrande from Oxford, Dr. Flora Peyvadi from Milan, and Professor Wolfgang Schramm from Munich in Germany.

Looking forward to welcoming all our European friends and colleagues to our fair city!

## SEPTEMBER

### **Carrier Day** **27th September**

We are hoping to organise another Carrier Day later on in the year in the Midlands area.

## SEPTEMBER/OCTOBER

### **Regional Visits** **30th September to** **3rd October**

We arranged regional visits in January and February and are hoping to do the same again later on in the year. All members are encouraged to attend these regional visits to hear updates on the Society's activities and to discuss any issues of concern.

## OCTOBER

### **Member's Weekend** **17th - 19th October** **Venue:** **County Arms Hotel,** **Birr, Co. Offaly.**



Sports Day at last years members weekend

Due to the ongoing and increasing success of this weekend for the past 2 years, we are pleased to announce that this excellent weekend for all members will take place again this year in the County Arms Hotel. We are at the moment in the process of planning an exciting programme with something of interest for everyone, including a programme for children over 11 years, at the Birr Outdoor Education Centre which is beside the hotel.

Full details of the programme will be available shortly. Please check the website for further details.

Places will be limited for this weekend, therefore we would ask you to return your booking forms as quickly as possible when they are posted out to all members during September.

## NOVEMBER

### **Parent's Day** **8th November**

For mothers & fathers of teenagers with a bleeding disorder age 12 and over.

## MARCH 2009

### **AGM** **6th, 7th, 8th March**

The dates are confirmed for next years AGM. We are busy trying to find a suitable venue for our biggest event of the year and would hope to have it confirmed very soon.





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