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Magazine of the Irish Haemophilia Society

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IRISH HAEMOPHILIA SOCIETY

Thursday, 18th December 2008

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Welcome to Haemophilia.ie

The Irish Haemophilia Society was founded in 1968 by members of the medical profession, people with haemophilia, their families and friends who felt the need to provide support and advice for members and to improve the quality of life for people with haemophilia.

Whats New

The HAA Card

What does it entitle me to? Find out exactly what it does entitle you to. Michele Tait, Hepatitis C National Co-ordinator tells us. read more here

Peer Support Post Tribunal Workshop

We hope to bring members and their partners together who have completed the Compensation Tribunal process. read more here

Latest News

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A round-up of this week's health news in brief. Boundary behind private hospital Boundary Capital, the investment firm led by Niall McFadden...more

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Last Updated: Thursday, 18th December 2008

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Spring 2009

Mini Marathon 2009.....

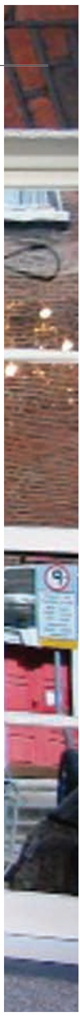
The Flora Women's Mini Marathon takes place on Bank Holiday Monday 1st June 2009. The Mini Marathon is Ireland's largest one day charity event with nearly €10 million raised for charities in 2008. The marathon starts at 3pm leaving from Fitzwilliam Square and finishes up at St. Stephen's Green. Participants must be at least 14 years of age on the Mini Marathon Day. Please also note that the event is strictly for females only, males are not allowed participate. Entry Forms are available every Thursday in the Evening Herald and the closing date for entries is 21st April 2009.

This year we are hoping to significantly increase our numbers to help raise awareness of haemophilia, and also to raise funds for the Society. The Mini Marathon continues to be a very important source of income for the Society, so we would like to encourage as many female members as possible and their friends to participate and raise funds for the Society.

As usual on the day, we will provide facilities for those taking part in Buswells Hotel in Molesworth Street. Staff from the office will be in attendance at the hotel from 1pm, where you can pick up a free t-shirt, avail of changing facilities, a cloakroom, refreshments before and after the event, and also receive a commemorative scroll. And don't forget ladies for those who raise €150 and over, you will be entered into a draw for a weekend away for two.

If you decide to take part and would like a sponsorship card, please contact Nuala in the office on 01 6579900 or you can email Nuala at nuala@haemophilia.ie.

Debbie Greene



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AGM & Conference 2009.....

The AGM and Conference took place over the weekend 6th – 8th March in the Carlton Shearwater Hotel in Ballinasloe, Co. Galway. Because of the large numbers attending the AGM weekend, and the number of programmes running simultaneously it can be quite difficult to find a hotel with all the facilities we require. I think anyone who stayed at the Carlton will agree that the hotel more than met all our needs this year, and it is a venue which will stay on our short list for future events.

The programme proper began on Saturday morning but for most delegates the weekend starts as soon as they check in on Friday and begin to meet up with their friends. I feel that organising the registrations on Friday evening encourages members to spend some time with friends, and for those attending for the first time it gives them the opportunity meet the staff in a relaxed atmosphere and to get to know other members.

The business meeting took place on Saturday morning and delegates had the opportunity to hear from the Officers of the Board and the CEO, as they presented their various reports on what has been happening throughout the year since the last AGM, as well as the plans for the coming year. One member of the Board, Barbara Guilfoyle, stepped down this year. Since there was one place available and we had received one nomination there was no need for an election. Mary Hanney who had accepted a nomination was deemed to have been elected and was welcomed onto the Board by the Chairman.

At the end of the meeting Debbie Greene and Nuala McAuley launched the newly designed website and demonstrated how to navigate the different sections. Debbie said that it was still a "work in progress" and said there were a number of new sections which have to be finalised. Check it out for yourself at www.haemophilia.ie and let us know what you think of it.

Following lunch the first presentation was from Dr. Mammen Chandy who is the Director of the CMC Haemophilia Centre in Vellore, India. Dr. Chandy spoke eloquently about the area he works in and how the centre came to be what it is today, a 1700 bed medical centre, through the vision of one woman. Ida Scudder a young American woman was visiting her medical missionary father in India in the late 1800's when she was asked one night to assist three different women in childbirth. Custom prevented these women being assisted by a male doctor and because she had no training she could not help them and each of them died in childbirth. This inspired her to return to America for medical training and following her graduation to go back to India where she opened a one bed clinic in Vellore in 1900. In 1909 she started the school of nursing followed some years later with the opening of a medical school for women. With the training of women as doctors and nurses, Indian women began to have access to health care professionals.

Dr. Chandy then spoke about his work in the haemophilia centre in Vellore. He spoke about the incidence of haemophilia and working to provide care with inadequate resources. Because home therapy is available for less that 5% of patients, the management of acute joint bleeds includes rest, ice and analgesics. He spoke about the importance they place on the role of physiotherapy once the bleed has stopped. Patients are educated on the type of exercises to do to prevent muscle wasting and contractures. Dr. Chandy highlighted the importance of education for the patient and his family, health care workers and the wider community. He said that the centre at Vellore has up to date laboratory facilities for genetic diagnosis of bleeding disorders, for carrier detection and antenatal diagnosis. To hear about what Dr. Chandy and his colleagues have done with limited resources was inspiring and to quote Dr. Chandy, when he spoke about their work at Vellore, they "light a little candle rather than curse the darkness".

Later in the afternoon Professor John Bonnar Chair of the National Haemophilia Council introduced Dr. Barry White who gave an update on Haemophilia Services in Ireland. Dr. White began by apologising that Dr. Beatrice Nolan could not attend the meeting as she was on call for the weekend. Dr. White's presentation covered the work of the National Haemophilia Council throughout the past year. He spoke about the outcome of the audits in St. James's, Crumlin and Cork. The audits identified the need for out of hours and inpatient facilities at St. James's, and Dr. White confirmed that work is progressing on this and that it is included in the budget for the current year. The audit recommended the appointment of a full time haemophilia consultant to the paediatric service in Our Lady's Children's Hospital Crumlin, and Dr. White announced that Dr. Beatrice Nolan has recently taken up this appointment. The audit report on Cork was critical that shortcomings identified from the previous audit had not been addressed, and stressed the urgent need for a haemophilia centre, a consultant

Delegates attending the AGM & Conference.....

Dr. Mammen Chandy from India who gave an excellent presentation on Haemophilia in India.....

Father & Son Paul Kirwan and Michael Kirwan.....

Nuala Mc Auley demonstrating our new website.....

Members Edel Jackson, Susan Clarke, and Marion Rabbette.....

Dr. Barry White, Director NCHCD & Dr. Safa Eltom, Consultant Haematologist, Donegal.....

Pat Downey presenting the Maureen Downey Grant to Etna Butler who collected the award on behalf of her son Daryl.....

Catriona Moriarty receives the Margaret King Educational Award from Chairman Michael Davenport.....

Hilary O'Sullivan presenting the Fundraiser of the Year Award to Marion Rabbette who collected this award on behalf of her son-in-law Tom Sheerin.....

Brian O'Mahony presenting Margaret Dunne with Honorary Life Membership.....

The Dunne Family, and how they have grown.....

Sister Act: Barbara Wynne and Jackie Wright.....

and, dental, social work, and physiotherapy support. He advised that a space has been identified within Cork University Hospital to house the haemophilia centre and that work is expected to begin on refurbishment shortly. Dr. White outlined plans for a new telephone device which has been developed for patients to record and report their usage of factor. This device, when it is in place will take the place of the pink report forms which have been used up to this. There were a number of questions from the floor on how this will work and Dr. White confirmed that it is expected that this will be rolled out in 2009. He spoke about the need to reduce the usage of factor and confirmed that this can be done by cutting out waste and trying to ensure that patients treat themselves effectively but without over treating. He also announced plans for HIV clinics to be held in NCHCD instead of GUID starting in April. Delegates felt that this was a welcome development and one that has been sought for some time. Dr. White stressed that this will apply to routine reviews only.

In a late addition to the programme some time was given for questions and answers on vCJD following a recent report from the UK that a patient with haemophilia who had died, from a cause unrelated to vCJD, was subsequently found to have evidence of infection with vCJD in some of his tissues during a routine post mortem. Dr. William Murphy Medical Director of the IBTS joined Dr. Barry White for this part of the programme. They were also joined by Dr. Paul Giangrande from the Haemophilia Centre in Oxford and the CEO of the UK Haemophilia Society Mr Chris James.

Following a busy day there was just time for a short break to get ready for Mass. I was surprised and delighted when Fr. Paddy announced that he was celebrating the Mass for Jim and I, since it was my last AGM before retiring. As usual it was very meaningful and we enjoyed the singing of Joe Rabbette during the Mass.

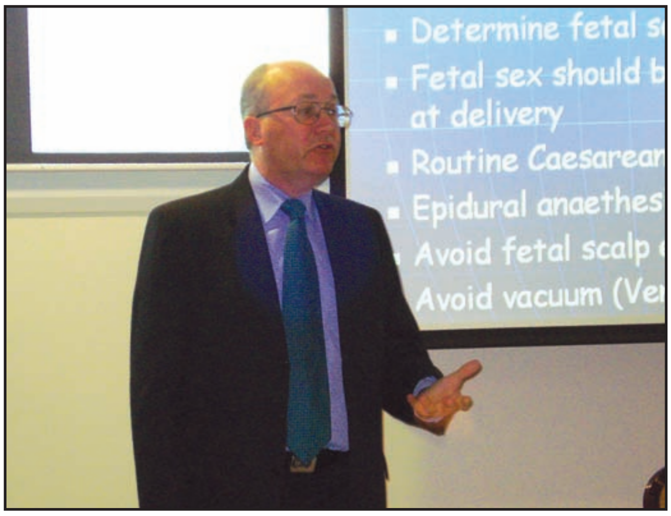
Each year the Society awards a number of scholarships to assist with the cost of third level education. For the current academic year a total of €16,000 in scholarships was paid out. Within this there were two special awards. The Maureen Downey Award for €4,000 for a person with haemophilia and the Margaret King Education Award for €2,000 for a family member of a person with haemophilia.

This year the Maureen Downey Award went to 21 year old Daryl Butler who has severe haemophilia. Daryl is studying medicine in University College Cork having completed his pre med in UCD. Daryl said his intention is to follow his Bachelor of Medicine degree with a one year Masters in Science. As well as being busy studying Daryl has found time to volunteer in our young adults programme and he took part in a debate with Ger O'Reilly at our October weekend in Mullingar. Daryl has also volunteered in Barretstown Gang Camp. Etna Butler accepted the award from Patrick Downey on behalf of her son Daryl.

The Margaret King Education Award went this year to Catriona Moriarty. Catriona is in her second year studying for her degree in General Nursing at Trinity College. She is the second eldest of a family of six and her brother Eoin has haemophilia. Catriona is a leader in the Kidlink programme. Catriona accepted her award from Chairman Michael Davenport. We are very grateful to all our fundraisers who organise or take part in events in aid of the Society and each year the Bill O'Sullivan Fundraiser of the Year Award is presented at the AGM. This year the award went to Tom Sheerin. Tom is the father of a young boy with haemophilia and with the help of his musical family Tom organised a very successful gig and raised €2276. Marian Rabbette accepted the award from Hilary O'Sullivan on behalf of Tom Sheerin

Each year up to 50 members and friends take part in the Mini Marathon on behalf of the society. In 2008 they raised over €7500 in sponsorship. We provide refreshments and changing facilities for all the runners and each year anyone who raises over €150 is entered into a draw for a weekend for two. Jennifer Homan a friend of one of our members won the prize this year.

Before the B Sharps took their place on stage to entertain us for the evening Brian paid a very moving tribute to me and presented me with a framed certificate of Honorary Life membership and a beautiful bouquet. I was very moved both by what he said and the huge response of love and goodwill from everyone there. I was particularly delighted that all my family were there, twenty of us in all, since the Society has been so much part of my life for so long. I had prepared a few words to say but I don't know if I conveyed what it has meant to me to be so much a part of peoples lives over the past twenty years and the special memories I have of that time. I have lost too many friends, people I will always remember who helped shape the Society into what it is today. I will retire at the end of April and I have no doubt I will miss everyone but I do intend to keep in touch and hope to meet up with members at the conferences for many years to come.



Dr. Paul Giangrande, Consultant Haematologist, Oxford during his presentation on Carriers & Women with Bleeding Disorders.....

Dr. Evelien Mauser-Bunschoten who spoke about Ageing and haemophilia on Sunday morning.....

On Sunday morning there were two sessions running simultaneously. I attended Dr. Paul Giangrande's presentation for carriers and women with bleeding disorders. We heard about von Willebrands disease, the inheritance pattern, how it affects both men and women, and the treatment options available. Dr. Giangrande then went on to speak about carriers of haemophilia and the management of carriers during pregnancy. His presentation also touched on the more rare bleeding disorders. Dr. Giangrande was happy to answer any specific questions and during discussion he stressed the importance of knowing your carrier status. There was some discussion as to what is the appropriate age for girls to undergo genetic testing to determine their carrier status. This focused mainly on their ability to understand the implications of being diagnosed a carrier, and I think it was generally agreed that it was more important for parents to be aware of their daughter's factor level while she is young. It was also agreed that it is very important for a potential carrier to know her carrier status if she is planning a family. Dr. Giangrande went on to speak about the developments in reproductive choices and antenatal diagnosis. I think this was a good session with plenty of interaction with the delegates, and included carriers who already have children, younger carriers who have yet to experience this, some mothers of younger carrier daughters, some women with von Willebrands Disease and one brave man who has a carrier daughter. I noticed some of the mothers stayed back at the end, no doubt comparing notes and learning from each others experiences.

Running simultaneously with Dr. Giangrande's presentation was a presentation from Dr. Evelien Mauser Bunschoten from the Van Creveldkliniek in Utrecht who spoke about haemophilia and ageing, and I believe this was also an excellent session.

The last session on Sunday morning was the open forum jointly chaired by Michael Davenport and Brian O'Mahony. The open forum formula gives delegates the opportunity to address issues of concern to them. It is also a way to find out from members if the programme content is relevant and to make suggestions for future events. Because of the success of this format it is our intention to continue to offer this opportunity to delegates at future events.

The weekend concluded with the full group, adults and children, coming together for lunch after what I think was a very successful AGM and conference.

Margaret Dunne

Our fantastic Creche Supervisors Carmel Downey, Deirdre Ryan and Marie Fay.....

Administrator Margaret Dunne and Board Member Ger O'Reilly.....

Staff Declan Noone and Debbie Greene with volunteer Barbara Guilfoyle.....

Members Aileen & Martin Moloney.....

Attendees at the Open Forum on Sunday morning.....

Staff Nina Storey and Nuala McAuley at registration.....

AGM 2009: Kidlink & Creche.....

This year once again there was an exciting Kidlink programme organised. As usual the Kidlink group met up on Friday evening and wasted no time in getting acquainted with their friends. The theme running through the Kidlink programme was the differences between the Irish and Indian experience. On Saturday morning following swimming the older boys and girls had an opportunity to hear from Dr. Mammen Chandy about haemophilia in India. This gave them an insight into what it is like to live in a country where people struggle for their basic needs and where haemophilia is not a health priority. From looking at the video message they later prepared for their counterparts in India I feel that Dr. Chandy did make a huge impression on them. The younger Kidlink members heard about India through a fun quiz using simple words and pictures.

For the whole group Saturday afternoon was taken up with making a film and when we saw the finished piece on Saturday evening it was very impressive. I love the way the young people throw themselves into whatever activity is arranged. I have no doubt that this was the first time for most of them to take part in anything like this. It seems to me that we have a lot of talent in this group both the performers and the behind the scenes technical people. The Kidlink programme could not be provided without all of our leaders, who give up their weekend, or Alison Daly who works with us in putting it all together and is so enthusiastic when working with our young members.

For the very young members the crèche was organised once again by Carmel Downey and Deirdre Ryan who were ably assisted this year by Marie Fay. From feedback we receive the crèche facility is very much appreciated particularly by new parents who are anxious to learn as much as they can by attending the different sessions. It also gives them an opportunity to speak with other parents and maybe pick up some tips. We are aware that for those attending their first conference it is not easy to leave a young child in the crèche, and parents are reassured that they will be contacted immediately if the need arises. All of the children I saw at the end of the weekend were very happy and proudly showed off their amazing artwork. Again this assistance could not be provided without the commitment and support of the crèche staff who give up their weekend for us.

Margaret Dunne

Kidlink Group who had a wonderful time at the AGM.....

Alison Daly who always does a great job with the Kidlink Group.....

Our High School Musical Girls.....

Kidlink & Youth Group volunteers, Paul Dunne, Amy Carroll, Barbara Guilfoyle and Catriona Moriarty, thank you all.....

The children in the Creche had a ball as you can see from this photo.....

Lets Make a Movie: Lights, Camera, Action.....

Now what shall we dress up today as.....

Lucia Prihodova volunteer with Jessica Byrne

Who has the biggest muscles.....

New look website just launched.....

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I am delighted to be able to announce that our new look website was launched at our recent AGM & Conference. The address stays the same which is **www.haemophilia.ie.**

We started working on researching design and content last November and I hope you will agree after logging on, that the website now looks more appealing, has more structure, is modern and has something for every member of the Society including adults, parents, children, and young adults. We would like to encourage you to log on and have a look and let us know what you think. Over the course of the next few months we hope to really develop the website and keep it updated on a regular basis.

On the homepage you will find **Contact Details**, a **Whats New section**, a list of the Various Sections on the left hand side, and also a **Zenark Media** section on the right hand side. Zenark Media allows us to feed any relevant newspaper articles directly onto our website on a daily basis. Also on the homepage a new feature is the facility for members to log on and sign up for an electronic version of our magazine. In time we are hoping that more and more members will sign up for this.

On the left hand side you will find a list of the various sections. INFORMATION is our first section and within this section you will find subsections on: **Bleeding Disorders, HIV/Hepatitis C, Factor Safety Issues, Treatment Centres**, and sections for **Adults, Parents, Young Adults and Children**. This Section gives very good information in plain english. If you click on any of these sections you will then find more sub sections. We are also hoping towards the end of this year to have a type of Discussion Forum in this section, whereby members can log on make some comments, perhaps share experiences, build friendships and learn from other members. This has not yet been finalised, however we are researching this at the moment. For the Children's Section Nuala in the office is putting together some fun pages which will include jokes, riddles, puzzles and competitions.

The next section refers to the ORGANISATION itself, and in this section you will find sub sections on: **About the I.H.S.** which gives a brief history of the Society and is very interesting especially for new members, **Services & Support, Events & Activities, Get Involved** and our **Galleries** section. As Nuala explained to members at the AGM another new feature to the website is the ability to register for events online, which we hope will be useful and convenient for a lot of members. Registering online for an event will be exactly the same as completing the booking form we send out in the post. Registering online obviously is faster and also secures your place quicker as our events are growing more and more popular every year. In the Get Involved section you can register or renew your membership online.

REFERENCE is our last section and within this you will find sub sections on **Publications, Statutory Bodies, a Global Perspective, Media Information, and Links.**

In the Publications section you can download our magazines, annual reports and various other information booklets. This year we are hoping to produce some inhouse publications to put onto the new website, and we are also hoping to update some of our older publications including:

- Women with bleeding disorders
- Dental care
- Counselling
- Ageing
- Entitlements & Benefits

The section called Statutory Bodies gives good information in relation to the National Haemophilia Council, the Product Selection Board, and the Consultative Council on Hepatitis C. In Global Perspective you will find information on the World Federation of Hemophilia, the European Haemophilia Consortium, and also all their Calendar of Events.

During lobbying campaigns we find that we receive a lot of calls from the media, so we felt by putting up some basic information on haemophilia it would give them a better understanding of the condition.

Finally in our Links section you will find some very useful links including:

- H.S.E.
- Barretstown Gang Camp
- Hepatitis C Compensation Tribunal
- National Haemophilia Council

Well we hope this gives you a good insight into our brand new website. Why not log on and see for yourself and let us know what you think? Nuala and myself would be delighted to hear any feedback or suggestions you might have.

Debbie Greene

Important Message.....

To enhance our magazines and website, we use photographs that have been taken at our events and activities. If you would prefer not to have your photograph included in our publications, please contact Debbie Greene in the office on 01 6579900.

Hepatitis C Information Day.....

The Consultative Council on Hepatitis C Information Day took place on the 21st of February 2009 at the Croke Park Conference Centre. The theme of the day was "Where we are 30 years on". The event was very well attended with approximately 280 people attending on the day after battling through over 80,000 protesters against the pension levy in the city centre. The conference started with a welcome from Michelle Tait and a plenary talk from Dr. Liz Kenny. Dr. Kenny spoke briefly about the last 30 years and developments in treatment, the Insurance Scheme, the Information Days and the upcoming Hepatitis C International Conference taking place in Dublin Castle in June of this year. She launched the new 'Living with Hepatitis C' booklet, and the first follow up report on the National Hepatitis C Database. She also mentioned that the Travel Insurance Scheme was up and running, and that she was very happy to finally see this last part of the Insurance Scheme in place.

Following the plenary talk there were a number of workshops which ran for the rest of the day. These included workshops on The Fibroscan, Treatment, Use of the Database Information, Men's Issues, Liver Transplantation, and Tummy Troubles. A new introduction this year was a workshop specifically for carers, and also the provision of a chatroom for the under 35's to facilitate discussion on topics relevant to this group. There were also two sessions allowing delegates to meet with the Liaison Officers and the Hepatalogy Nurses to discuss any issues of concern. The Database workshop, which was presented by Brian O'Mahony, dealt with the information from the newly launched Hepatitis C Database report. This workshop started with a 'Why we needed the database?', and how it was useful in showing the natural history of Hepatitis C and liver disease, the participation rates in treatment, the frequencies of side effects and the uptake in the health services. The database statistics highlighted the differences between all the infected Irish groups. These statistics will be very useful in determining the relevant issues for each group and can be used in planning services and support for members of the various groups. Some of the most interesting statistics from the new database report is that in comparison with all the other groups (Anti-D, Transfusion/Renal and Clotting factors) people infected by clotting factors had the highest percentage of the signs of liver disease (28%) and deaths related to liver disease (10%). However, when it comes to treatment, people with haemophilia and von Willebrand's have some of the lowest percentages of people stopping treatment early. This data has also showed that the factors associated with having more severe liver disease include, high alcohol intake, age, age at infection, high ALT's, duration of infection, gender weight and genotype. This information has practical utilisation in planning services such as alcohol education, peer support and advocacy (i.e. access to a Fibroscan for people with bleeding disorders). What was also highlighted was the limitations of the database. It shows trends and not individual data. There are limited numbers in the database and it includes information from charts only. This was a very informative workshop and reiterates the importance of joining the database not only for you as an individual but for all infected with Hepatitis C. If you would like to sign up to the database or are unsure if you already have, please check next time you are at the National Centre.

The Fibroscan workshop presented by Dr. Liz Kenny discussed the uses of the machine in non-invasive assessment of liver fibrosis. Dr. Kenny discussed current indicators of liver disease, described blood tests, biopsy with the advantages and disadvantages, and the need for a non-invasive reliable method of determining liver damage. She carried on to talk about how the machine works, why it is used and the advantages and limitations of the Fibroscan. The Fibroscan machine works on the basis of elastic properties of tissues. Basically as the liver starts to develop fibrosis and progresses to cirrhosis, its elastic properties change and the liver becomes stiffer. A simple analogy is like chewing gum. It's soft and flexible when it comes out of your mouth but after a while it becomes more solid or stiffer. Using the Fibroscan, a sound wave is passed through a probe and bounced off the liver. The time it takes for the sound wave to leave the probe, bounce off the liver and return back to the probe is measured and this can be translated to a reading showing how elastic or stiff the liver is. This value can then be used to determine the amount of fibrosis or cirrhosis present in the liver. The probe is on the skin between the ribs. The examination with the Fibroscan takes around 5 minutes and it will take 10 readings. The values for each reading is then used to determine an average value for the stiffness of the liver and hence the amount of liver disease present. The machine can be used by a trained doctor. There are a number of advantages to the Fibroscan. It is non-invasive, can take multiple readings which reduces errors, it can assess a large area of the liver and the results are immediate. The accuracy of the Fibroscan can also be increased when used in conjunction with blood tests. However this method also has a number of limitations. It is less accurate when measuring fatty liver disease, measuring liver disease in obese people, and most importantly it has difficulty in measuring early stage (Stages 2-4) of Fibrosis, using a scale of 0-6. Taking into account the advantages and disadvantages, using the Fibroscan for monitoring is useful. However, until the machine develops further the gold standard, a liver biopsy is still used. Dr. Kenny also briefly mentioned the new trans-jugular biopsy. This involves a catheter style needle inserted into the jugular at the neck and moved through the venous/arterial system to the liver where it takes the biopsy. This is being used for some patients with bleeding disorders. There is a reduced risk of bleeding as it is within a closed system as opposed to a regular biopsy which moves through or past a number of systems.

In the Liaison Officers workshop, Michelle Tait spoke about some of the entitlements under the HAA Card. She also noted that there wasn't as much knowledge in the general community of GP's, Optometrists, Pharmacists, Physiotherapists, etc and that some of these professionals are not aware of the entitlements. She suggested to help with this to contact your Liaison Officer prior to going to your appointment, and they will ensure that they are made aware of the entitlements of the card.

The Men's Issues workshop provided a number of interesting topics for discussion between men with Hepatitis C and their partners. The main topic was dealing with treatment from both perspectives, the patient and their partner, and the most important point was having an awareness of self. This is fancy words for something simple yet easily forgotten. Whether you are on treatment or not make sure that you take time just for yourself to do something that you enjoy and provide some form of escape whether it is a massage, a book or a movie. There was also some minor discussion of hiding on the grounds of Croke Park in order to see the rugby game the following day. Overall the session was very well attended and facilitated well by Shay Keating.

The Tummy Trouble workshop mostly discussed common digestive problems associated with the general public such as heartburn, bloating, diarrhoea or constipation but these can be more common in people with Hepatitis C. This can be due to irritation of the bowel and can be diagnosed as Irritable Bowel Syndrome. The talk discussed food types like cheese, yeast, bananas, eggs and dairy products that can cause an allergy or intolerance (slow reaction that can last for up to 2 days depending on the amount ingested) that can lead to discomfort. There are two main options for treatment of these problems. Removing these products from your diet is the first option and the second is using supplements or homeopathic medicines to ease the symptoms. A word of caution was advised when taking supplements. It depends on general health and specific symptoms and it is worth talking with a qualified person in the area before starting. The workshop also talked about the use of complementary therapies such as acupuncture, massage and reflexology as a way of dealing with the symptoms.

The Hepatitis C treatment workshop dealt with the importance of being well prepared and informed when starting treatment. This workshop also discussed how important it is to: obtain social support from your family, consult others with similar experience and how important the timing is when starting treatment. It was also pointed out the importance arranging your time so the treatment process is eased as much possible by checking your entitlements and avoiding unnecessary complications by getting all other medical check-ups before the start of treatment. There were a number of people who spoke about their personal experiences of treatment and shared some tips for dealing with side effects, which seemed to help them.

The Information Day also had an excellent publications area which included stands from the Irish Haemophilia Society, Transfusion Positive, Positive Action, and a Complementary Medicines stand. John Dwyer, Administrator of the Hepatitis C Insurance Scheme was also in attendance along with a Travel Insurance Company and both were available to answer any questions on any part of the Insurance Scheme.

Overall the Information Day was a great success with very concise and clear information throughout all the workshops and talks. Congratulations to the organising committee which includes our very own Margaret Dunne, and all involved for a great day and special thanks to Fiona O'Connell and Michelle Tait. I will also take this opportunity to inform you of the upcoming Hepatitis C International Conference that takes place from 17th - 19th of June 2009 in Dublin Castle. This conference will have some very interesting and informative sessions on the advances made in the last 30 years, and what is coming in the near future. A subsidy is available for IHS members for registration. Please contact Nina Storey in the office if you would like to attend.

Declan Noone

Safety & Supply Update.....

Press Conference at I.H.S. headquarters on 17th February 2009

Communication on vCJD

On February 15th an article appeared in the Sunday Telegraph in the UK in relation to a man with haemophilia who had prions in his spleen at autopsy. This referred to a 74 year old man, with haemophilia, who died in the UK some months before, and had a routine autopsy. This man did not die of vCJD, and in fact he did not have clinical vCJD. He died of other causes. However, when the autopsy was preformed prions (the abnormal proteins that cause vCJD) were found in his spleen. The most likely cause of these prions being in his spleen was the use by this man of plasma derived factor concentrates in the past. This was in fact the first time that prions had been found in any person with haemophilia anywhere in the world. It is important to note that of the thousands of people with haemophilia in the UK who received plasma-derived factor concentrates in the past, none of these has developed vCJD. This information is relevant to those who used plasma-derived factor concentrates in the UK between 1986 and 2001, or those who used plasma-derived factor concentrates manufactured from UK plasma at that time. These factor VIII and factor IX concentrates were never imported into Ireland from the UK but some people with haemophilia from Ireland would have received treatment while living or working in the UK. In addition, a number of persons with rarer bleeding disorders would have received treatment with UK plasma derived factor concentrates in Ireland. We recognised that this would be an issue of concern for those who had received UK plasma derived product and an issue of interest and possible concern for all people with haemophilia.

We followed a communication strategy similiar to our response in 2004 and 1998 when similar events occurred. Letters were sent jointly from the National Centre for Hereditary Coagulation Disorders (NCHCD, St. James's) and the Irish Haemophilia Society on February 16th to all persons with haemophilia and related bleeding disorders throughout the country. From February 17th to 27th a helpline operated from the NCHCD. On February 17th a press conference was held at the IHS headquarters in Dublin where Dr. Barry White, (Director NCHCD) Dr. William Murphy (Medical Director, IBTS) and I gave details to the media on the current situation. These were followed by special meetings in Cork on February 27th and Dublin on February 28th. Finally, a further session was held the following weekend at the IHS AGM on March 6th in Ballinasloe. In addition to Dr. White, Dr. Murphy and myself this latter session was attended by Dr. Paul Giangrande from the UK and Mr. Chris James, CEO of the UK Haemophilia Society. We earnestly hope that this four pronged communication strategy ensured that all people with haemophilia in the country had access to the information they required in a timely manner. Furthermore we believe that it assisted in ensuring that the media coverage was fair, balanced and factual. We will of course provide further updates to members as and when the situation develops.

New Product Developments

A new third generation recombinant factor VIII is expected to be licensed by the EMEA in Europe. This new product manufactured by Wyeth will be the successor to their current B domain deleted recombinant factor VIII, Refacto. This new product will be third generation as it will contain no human or animal proteins in the cell culture. There are

two other interesting alterations in this product: the murine (mouse monoclonal) antibody will be replaced by a synthetic ligand and there will be a nano-filtration (virus removal) step at the end of the manufacturing process. Green Cross Corporation in South Korea has recently received marketing approval from the Korean Food and Drug Administration for a new B domain deleted recombinant factor VIII product which will be named GREENGENE. A new recombinant factor IX concentrate produced by Inspiration Biopharmaceuticals has begun Phase I clinical trials to assess the safety, tolerability and pharmokinetics in 34 patients. This company are also working on the development of new recombinant factor VIII and factor VIIa concentrates.

Prophylaxis and Compliance

In a study carried out in 6 European countries (France, Germany, Italy, Spain, Sweden and the UK) patient adherence to prescribed haemophilia treatment was 80 - 87%. This study was based on interviews with 180 people with haemophilia. The four leading reasons for not using the prescribed amount of clotting factor or skipping the administration interval were :

1) Reduction in, fluctuation or disappearance of symptoms
2) Forgetfulness
3) Lack of time for treatment
4) Convenience issues

This study highlights once again the need for compliance with prophylaxis regimes and the need to ensure that the correct doses are being taken at the correct intervals. This is a subject that will be covered at the forthcoming Parent's Conference at the end of April. This is being organised jointly by the Irish Haemophilia Society and the comprehensive Haemophilia treatment centres in St. James's Hospital and Our Lady's Children's Hospital, Crumlin.

Archer Inquiry Report in the UK

In late January the inquiry into HIV and Hepatitis C infection of people with haemophilia in the UK, which was conducted by Lord Archer, issued its report. The terms of reference of the inquiry were "To investigate the circumstances surrounding the supply to patients of contaminated NHS blood and blood products, its consequences for the haemophilia community and others afflicted and suggest other further steps to address both their problems and needs of bereaved families." I had the pleasure of working with the UK Haemophilia Society during their preparation for the Archer Inquiry and I also gave evidence to the Inquiry. The recommendations of the Inquiry were very forward looking and positive. Their first recommendation was that "A statutory committee should be set up to advise the government of the UK on the management of haemophilia, to include the selection and procurement of the best therapies available, readily available access to any necessary treatment and all provisions necessary to address the financial and other needs of haemophilia patients." The report stressed the importance of patient representation on this body through nomination by the Haemophilia Society. Lord Archer recognised the requirement for a statutory body such as the National Haemophilia Council in Ireland which gives the I.H.S. a real say in setting policy on haemophilia. The other major recommendations include areas which have been achieved in Ireland such as

special medical cards entitling the holder to benefits not freely available under the NHS (similar to the HAA Card) and direct financial relief for those infected with HIV and Hepatitis C (it was stressed that the payments to be made should be at least equivalent to those payable under the Irish Scheme.) Recommendations were made on the requirement for insurance and for funding for the UK Haemophilia Society. The UK Haemophilia Society currently receives very little funding from their government. Lord Archer in his report clearly understood that this was an untenable and unacceptable situation. We join with our colleagues in the UK Haemophilia Society in calling on their government to respond rapidly, decisively and compassionately to the very practical recommendations set out in this report.

Brian O'Mahony

I Have A Dream.....

Psychosocial session attended by adults, parents and children with haemophilia

The old city of Minsk

I have just awoken from a dream where a member is ill…and I feel helpless. Now, I am thinking of the people I have met during my five day visit to Minsk, Belarus. I cannot stop thinking of these people, their faces are in my mind, and I feel their passion, for it has touched my heart! Let me explain…

> *"The new board members of the Belarus Association of Haemophilia Patients are passionate, organised and determined."*

I went to Minsk as a World Federation of Hemophilia volunteer from the Psychosocial Committee. My first meeting with two board members of Belarusian Association of Hemophilia Patients was on Friday morning. I went with Adriana Bida, Programme Officer from the World Federation of Hemophilia to an apartment block in a residential area. Stepping through slush, we had to enter the building by the back door – a heavy black iron door which opened into a small one roomed apartment. This is the office of the Belarusian Association of Hemophilia Patients. We received a warm welcome from Sergei Zinkevich, President and Liudmila Golitsyna, Board Member. They had been working very hard to organise their National Conference to be attended by both patients and doctors. Speaking passionately Liudmila says she hasn't slept for days. Sergei is quieter. Mobile phones keep ringing as they tell us of their difficulties. Today, they are having a meeting

Entrance with many steps to Ninth Hospital where adults with haemophilia attend

with the Ministry of Health to get written permission to have a First Aid Medical Team with factor at the Conference.

Next Adriana and I visit the Ninth Minsk Clinical Hospital. This is where people with haemophilia attend the Haematology Department. We meet Dr. Yacheslow Dimitrivev, National Chief Medical Officer for Clotting Disorders. Dr. Dimitrivev takes us to see the haematology laboratory where Dr. Elena Oganova, Head of the Laboratories is warm and friendly. Dr. Oganova proudly shows us her fully automated laboratory. Due to major rebuilding at the hospital, three staff work in a very small room. We then visit her office complete with armchairs, couch, tea making facilities and many plants. She eagerly talks about her work. We hear how people with haemophilia have benefited indirectly from the Ninth Hospital doing liver transplants. The fully automated laboratory can do tissue typing and all factor levels except factor XIII.

Anne Duffy from the I.H.S. and Adriana Bida from W.F.H.

On Saturday and Sunday I attended the National Patient Conference. It was attended by 180 members and five doctors, together with other health care professionals. The meeting took place in a large lecture hall in the Medical Institute. Children sit alongside their parents and adults with haemophilia. Their behaviour was remarkable for two whole days. One parent told Adriana her secret.…the promise of a McDonald's meal worked wonders. I was asked to facilitate two one hour groups of patients on psychosocial issues. As this turned out it they took place in a lecture hall, so we had a discussion about their concerns with many questions and little answers. Their main concern was the lack of factor available to patients outside of Minsk. While I had to work through a translator, I felt that I got an insight into the plight of these people and their desire to improve the services and their lives.

Sergei Zinkevich, Liudmila Golitsyna, and Yuri Zyoluv enjoying dinner after the conference

I have been impressed with the new board members of Belarusian Association of Hemophilia Patients. They are passionate, organised and determined. They arranged six buses to bring the members from all over Belarus to Minsk. Each member completed detailed information forms including what they needed from the Conference. Belarus joined the Global Alliance for Progress programme last year. The World Federation of Hemophilia are helping with fellowships for laboratory personnel and orthopaedics. Yuri Zhulyov, President of the Russian Hemophilia Society who will speak at our Annual Conference in 2010 said that he has seen great improvements in the last two years made by the Belarusian Association of Hemophilia Patients.

Anne Duffy

Calendar of Events.....

APRIL

PARENTS WEEKEND

Date:
Friday 24th - Sunday 26th April 2009

Venue:
The Marriott Hotel, Ashbourne, Co. Meath.

The Irish Haemophilia Society is pleased to announce details of our first ever Parents Weekend which is being organised in association with Our Lady's Children's Hospital Crumlin, The National Centre for Hereditary Coagulation Disorders at St. James's Hospital and Cork University Hospital. We have worked closely with Dr. Beatrice Nolan at Our Lady's Children's Hospital Crumlin, and other team members to offer you what we hope will be an informative programme covering many issues of interest to parents of children with a bleeding disorder. The programme will include presentations from members of the care teams and some presentations on personal experiences of living with a bleeding disorder in the family.

PROGRAMME

Friday 24th April

19.00 – 20.00	Registration & Introduction

Saturday 25th April

10.00 – 11.00	Prophylaxis & Compliance
11.00 – 12.00	Sports & Haemophilia
12.00 – 12.30	Insurance cover for sports
12.30 – 13.30	Lunch
13.30 – 14.30	Anxiety & Fears about Needles
14.30 – 15.00	Coffee break
15.00 – 16.30	Letting go, Handing your child over
16.30 – 17.30	What about me? A Sibling's Perspective
20.00	Dinner

Sunday 26th April - Independence

10.00 – 11.00	Relationships
11.00 – 12.00	Self Infusion, Pathway to Independence
12.00 – 13.00	Open Forum
13.00 – 14.00	Lunch

CHILDREN

To allow parents attend the full programme, creche facilities will be available from 09.30-17.30 on Saturday, and on Sunday from 09.30-13.00. Children over 7 years of age will be supervised on Saturday from 09.30-17.30 and on Sunday from 09.30-13.00.

JUNE

MINI MARATHON

Date:
Monday 1st June 2009

The Flora Women's Mini Marathon takes place on Bank Holiday Monday 1st June 2009. The Mini Marathon continues to be a very important source of income for the Society, so we would like to encourage as many female members as possible and their friends to participate and raise funds for the Society. For further information please go to page 2 of the magazine.....

CONSULTATIVE COUNCIL ON HEPATITIS C: 3RD INTERNATIONAL CONFERENCE

Date:
Wednesday 17th to Friday 19th June 2009

The upcoming International Conference on Hepatitis C, 'The Third Decade and Beyond', is due to take place on 17th – 19th June 2009 in Dublin Castle. A host of International and Irish experts working in all areas of hepatitis C related services will be participating in this 2 strand conference with programmes for clinicians, researchers and patients. The Irish Haemophilia Society is pleased to be able to offer a subsidy to members who wish to attend this important conference. For registrations received after 27th March the fee for members will be €75 (normal rate €125). If you wish to avail of this subsidised fee please return your registration form directly to the office and we will process and confirm your booking.

JUNE

HIV/HEPATITIS C CONFERENCE

Date:
Friday 19th to Sunday 21st June 2009

Venue:
The Park Plaza Hotel, Tyrrelstown, Dublin 15

PROGRAMME

Friday 19th June

19.00 – 20.00	Registration & Introduction

Saturday 20th June

10.00 - 12.30	Update on treatment & Monitoring
12.30 - 14.00	Lunch
14.00 - 17.00	Living with HIV/Hepatitis C or Partners Issues
17.00 - 18.00	Full group: Workshop
20.00	Dinner

Sunday 21st June

10.00 - 12.00	Full group: Workshop
12.00 - 13.00	Update on tax
13.00	Lunch

SEPTEMBER

RELATIVES DAY

Date:
Saturday 5th September

Venue:
I.H.S. Office

This Information Day is an introduction to a better understanding of haemophilia for grandparents, uncles and aunts for whom haemophilia is a new experience. This will be an opportunity to get answers to all those unasked questions. Keep checking our website for further updates.....

SEPTEMBER

REGIONAL VISITS

Date:
Monday 28th to Wednesday 30th September

We are organising a number of Regional Visits during September this year. Dates and venues will be confirmed shortly.....

OCTOBER

MEMBERS WEEKEND

Date:
Friday 16th to Sunday 18th October

Venue:
To be confirmed

Following on from the success of our ever popular Members Weekend, we are pleased to inform you that a similiar weekend will take place again this year. We are in the process of looking at a Preliminary Programme which we hope will provide a mix of information and practical interactive sessions for all. The format for the weekend will be similar to last year in that we will provide Crèche Facilities for children up to 6 years of age. The Kidlink Programme will be open to children from 7 to 11 years of age. And for those aged 12 years and over, we are hoping to organise a residential adventure weekend. As soon as the venue and programme is confirmed we will be writing to all members. In the meantime further updates will be available on our website.....

NOVEMBER

REGIONAL VISITS

Date:
Monday 9th to Wednesday 11th November

We are hoping to organise a second round of Regional Visits towards the end of the year to enable members update themselves with our services, activities and to raise any issues of concern they may have.

Hello everyone! Welcome to the Irish Haemophilia Kidlink & Tots Club. We hope you enjoyed the AGM. From your evaluations forms it certainly looks like you all had a great time. What was your favourite part of the weekend? Perhaps it was swimming, making the fantastic movie, or listening to Dr. Mammen Chandy from India. I hope you all received a copy of the movie in the post from Declan. For those of you who went to the creche Carmel, Deirdre and Marie said that all the girls and boys were very well behaved, and enjoyed themselves very much. So well done to all of you. And don't forget girls and boys to have a look at our new website where you will find some very interesting information about haemophilia, some jokes, games and competitions. If you have any questions that you want answered or if you have any suggestions for our Kidlink page, we would love to hear from you just email us at info@haemophilia.ie

Debbie Greene

JOKES CORNER

Doctor, Doctor I think I'm a bell?
Take these and if it doesn't help give me a ring!

Doctor, Doctor I've got wind! Can you give me something?
Yes - here's a kite!

What kind of dance do you do on a trampoline?
Hip-Hop

Boys rule ok

Irish Haemophilia Society

Cumann Haemifile na hEireann

We represent People and families with
Haemophilia,
von Willebrands Disease,
Rare Bleeding Disorders

Programmes

Education
Publications
Counselling
Family Support
Advocacy
Conferences

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