

Irish Haemophilia Society

Newsletter

Edition
Autumn 2007



IRISH HAEMOPHILIA SOCIETY
FIRST FLOOR
CATHEDRAL COURT
NEW STREET
DUBLIN 8
TEL: 01 6579900
FAX: 01 6579901

Website: www.haemophilia.ie
Email: info@haemophilia.ie

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“A Landmark Day for the Irish Haemophilia Society”



Luz Maria Heaney, President Mary McAleese and Conor Birkett
presenting the President with a bouquet of flowers

At last the big day had arrived. Thursday 14th June 2007, the day our Patron Mary McAleese, President of Ireland would officially open our new headquarters. The invitations had gone out, the catering, photographer and flowers were all ordered. I knew everything should go to plan, but just like organising any party I wondered had I done enough to make sure the day would be enjoyable and memorable for everyone.

[Margaret Dunne tells us more on Page 3]

MEMBERS WEEKEND 19TH-21ST OCTOBER 2007

**The Bloomfield House Hotel,
Mullingar, Co. Westmeath.**

PRELIMINARY ADULT PROGRAMME

Friday 19th October

- 17.30-19.00 Registration
19.00-20.00 Twinning Reception

Saturday 20th October

- 10.00 - 10.45 Haemophilia Quiz for adults and children
10.45 - 11.15 Tea/Coffee Break
11.15 - 12.15 Debate: Is Haemophilia a Disability?
12.15 - 1.00 Portacaths
13.00 - 14.00 Lunch
14.00 - 15.30 Fitness for living
15.30 - 16.00 Tea/Coffee Break
16.00 - 17.30 Fitness for living
19.15 Mass
20.00 - 23.00 Dinner & Rugby World Cup Final

Sunday 21st October

- 10.00 - 11.00 Update HIV & Hepatitis C treatments
10.00 - 12.15 Outdoor Games for EVERYONE
12.15 - 13.15 Open Forum - Services/Activities of I H S
13.30 Lunch and depart

CRECHE FOR YOUNGER MEMBERS UP TO SIX YEARS

Our experienced crèche supervisors will organise all activities for the two days for the younger ones and will make sure that everyone has a good time.

Crèche opening hours

Saturday 09.30 - 17.30

Sunday 09.30 - 12.30

KIDS CLUB FOR CHILDREN 7-10 YEARS

Saturday 20th October

- 10.00 - 10.45 Haemophilia Quiz
11.00 - 12.45 Kids Club
13.00 - 14.00 Lunch
14.00 - 15.30 Fitness for living workshop
16.00 - 17.30 Kids Club

Sunday 21st October

- 10.00 - 13.00 Outdoor Games

LILLIPUT ADVENTURE CENTRE - 11 YEARS & OVER

Friday 19th October

- 18.00 Dinner at Bloomfield Hotel then depart for Lilliput where you will stay until Sunday

Saturday 20th October

- A full day of activities

Sunday 21st October

- Back to Bloomfield Hotel for Outdoor Games

LILLIPUT ADVENTURE CENTRE

Fantastic, brilliant, deadly.....

These were just some of the words used to describe the Lilliput Adventure weekend last year. Last year's activities included the 'Zip Line' which I am sure many of you are familiar with. We also had 'Bog Hopping', 'Stack Em High', which has to be seen to be believed and 'Pier Jumping'. All food is provided and of course there are always the late night snack goodies. This weekend is a great way to meet other members of your own age, and perhaps make new friends.

BOOKING FORMS

From feedback received from the Evaluation Forms at our AGM in March earlier this year, it is expected that there will be a lot of interest in this weekend. Booking forms have been posted out to all members. However, as there will be a limited number of places available we would advise you to get the booking forms back to us as soon as possible.

**PLACES ARE LIMITED
FOR THIS WEEKEND
PLEASE RETURN YOUR
BOOKING FORMS TO US
AS SOON AS POSSIBLE**

At last the big day had arrived!

The President was due to arrive at 12.00noon, and guests had been asked to be at our new H.Q. before 11.30am. Just after 10am the first guest arrived, and from then on the time just flew by as more guests arrived and we proudly showed them around our new home. There was a definite buzz of excitement as it got nearer to 12 o'clock.



President Mary McAleese during her speech at our new H.Q.



President Mary McAleese unveiling a commemorative plaque

The President arrived shortly before 12.00noon. Michael Davenport our Chairman welcomed her, and invited the President to address the guests before unveiling a commemorative plaque. The President delivered a moving and thoughtful speech which you will find on page 4.



President Mary McAleese pictured with some of our VIP guests
Dr. Bruce Evatt, Justice Roderick Murphy & Professor John Bonnar



President Mary McAleese mingling with members of the I.H.S.

The President mingled with guests and took time to speak individually with everyone present. Her presence lent a very special atmosphere to what was indeed a landmark day, and I think the sentiments expressed in a letter which we received from William Murphy (which you will find on page 5), sums up the occasion perfectly.



President Mary McAleese pictured with the Board of the I.H.S.



President Mary McAleese pictured with the staff of the I.H.S.

We're home and we're here to stay!

Margaret Dunne

Remarks by President McAleese at the official opening of the Irish Haemophilia Society's new Headquarters, Thursday 14th June 2007

"This is a landmark day for members and supporters of the Irish Haemophilia Society and it is a real delight to have been asked to share it with you. I thank Chairman, Michael Davenport and the Society for asking me to perform the official opening and in doing so I salute the huge team effort that brought these fine new headquarters into being.

They open in perfect time for next year's celebration of forty years service by the Society to haemophilia sufferers, carriers and their families as well as others with bleeding disorders. It has been a rollercoaster these past four decades with, on the one hand huge improvements in treatment and management of the condition and on the other, the appalling story of HIV and Hepatitis C infection as a result of treatment.

This Society has been an advocate, champion, guide, friend and support throughout these very heady years. Today, thanks to your efforts and those of the medical, pharmaceutical and research professions, the vast majority of people are now treating themselves at home with safe and effective factor concentrates. That fact alone gives people enhanced independence, enhanced safety and control over their lives. Today, children with haemophilia can be treated prophylactically allowing them to lead as normal a life as possible, blending in more easily with the lifestyles of their friends than in any previous generation.

The state-of-the-art National Centre for Hereditary Coagulation Disorders is another excellent example of improved services and also improved communications between patients and professionals with both actively involved in decision-making.

Today, across many sectors that were previously simply medicalised with expertise flowing only one way, there is a growing recognition that the wisdom, experience and insight of all the constituencies involved is a crucial resource in designing and sustaining the models of practice that work best.

The Society has an important role in shaping haemophilia policy and in advising the Minister for Health on haemophilia policy through the National Haemophilia Council, chaired by the very distinguished Professor John Bonnar. The Society also has a direct involvement in the selection of medications for haemophilia through the Haemophilia Product Selection and Monitoring Advisory Board so ably chaired by National Haemophilia Director, Dr. Barry White.

So, nationally, this Society has already created a stunning legacy of achievement and as a leading player in the World Federation of Haemophilia this Society's international contribution is second to none.

".....The Society has created a stunning legacy of achievement."

"....the Society has been an advocate, champion, guide, friend, and support throughout these very heady years."

I know this day is more than tinged with sadness at so much grief and loss, so many lives robbed of years they should have lived.

There is a plan to have here a memorial to the ninety-one people who have already passed away and it is right to remember them in such a way but today we honour them with another kind of memorial in these headquarters, for it is in and through the work carried out here that a much better future will be crafted for our citizens with haemophilia and related bleeding disorders.

To Michael and Brian O'Mahony, congratulations on these wonderful new headquarters and, on behalf of all of us who benefit from the Society's work in seen and unseen ways, I warmly thank Michael and Brian and the members of the Executive for the dedication they have shown over the past number of years in working so effectively with the statutory agencies to ensure the

"....a much better future will be crafted for our citizens with haemophilia and related bleeding disorders."

very best service possible for all those with

haemophilia. May that partnership flourish in the years ahead.

I wish you all every success in your new offices.

Thank you."

President Mary McAleese greeting members including William Murphy



Ballyheadon,
Annestown,
Co. Waterford.

18th June, 2007

*Irish Haemophilia Society,
First Floor, Cathedral Court,
New Street,
Dublin 8.*

Dear Brian, Margaret, and all the staff,

I write to thank you for affording me the opportunity of being part of your celebrations last Thursday. It was indeed an historic occasion - an occasion that will be fully appreciated in the years to come as future generations make their way to Cathedral Court to avail of some of the services provided in your magnificent new premises.

I congratulate you on having the courage and business acumen in making such a purchase.

Thanks also for having the President of Ireland on hand to perform the opening ceremony. Her very presence was awesome and I can tell you now that when she offered me her outstretched hand I was aware that this was not just a handshake from a certain Mary McAleese, but rather, by proxy it was from every citizen of the nation. Such an honour remains with me forever.

Again, many thanks from me and many blessings from God.

Yours as always,

William Murphy
William Murphy

A Message from the Chief Executive

OCTOBER MEMBERS WEEKEND

The mid year members conference will take place at the Bloomfield House Hotel in Mullingar from October 19th to 21st. Booking forms for this event will be sent out in early September. We would advise members who intend going to this conference to book early to avoid disappointment, as places are limited, and the conference was fully subscribed last year. An innovative and exciting programme for this year will include sessions on physiotherapy and fitness tailored for specific categories of participants, a debate and an update on Hepatitis C and HIV treatments.

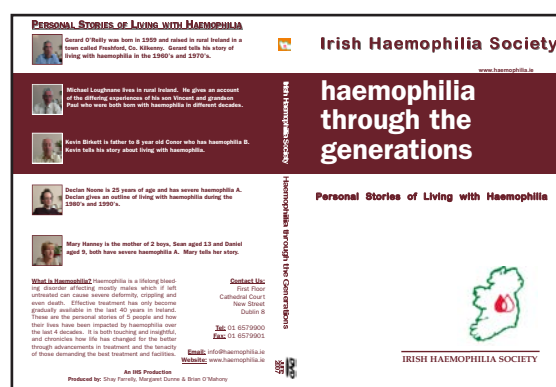
Following the last family conference in October 2006 and the Annual General Meeting in March 2007, and in line with our strategic plan, we evaluated the outcome of the meetings and we will be making some alterations in procedures for family weekends and AGM's. These alterations will be to optimise safety, responsibility and participation in the meetings and conferences for all members of the family. The Society provides a dedicated Kidlink programme with specified co-ordinators. It is imperative that any child or teenager who is booked into the Kidlink programme must attend the programme or in the event that they are not attending any part of the programme they must be signed out by a parent if they are leaving at any time. It will also be necessary for parents when they are registering their child for the Kidlink programme to attend with the child at the time of registration, at which time the programme for the weekend will be reiterated. We will also be applying a cancellation fee for any attendee who cancels in the days leading up to the conference, except in cases of genuine emergency or illness.

For the Annual General Meeting next year we hope to be in a position to have the entire group including the adults, children, teenagers dine together on the Saturday night. Having said that we will also have to specify a time beyond which children will not be allowed on the dance floor.

It is also worth noting that attendance at the October conference and the AGM for members is heavily subsidised by the Society. We have been gratified by the high level of attendance at sessions and workshops held during the conference by members. This weekend is about building a strong sense of community. By actively participating, you are leading by example in our efforts to ensure that the children, teenagers and young adults participate.

You will find full details of the programme for this weekend on page 2.

HAEMOPHILIA THROUGH THE GENERATIONS DVD

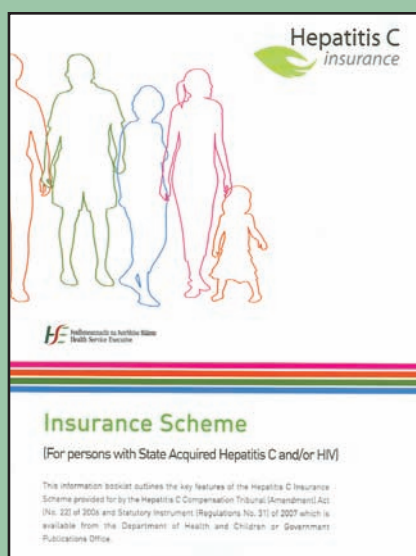


When planning the IHS conference which was held in October 2006, we decided to organise a session which would allow participants to hear about the reality of growing up with haemophilia in different decades. It is gratifying that children who are on prophylaxis and who have always known only prophylactic therapy for haemophilia have no concept or idea of the reality of living with on demand treatment, inadequate treatment or no treatment. For them, the past truly is a different country and a different reality. This is as it should be, however we believed it would be very beneficial for all concerned if they had an increased understanding and appreciation of what the reality was of living with haemophilia in the past. This would perhaps assist them in contextualising their own haemophilia, and in realising that whatever problems they may have, they are fortunate to be treated in the current decade and not in the past. The session at the October family weekend in 2006 was a remarkable one.

Gerard O'Reilly spoke about growing up with haemophilia in the 1960's, Declan Noone spoke about growing up with haemophilia in the 1980's, Kevin Birkett and Mary Hanney spoke about treating their children in the current decade, and Michael Loughnane bridged the generations by speaking about his son Vincent growing up with haemophilia in the 1960's, and the difference now in seeing his grandson who is 16 and also has severe Haemophilia. Following the conference we received a lot of feedback from members who had been in attendance saying that they really had enjoyed this session. It was also clear that doctors and nurses who are currently treating haemophilia, especially new doctors and nurses coming into this field of thrombosis and haemostasis, would benefit from hearing the stories. Therefore we have produced a DVD called 'Haemophilia through the Generations'. The DVD which was directed by Shay Farrelly, is available free of charge to any member of the Society. If you would like a copy of this DVD, please contact the office and we will mail you a copy. Copies of the DVD will also be available during the October weekend and at the upcoming Insurance Meeting.

A Message from the Chief Executive

HIV / HEPATITIS C INSURANCE SCHEME



At the time of going to print we are hoping that the long awaited Insurance Scheme for persons with HIV & Hepatitis C will have commence September 12th. This Scheme will allow persons with haemophilia and von Willebrands who have HIV and/ or Hepatitis C to avail of life insurance up to a maximum of €425,000 (or €525,000 in certain circumstances), mortgage protection insurance up to a maximum of €394,000 and re-mortgage insurance up to a maximum of €100,000. The insurance will be provided at the same rates which will be provided to any member of the public who does not have HIV or Hepatitis C. You will recall that the legislation bringing this into effect was passed in July 2006, and the regulations implementing the legislation were passed in January 2007. We have been working since then on implementation protocols and setting up the administration of the Scheme. If the Scheme does commence on September 12th it is our intention to hold a general meeting to once again reiterate the major features of the Scheme. We will then facilitate individual advice to members from a specialist firm. We will be announcing dates when this firm will be available to meet members at the office in Dublin, and they will also be available to meet with members in Cork, Limerick and Galway on specified dates. As soon as we are in a position to confirm the initiation date for the Scheme, we will be writing to all members who are eligible to participate in the Scheme, giving details of the general meeting and giving details of the dates when they make book (if they wish), individual consultations. It is important once again to reiterate that certain benefits of the Scheme will only be maximally available to members if they take out the insurance during the first year of the Scheme. This is the reason that we are very anxious to insure that all eligible members have an opportunity to discuss their individual requirements with an expert in the shortest possible timeframe.

SAFETY AND SUPPLY NEWS

Research to develop factor VIII that does not cause inhibitors

A new grant will fund "proof-of-principle" studies, in special strains of mice, to see whether re-engineered FVIII protein can avoid the usual antibody responses which cause inhibitors in some hemophilia patient. Further information can be found on: www.pbn.com/stories/26146

Higher dose NovoSeven approved in Europe

NovoSeven's label in Europe has been extended and is now available in a single 270ug/kg dose, in addition to the original 90ug/kg dosing regimen. More information can be found on: www.emea.europa.eu/humandocs/Humans/EPAR/novoseven

Rise in reported Hepatitis C cases

The number of reported cases of Hepatitis C in Ireland for the first 28 weeks of 2007 was 836, compared to 630 for the same period in 2006 according to figures released by the Health Protection Surveillance Centre. (HPSC) Hepatitis C can be spread by sexual contact and was, in the past spread by medical treatment. The main cause of Hepatitis C is now intravenous drug abuse with up to 81% of users testing positive for Hepatitis C.

National Haemophilia Council (NHC) Annual Report

The NHC Annual Report for 2006 has been published and is enclosed with this newsletter. The Irish Medical News coverage of the report (see inset) highlighted the need for improved hospital services for people with haemophilia which was apparent from the results of the most recent external audits of the centres in St. James's, Crumlin and Cork. The coverage also highlighted the requirement for the Irish Haemophilia Society to be represented on future audit teams.

Children's Hospital to be 10 Storeys

The proposed new children's hospital in the Mater Hospital in Dublin will be 10 storeys high and will cost some €700 - €800 million, nearly double the early cost projections for the project. Private presentations have been made to staff at Our Lady's Hospital for Sick Children, Crumlin and Tallaght hospitals. These hospitals, along with Temple Street Hospital are due to be replaced by the new facility which is due to be built by 2011. It is understood that, although the proposals are in draft form, senior management and medics in Crumlin remain dissatisfied and are seeking clarification on areas including access to the site which is in a busy traffic zone. (Source Irish Independent)

From the Irish Media

You will find some more interesting articles from the Irish Media on page 20. For your information many others articles are available and updated daily on our website: www.haemophilia.ie

Brian O'Mahony

WFH Twin of the Year Award

2006 ORGANIZATION TWIN AWARD

HAEMOPHILIA SOCIETY OF BOSNIA & HERZEGOVINA

IRISH HAEMOPHILIA SOCIETY



With the ongoing support of their Irish twin, Bosnia and Herzegovina made significant headway in 2006 through their diversified fundraising initiatives, improved volunteer recruitment, and diligent lobbying of the Ministry of Health for an increased supply of factor, and for the official recognition of their national Hemophilia Treatment Centre. They also organized their first hemophilia symposium, which drew over 100 participants from 5 countries and major media coverage, sent delegates to the Irish Conference on Hepatitis C, and established preliminary contacts with the Bosnian Serbian Republic.



THE WFH TWINNING PROGRAM:

Twinning links hemophilia organizations and treatment centres in developing and developed countries.

The WFH helps twins arrange trainings, exchanges, workshops, patient education and other activities to improve hemophilia treatment and care.



The World Federation of Hemophilia have awarded the Haemophilia Association of Bosnia & Herzegovina and the Irish Haemophilia Society with the '2006 Organisation Twin Award'. In a letter received from the World Federation of Hemophilia, Mr. Cesar Garrido (Chair of the Hemophilia Organisation Twinning Committee) said:

"The WFH Hemophilia Organisation Twinning Committee met recently to review the programme and consider reports received from twins around the world. This year, I am delighted to inform you that your twinning has stood out from an impressive pool of candidates.

The committee voted, and it was agreed to present the 2006 Hemophilia Organisation Twin of the Year Award to:

BOSNIA & HERZEGOVINA - IRELAND

We were all impressed by the scope of the activities undertaken in 2006 through your twinning partnership, particularly your lobbying efforts for HTC recognition and increased factor supply, your diversified fundraising activities, the recruitment of new volunteers, and the organisation of the first haemophilia symposium in Bosnia.

The award will officially be presented at the Awards Ceremony of the WFH World Congress in Istanbul, Turkey. We hope that this recognition and appreciation will encourage you to carry on your efforts within the hemophilia community. Please accept our congratulations, and pass on our thanks to the many members of your team who support this important activity."

Treatment for All

Global Alliance for Progress (GAP)

GAP is the flagship programme of the World Federation of Hemophilia (WFH). The programme has the objective of providing for the diagnosis and treatment of up to 50,000 persons with haemophilia in up to 30 countries over 10 years. The programme operates by taking a co-ordinated approach to the development of several aspects of haemophilia care. These include improving the medical expertise and laboratory diagnostic capability, improving the treatment products available to treat persons with haemophilia, improving the ability of the patient organisation to advocate, lobby and support their members, and develop a national haemophilia care plan with the active support and participation of the government. The GAP programme was initiated in 2003 in Egypt, Georgia, Mexico and the Philippines. Three further countries Thailand, Russia and Armenia were added in 2004. Azerbaijan and Jordan were added in 2005, Lebanon in 2006 and Ecuador in 2007. Work is also ongoing in China, which due to the vast size and complexity of the country, is in a pre GAP phase.

The results have been remarkable. By July 2007, 7657 persons with haemophilia and 262 persons with von Willebrands have been newly diagnosed and registered in the 12 countries. The governments of Thailand, Russia, Georgia, Jordan and Azerbaijan have started full national haemophilia care programmes, and more than doubled their haemophilia budgets. The Ministry for Health in Mexico has publicly announced that haemophilia is now included in the public health system for the first time, and they will begin a prevention programme of prophylaxis for children in 2007. Since the beginning of GAP in 2003 over 203 million units of clotting factor concentrates have been used in these countries, most of this donated. Comprehensive care centres have been established or expanded. National patient registries have been initiated and treatment protocols have been developed.

The provision of diagnosis and treatment to persons with haemophilia in every corner of the globe is a responsibility that we all share. To this end, the Irish Haemophilia Society has made a 3 year commitment to the GAP programme of WFH in the amount of US\$25,000 per year for 2006, 2007 and 2008. This contribution is important to WFH, and I hope it will also serve as an example to other haemophilia organisations who may wish to commit resources to this global programme.

Brian O'Mahony

In a letter below the World Federation of Hemophilia thanks the Irish Haemophilia Society for supporting the GAP Project.

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FOUNDER
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FATRON
Jan Willem André de la Porte

CEO/EXECUTIVE DIRECTOR
Miklos Fulop

1425 René-Lévesque Blvd. West
Suite 1010
Montréal, Québec H3G 1T7
Canada
Tel.: (514) 875-7944
Fax: (514) 875-8916
E-mail: wfh@wfh.org
Web site: www.wfh.org

July 4, 2007

Mr. Michael Davenport
Chairperson
Irish Haemophilia Society
First Floor, Cathedral Court
New Street, Dublin 8

Dear Michael:

On behalf of the World Federation of Hemophilia (WFH), I would like to thank the Irish Haemophilia Society (IHS) for its support of WFH's GAP program in 2007. Your generous contribution of \$25,000 USD to the GAP program is exceptional and sincerely appreciated.

Each year, WFH continues to improve treatment and care in emerging and developing countries. Through our programs, we have seen many lives changed for the better. Every day, five new patients with hemophilia are diagnosed worldwide. Our training and education programs for medical professionals strive to ensure safe and effective treatment for all patients. Children with hemophilia have been given a chance to do simple things such as walk and play. We would not have accomplished all this without your help. Your gift is an inspiration to the hemophilia community in so many ways.

In 2006 WFH adopted the vision of *Treatment for All*: safe, effective treatment and medical care for people with bleeding disorders everywhere. In 2007, we continue to work towards this mission. The theme for World Hemophilia Day in April was "Improve your Life!" The event promoted proper exercise, particularly in developing countries where hemophilia treatment is scarce. WFH is also working to extend hemophilia services to people with other bleeding disorders, and continues to work with doctors and health professionals to promote blood safety.

WFH believes in IHS' work to improve care and support for all people with bleeding disorders, and is proud to share this common goal with you. You have helped people suffering with bleeding disorders not only in your own country, but also in developing countries around the world. IHS' initiative is a wonderful example of organizations helping organizations, and we hope that others will choose to follow in your footsteps.

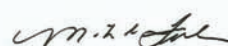
Your contribution has provided part of the resources to make GAP the WFH's flagship program. Since its beginnings in 2003, participation has grown to ten countries. Health Ministries in seven countries have signed formal agreements to establish national hemophilia care programs and increase the supply of hemophilia treatment products. Already, the purchase of clotting factor has increased by over 203 million IU. GAP has been instrumental in stimulating the hemophilia communities in participating countries and focusing their efforts to dramatically improve care and treatment.

If you are interested in receiving updates on any of WFH's programs, please do not hesitate to contact me.

Because of you, thousands of lives will be saved this year. IHS' support is extraordinary and we are grateful to have you as part of our global caring community. I look forward to continuing this alliance in the future.

Once again, *thank you* for your generous support.

Kind regards,



Miklos Fulop
CEO/Executive Director

WORLD FEDERATION OF
HEMOPHILIA
FÉDÉRATION MONDIALE DE L'HÉMOPHILIE
FEDERACIÓN MUNDIAL DE HEMOFILIA



Indonesian child with hemophilia receives medical treatment.

Debbie Greene in conversation at the E.H.C. Conference with **Catherine Hudon,** Regional Programme Manager, Europe - WFH



DG: Perhaps you could start with telling us a little bit about yourself?

CH: I was born in Montreal 32 years ago. My father was a police officer and my mother stayed at home during my childhood. Before that she worked as a salesperson. They are both retired now. I also have an older brother. I studied Political Science and International Relations in University in Montreal and continued to do an M.A. in Budapest at the Central European University where I specialised in post-communist transitions. Most students were from the region, so that was really interesting and I learnt a lot from socialising with them. I am also close to completing a Public Health graduate degree.

DG: How long are you working for the WFH?

CH: I started five years ago at the Seville Congress. I guess time flies when you're having fun because it feels like it was just a few months ago. I had worked for two years in Croatia for the Organisation for Security and Co-operation in Europe (OSCE) and my work consisted of managing grants for NGOs and reporting on human rights violations.

Claudia Black the WFH Programme Director believes, rightfully in my opinion, in the importance of cultural experience to do programme work. That was one of the reasons I was selected for this job.

DG: Describe what you do as WFH Regional Programme Manager for Europe?

CH: Programme Managers are "jacks of all trades". I am in charge of not so much implementing the programmes, but I am in charge of guiding, co-ordinating and making sure that everything is cohesive and coherent, so yes there is management involved, and I am the link, sort to speak. You report back to the Programme Director and also to the WFH Executive. I don't enjoy so much the reporting part per se, but enjoy being in the field. Travelling is enjoying but also tiring. I act as a bit of a travel agent for myself and for the volunteers who go with you on the trip which can last for me for two to three weeks, three to four countries at a time and about five times per year. An important part of the job is to also be a lobbyist in a way since ideally, success is when Ministries of Health agree to introduce or increase haemophilia care in their country.

DG: You come across as really enjoying your job.

CH: I do, I find it so rewarding, and gratifying. I was in a country once and the toast was about the friendship which will last when we were finished working and I had tears in my eyes thinking how can I ever leave this job one day. There aren't clear-cut projects, the programmes and the relations with people last for several years, so you stay attached and committed very easily.

DG: What is the most rewarding part of your job?

CH: What is great about this job and I think it might be the case in health care in general is that the impact you (and the resources) can have on people's lives is very concrete. Increasing or having a government starting to buy factor concentrates for a country is very rewarding, and the patients will see their quality of life improving. What I also find rewarding is sometimes you are faced with individuals who might be very reluctant to get involved or be part of a programme. What I personally find very rewarding is when you find the right carrot or the right tools to convince somebody to get involved, and then a year or 2 after they are so happy and so proud of the work that has been accomplished. This is very rewarding.

"Treatment is not only factor", it is "Comprehensive Care as well". This is possible even with little money, it is just a matter of education and good will.....

DG: What country do you think has benefited most from the GAP programme?

CH: In Europe there are 4 GAP countries: Russia, Armenia, Georgia and Azerbaijan. Georgia just closed last year. I think they all have really benefited from the GAP programme but in different ways, and by the way the man behind the concept of GAP is of course Brian O'Mahony. The legend has it that when he came up with this plan, he was on a KLM flight between Amsterdam and Montreal. So all this fruitful work for the WFH staff was created on a single flight!

DG: Do you think that the WFH vision 'Treatment for All' is a huge challenge?

CH: Yes it is but its good to be idealistic because we have to aim high to achieve goals. Unfortunately I don't think that the 70% of people who receive little or no treatments will receive that any time soon because treatment is usually related to economic status of the country so its really not just up to us to achieve that. But I fully agree with the principle that everyone should have treatment.

DG: What would be your hopes for the future in relation to haemophilia?

CH: Of course the famous cure. Otherwise my hopes would be that in every country they have at least some kind of improved quality of life through better treatments, and as the chair of the Musculoskeletal Committee would say "Treatment is not only factor" it is "Comprehensive care as well". So if factor concentrate is not available everywhere then at least comprehensive care should be available everywhere. This is possible even with little money, it is just a matter of education and good will.

DG: What do you think of this EHC Conference?

CH: I think that you are actually lucky in Europe to have the EHC because some countries from the region do not have the opportunity to have an annual conference where you can network and where you can actually have stronger ties within a region. It's very useful and I also think there is a need for a strong EHC, especially to advocate at EU level particularly the way the European Union is developing at the moment. I think the EHC is on the right track if it keeps going in that direction.

DG: As you know in 2008 the EHC Conference takes place in Dublin, what topics would you like to see on the programme?

CH: The theme for World Haemophilia Day this year was the importance of physiotherapy and going to see your physiotherapist on an annual basis, so I really would like to see on the programme the topic about physiotherapy with limited factor supply. I like the aspect of having a debates, I think it is very useful. I think lectures are good but interaction is better and essential.

DG: Will you attend the conference in Dublin?

CH: You bet.....I wouldn't miss it for the world, this will be my first visit to Ireland, I will have to stay a few days extra for some sightseeing, and to visit your brand new headquarters, which I believe are fantastic.

DG: We all look forward to that Catherine, thanks for taking the time to speak to me.

Debbie Greene

Calendar of Events 2007 / 2008

CARRIER INFORMATION DAY

SATURDAY 22ND SEPTEMBER 2007

THE HERITAGE HOTEL PORTLAOISE

Following on from the success of our Carrier Information Day in June this year, a second Information Day will take place on Saturday 22nd September in the Heritage Hotel in Portlaoise to facilitate members from other parts of the country. This Information Day will have the same format as the earlier one, and will be open to all carriers and possible carriers i.e. sisters and other female relatives of the person with haemophilia and women with bleeding disorders from 12 - 30 years.

PROGRAMME

- 11.00 - 12.30 Being a Carrier**
Factor Levels, Obligate Carriers
Carrier Testing
- Impact of being a Carrier**
Discussion followed by Q & A Session
- 13.00 - 14.00 Lunch**
- 14.00 - 15.30 Self Care - Practical Demonstration & Pampering**
Good Skin Care, Make Up Tips (12-16yrs)
- Pregnancy & Childbirth**
Involving the Haematology Team
Liaison - Obstetrician & Haematologist
Effects of pregnancy on factor levels
Testing new baby
Post delivery care for mother & baby
- 16.00 - 17.00 Group Discussion (12-16yrs)**
- Make Up Demonstration & Pampering**
Mini Facial
Manicure
Make up (17-30yrs)

Cost: €20 per person

Booking Forms have already been sent out to all members, and also can be downloaded from our website: www.haemophilia.ie

UPDATE ON TREATMENTS

WEDNESDAY 10TH OCTOBER 2007

VENUE: OFFICES OF THE I.H.S. CATHEDRAL COURT, NEW STREET, DUBLIN 8

Take this opportunity to meet the experts and update yourself on HIV and Hepatitis C treatments. This meeting will take place in the offices of the Irish Haemophilia Society on Wednesday 10th October.

MEMBERS WEEKEND

**FRIDAY 19TH - SUNDAY 21ST
OCTOBER 2007**

THE BLOOMFIELD HOUSE HOTEL, MULLINGAR, CO. WESTMEATH.



We are hoping that this years October Members Weekend will be equally successful as last years. On page 2 of this newsletter you will find full details of our programmes for the weekend. On page 6 of this newsletter you will see a message from our Chief Executive which gives members further details on this event. At this stage most of you will have received our letter of invitation and booking form. We are hoping that you will agree that this weekend is not to be missed. We would therefore urge you to get your booking forms back to us as soon as possible, as all places available for this weekend will be processed on a first come first served basis.

Looking forward to seeing you all in Mullingar.

Calendar of Events 2007 / 2008

NATIONAL HAEMOPHILIA COUNCIL

SATURDAY 24TH NOVEMBER 2007

This years Information Day takes place on Saturday 24th November in Dr. Steven's Hospital in Dublin. We would like to encourage as many members as possible to attend this Information Day. Notification of this event will be posted to all members shortly.

CONSULTATIVE COUNCIL ON HEPATITIS C: INFORMATION DAY

SATURDAY 16TH FEBRUARY 2008

The Consultative Council on Hepatitis C Information Day will be held on Saturday February 16th 2008 in the Croke Park Conference Centre. Details of programme will be available shortly however registration forms will not be circulated until after Christmas.

ANNUAL GENERAL MEETING 40TH ANNIVERSARY

DATES:

**FRIDAY 29TH FEBRUARY,
SATURDAY 1ST MARCH
SUNDAY 2ND MARCH, 2008**

VENUE:

**THE PARK PLAZA HOTEL,
TYRRELSTOWN, DUBLIN 15.**

We are planning an exciting programme and hope to have something of interest for all members.
Keep checking the website for further updates.

WORLD FEDERATION OF HEMOPHILIA: CONGRESS 2008

**JUNE 1ST - 5TH, 2008
ISTANBUL, TURKEY**

The WFH Congress 2008 takes place in Istanbul, Turkey. As the largest international meeting of members from the global haemophilia community, the Congress programme will include internationally recognized experts in treatment and research, making it the preeminent meeting for those interested in haemophilia and related bleeding disorders.

The Congress at a glance includes some very interesting sessions including:

Advancements in the Management of Viral Hepatitis

Rare Bleeding Disorders

Prophylaxis

Inhibitors Management

Von Willebrand Disease

Mild Haemophilia

Advancements

Paediatric Issues

Carriers, Counselling & Clinic Issues



The Irish Haemophilia Society will be happy to provide information and logistical support to any member who might consider travelling to the Congress. For further information regarding the Congress please go to:

www.hemophilia2008.org

EUROPEAN HAEMOPHILIA CONSORTIUM CONFERENCE

**DATES: 12TH, 13TH, 14TH
SEPTEMBER 2008**

VENUE: DUBLIN CASTLE

Europe comes to Dublin! Next year the European Haemophilia Consortium Conference takes place in Dublin. We are looking forward to welcoming all our European National Member Organisation delegates to our fair city.

Noticeboard

HELLO FROM AUSTRALIA

Hi, My name is Brett Williams.
I am a 30 year old Australian male with
severe haemophilia with inhibitors.

The reason for this notice is to make contact
with some Irish Haemophiliacs. One of my
hobbies is painting and I have an idea of an
Irish painting I would like to do, and need
some help with the Irish language. And the
second thing is that I am interested in
writing to people with haemophilia from
all over the world. I just wondered if
anyone is interested in having an
Australian pen pal who has haemophilia?

My email address is:

september18@uqconnect.net

Looking forward to hearing from you guys!!!

WOMEN'S MINI MARATHON



We would like to thank everyone once again
who participated in this year's Mini Marathon.

We are pleased to announce that to date the
total figure raised is €2957.60.

And don't forget, those of you who have raised
€150 or over, will be entered into a draw for
a weekend away for two. So for those who
have not yet returned your sponsorship, make
sure you do so by the end of October to be in
with a chance to win this prize.

SCHOLARSHIPS & GRANTS

MAUREEN DOWNEY MEMORIAL GRANT EDUCATIONAL SCHOLARSHIP



Thanks to everyone who sent in applications
for the above grants. The closing date for
these applications was Friday 21st September.

Members of the board of the Irish Haemophilia
Society have been nominated to judge the
applications. The winners will be announced in the
Winter Edition of our newsletter.

Good Luck to all of you!

MEMBERSHIP FEES

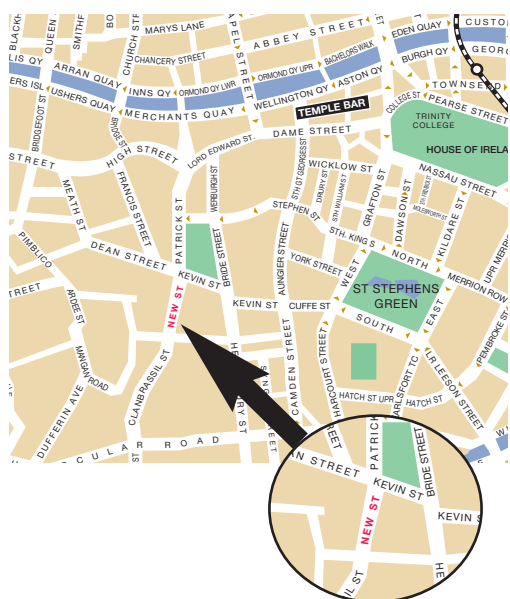


If you have not paid your membership
for 2007, we would ask you to do so
as soon as possible.

The current membership fee is €30
per year. Life Membership is €650.
You can pay by cheque, or if you
wish we can accept laser or credit
card payments.

Noticeboard

HOW TO FIND US?



Address: First Floor, Cathedral Court
New Street, Dublin 8
Telephone: 01 6579900
Email: info@haemophilia.ie
Website: www.haemophilia.ie

NEW LOOK HAA CARD (HEALTH AMENDMENT CARD)



The Health Amendment Card (HAA) is now in a new format. The new card is a plastic credit card size and will have the cardholders name and R number permanently printed on it.

All current cardholders should have received a letter from their local Liaison Officer giving details of these changes.

If you have any queries on this, please contact Anne Duffy in the office on 01 6579900, or alternatively contact your Liaison Officer directly.

PLANNED GIVING

Planned Giving is a means of securing a commitment for a constant level of income for the Society.

It is a mechanism whereby you can commit to making regular monthly contributions to the Society by means of a standing order from your bank account.

The donation is entirely voluntary and may be changed or cancelled by you at any time.

If you wish to participate in the Scheme, please contact the Society on 01 6579900.

CHRISTMAS CARDS



We have in our offices a supply of Christmas Cards for sale from last year. Due to the huge increase in the cost of postage we are unable to post orders out to members. However please feel free to call in at any stage for some cards. Please also note we will be bringing a supply of cards to all future events.

Information & Education Day

for Carriers & Women with Bleeding Disorders

The venue for the Information Day was Cathedral Court. Being the first such meeting in our new headquarters I was anxious that it should go well and that everyone would feel comfortable and relaxed and get something from the day.

We started with the obligatory tea and coffee and of course a tour of the office. Eadaoin O'Shea from St. James's and Maeve Foreman, Social Worker, presented the morning sessions which covered the topics "Being a Carrier" and "Pregnancy and Childbirth" for carriers and women with bleeding disorders.



Eadaoin O'Shea stresses the importance of "Information and Education"

Eadaoin spoke about what it means to be a carrier. In her presentation she stressed the importance of first of all knowing if you are in fact a carrier. She also said that 30% of carriers have lower than normal factor levels.

At the conclusion of this session Eadaoin pointed out that it was important to :

- Know your carrier status**
- Know your factor level**
- Inform the Centre when surgery is planned**
- Inform the Centre when you are pregnant**
- Be informed and educated**
- Don't take risks**

Having heard about carriers and carrier testing the ladies heard from Maeve Foreman who spoke to the group about the psychological impact of being a carrier. The ladies were organised into two groups to discuss what they had heard and ask any questions.

For some people it was their first time to have an opportunity to consider what it means to be a carrier and for those who do not yet know their status to consider whether they wish to be tested. Being able to discuss what they had heard in a comfortable and non threatening environment hopefully allowed everyone to voice any concerns they may have had.

Birth Plan

After a short break there was a presentation from Eadaoin on "Pregnancy and Childbirth". Eadaoin reiterated what she had said at the carrier session; that it was important to know the type and severity of haemophilia in your family, your carrier status and your factor level. The role of the Centre is to provide information and support for you, to liaise with the Obstetrician and to monitor factor levels. The foetal sex will have been determined during pregnancy and in preparation for delivery the Centre will prepare a plan for both mother and baby. This plan will include precautions during delivery, blood sampling for diagnosis and the availability of appropriate factor concentrate in the event of bleeding. Again there was time for questions and discussion following this presentation.

After a break for lunch it was time for some pampering from beautician Elaine Snyman. Everyone was treated to either a facial or make up with Elaine giving a running commentary while she worked and lots of make up and skin care tips. This part of the day was very enjoyable and gave everyone a chance to relax and get to know each other.



"I'm doing my best Margaret but I can't promise miracles"

Information & Education Day

for Carriers & Women with Bleeding Disorders

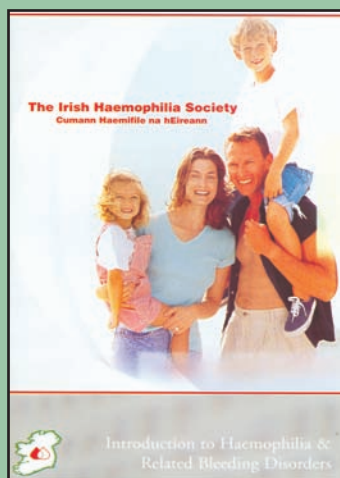
Overall I feel the day was very successful with just the right mix of information and relaxation.

The next Information Day which will have the same format is due to take place on 22nd September in the Heritage Hotel in Portlaoise. The Information Day will be open to all carriers and possible carriers i.e. sisters and other female relatives of the person with haemophilia and women with bleeding disorders from 12-30 years.

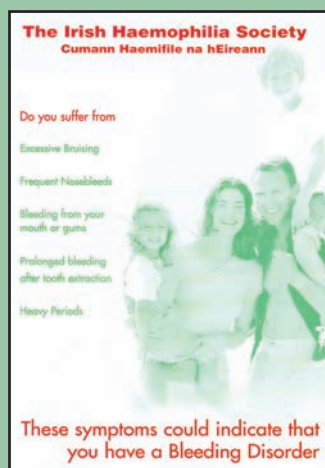
In the meantime, if you have any questions please feel free to call us and if we can't help we will do our best to put you in touch with someone who can.

Below is a selection of some of the publications available from the I.H.S. for Carriers and Women with Bleeding Disorders which you may find useful:

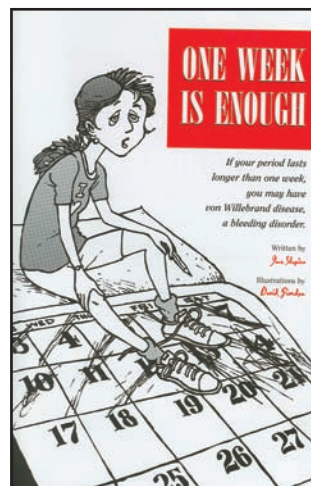
Introduction to Haemophilia & Related Bleeding Disorders



vonWillebrands Information Leaflet



One Week Is Enough



Planning a Family



Useful Websites:

Irish Haemophilia Society - www.haemophilia.ie

UK Haemophilia Society - www.haemophilia.org.uk

link: www.womenbleedtoo.org.uk

Canadian Hemophilia Society - www.hemophilia.ca

link: www.hemophilia.ca/en/2.5

National Hemophilia Foundation - www.hemophilia.org

link: www.hemophilia.org/NHFweb/main.pgs

On the next 2 pages you will find an article which was published in the July/August 2007 edition of Hemaware, the magazine of the National Hemophilia Foundation, and gives a good insight into the lives of two women living with a bleeding disorder.

Margaret Dunne

Young Women Talk Openly about Bleeding Disorders

By Phyllis McIntosh (Hemaware July/August 07)

What's it like to be a young girl growing up with a bleeding disorder? Lilliam Bervis, 20, who has mild von Willebrand Disease (VWD), recalls being the object of curiosity when she started physical education classes in third grade outfitted like a hockey player with helmet, knee pads and elbow pads. Alex Nothorn, 24, who experienced childhood food allergies as well as severe VWD, vividly remembers teachers and chaperones who were scared to be responsible for her. "You can imagine my mom showing up with this scrawny little kid saying, 'she can't eat wheat, she can't drink milk, and by the way, she could bleed to death at any minute' ", Nothorn laughs. "People were horrified!"

Both women learned early to be open about their bleeding disorder and to take a positive approach. As young adults, they lead busy, active lives and are preparing for professional careers. Bervis is a biology major at Florida International University near her home in Miami and works as a customer service associate for a department store. Nothorn, who lives in Boston, graduated from Cornell University in Ithaca, New York, in 2005, works as a medical assistant at a community health center and plans to begin medical school in 2008. Their message to other young women with a bleeding disorder is this: **It's a disability only if you allow it to be.** "Having a bleeding disorder has made me a stronger person," Nothorn declares.

“IT'S A DISABILITY ONLY IF YOU ALLOW IT TO BE”.

Growing Up

Bervis, diagnosed at age six, bruised easily and experienced frequent nosebleeds. "I always had to leave school because there was no nasal spray like Stimate at the time," she says. "DDAVP (the drug that allows the body to release whatever VWD factor is stored in the blood vessels) was only available intravenously, and treatment usually involved going to the hospital and having an IV for a couple of hours."

Nothorn, diagnosed at age three, was prone to serious bleeds. The most memorable occurred in fifth grade when, against her better judgement, she joined a pick-up soccer game on the playground. "A third grader accidentally kicked me in the leg, and I got a very bad bleed", she says. As teenagers, both young women experienced heavy menstrual periods that sometimes lasted for weeks, and were initially so painful that they had to miss school, spending the day sleeping or experiencing bouts of nausea and vomiting.

"DON'T LET YOUR BLEEDING DISORDER GET IN YOUR WAY".

Both have struggled to stabilize their cycles with hormone therapy, but still suffer severe cramps. Despite the occasional setback, the women stress that they do not feel they missed out on anything. Encouraged by parents, they went on school field trips and participated in non contact sports like swimming, running, hiking - even rock climbing.

Throughout their school years, both young women had the support of classmates who were aware of their condition. "They knew not to hit me or put me in risky situations, and they took care of me," Bervis recalls. "They would say, 'Don't do that, you're gonna get hurt.'" For Nothorn, "It was something that made me unique, and it was something we'd all joke about. When I was a freshman, I had a bleed and when I came back to class, they all started singing, 'Bleed on Me' to the tune of 'Lean on Me'.

Relationships with adults were less predictable. After attending a small elementary school where everyone on staff knew about her condition, Bervis found herself in an "unwelcoming" middle school that did not have a school nurse or a refrigerator in which to store her factor until she was in eighth grade. She does, however, have fond memories of her hemophilia treatment center (HTC), especially a program where she learned to self-infuse on a lifelike arm and on parents who volunteered their arms so she and other kids could practice.

Young Women Talk Openly about Bleeding Disorders



Nothorn has little recollection of her HTC but remembers all too well emergency room encounters with personnel who had never met anyone—and certainly not a girl—with a bleeding disorder. "I remember when I was nine, being alone in a room with a nurse who was nervously starting to mix my factor and doing it wrong, and I was trying to figure out how to assert myself," she says.

Getting Involved

While Bervis started going to summer camp for children with bleeding disorders when she was 10, Nothorn says she didn't know other people with bleeding disorders until she was 17. That's when the director of the New England Hemophilia Association enlisted her as a counsellor at a family camp. "I got out of the car, and there were about 150 people running around with Medic-Alert bracelets," she says.

"There were children and grandfathers on crutches and babies with bleeding disorders. It was overwhelming, but those five days were a turning point in my life." This summer she returns to camp for her eighth year as a counsellor.

Both women especially value their participation in the National Hemophilia Foundation's (NHF) National Youth Leadership Institute (NYLI), where they join peers from around the country to plan and present programs for other teens with bleeding disorders. As they embark on adulthood, they look to the future with little apprehension. For Bervis, frequent nosebleeds

continue to be the most noticeable - and - annoying - reminder of her von Willebrand disease, but she says philosophically, "it's something you can learn to live with." Nothorn wonders what pregnancy and childbirth will be like and whether her children will inherit her bleeding disorder, but says such concerns will not deter her from parenthood.

Words of Advice

For other girls growing up with a bleeding disorder, Bervis and Nothorn advise:

Speak up about your bleeding disorder.

"I grew up being told repeatedly by teachers and doctors that because I was a girl, I must not have a bleeding disorder, there must be some mistake", Nothorn says. Bleeding disorders, especially VWD, affect millions of girls and women in the US alone. "If women are afraid to speak up, people are going to keep thinking that hemophilia is just a boy's disease."

Get involved with others.

At camp, you can share experiences with kids in similar situations. You learn, as Bervis says, "that you're not the only person in the world bleeding from your nose every other day".

Most of all, live your life.

"You're only young once, and you only have one life," says Bervis, "so don't let your bleeding disorder get in the way".

News from the Irish Media

Call for Urgent Improvement in Hospital Care for Haemophiliacs

The Chairperson of the National Haemophilia Council, Professor John Bonnar has called for urgent additional healthcare professionals and improvements in hospital infrastructure for patient care in Dublin and Cork. In his statement in the 2006 Annual Report from the Council, Professor Bonnar said the requirements are "essential to provide appropriate standards of care for persons with haemophilia and we expect these facilities to be provided in the next one to two years. External audits of the quality of service at Irish Haemophilia Centres in Dublin and Cork were carried out in 2006. In the recommendations, the review found that a new consultant Haematologist to lead on paediatric haemophilia and thrombosis services is urgently required in Our Lady's Children's Hospital, Crumlin. In addition, the audit recommended that results of investigations should be filed more promptly and the process should be formally audited. In the recommendations for Cork University Hospital, the audit found that dedicated haemophilia space should be identified within the Hospital to form a physical space for the haemophilia centre. It also said that the medical records of patients with inherited bleeding disorders should be kept on-site and be readily available on a 24 hour basis.

Hepatitis C scandal: trial of biochemist can go ahead

Former BtSB head biochemist Cecily Cunningham yesterday lost a High Court bid to stop her trial, which could lead to a prison sentence of up to 10 years. The affected women's support group, Positive Action, welcomed yesterday's ruling, saying it was "a good day" for them. Mr. Justice Liam McKechnie, in the High Court, found that there had been an "inordinate and inexcusable" delay by the DPP in bringing about the prosecution, which breached Cunningham's constitutional right to a speedy trial. He ruled however, that in the "exceptional circumstances", there was a "far superior" and "paramount" public right to have the charges prosecuted. Mr. Justice McKechnie found the case was exceptional because of its serious and tragic consequences, and its impact on so many people. Cunningham was charged four years ago relating to the infection of seven named women, between 1977 and 1992. Under the Offences Against the Person Act, she is accused of administering, or causing to be administered, a "destructive or noxious thing", thereby causing grievous bodily harm. The only other person charged in connection with the Hepatitis C saga was Dr. Terry Walsh, formerly assistant National Director with the BtSB. He died and the proceedings against him collapsed.

Courts set to debate stance on secrecy

LITIGANTS should have their anonymity protected in "exceptional" cases, the Law Reform Commission has recommended. A new consultation paper by the government-appointed legal watchdog on the jurisdiction of the courts says that the mandatory rule requiring all parties to use their real names in civil litigation should be relaxed "where the needs of justice dictate". In the past, the courts have refused to allow those suing or being sued to keep their identities secret. Eleven years ago, the late Bridget McCole wanted to use the assumed name "Bridget M Roe" to sue the Blood Transfusion Service Board for infecting her with hepatitis C through the use of infected anti-D immunoglobulin. Her lawyers argued that Mrs. McCole wanted to protect her privacy because anyone known to be infected with hepatitis was likely to be subjected to "invidious discrimination". However, the High Court ruled that the public disclosure of the true identities of parties to civil litigation was "essential" if justice was to be administered in public. Miss Justice Mary Laffoy said that in a situation in which the true identity of a plaintiff in a civil action is known to the parties to the action and to the court but is hidden from the public, members of the public cannot see for themselves that justice is done. Former Chief Justice Liam Hamilton also refused, as president of the High Court, permission to a group of haemophiliacs infected with HIV to sue St James's Hospital without disclosing their names and addresses. In recent years Ireland's in-camera rule has been relaxed to allow certain classes of persons to attend court and report on cases otherwise heard in secret. The LRC says that a party should be able to apply to a judge to have their identity kept secret, but members of the public and media should be able to attend and report such proceedings as long as parties are not identified.

First HIV pill in a decade offers survival hope for millions

The first new oral drug for HIV in ten years has been cleared by European licensing authorities, promising much better control of the infection for millions of people. Maraviroc, discovered and developed by Pfizer in Kent, was approved by the European Medicines Agency advisory committee last week, and now only needs final marketing approval. It is also close to gaining a licence in the US. In trials, Maraviroc was about twice as effective as existing drugs in cutting HIV to undetectable levels in patients with long term infection. It does not cure the infection but, along with existing therapies, means that HIV is no longer a death sentence. The clue came from a group of haemophiliacs in Italy who did not get HIV despite being exposed to contaminated blood products. The reason was that they had a rare genetic modification in a receptor used by HIV to lock on to human immune system cells.

Please go to our website www.haemophilia where you will find these and many more articles that you can download. Articles are updated on a daily basis.