haemophilia.ie

Magazine of the Irish Haemophilia Society




June 2010

SECOND ANNOUNCEMENT

MEMBERS' CONFERENCE 2010

Preliminary Programme

Dates: **Friday 15th October to Sunday 17th October 2010**
Venue: **Carlton Castletroy Park Hotel, Co. Limerick**

Friday 15th October

6.30pm - 7.30pm	Registration

Saturday 16th October

9.30am – 11.00am	Mother's Workshop / Father's Workshop
	OR
10.00am – 10.30am	Entitlements & Benefits
10.30am – 11.00am	Using Social Media
11.00am – 1.00pm	Positive Living with a Bleeding Disorder
1.00pm – 2.00pm	Lunch
2.00pm – 3.00pm	Debate: "Guiding the child with haemophilia, who does it better, the mother or the father?"
3.00pm – 3.30pm	Coffee Break
3.30pm – 5.00pm	I.H.S. Services & Support
5.00pm – 5.30pm	Using Social Media (for Mother's & Father's)

Sunday 17th October

10.00am – 1.00pm	Drama Workshop - Full Group
1.00pm – 2.00pm	Lunch

CRECHE

Full creche facilities will be available for the weekend. All children must be booked in at the time of booking. If you book your child in for the creche, we would ask that you please do leave your child in the creche.

KIDLINK

The Kidlink programme will be based in the hotel and will start on Saturday morning. This programme is for children from 7 to 11 years. Parents, please remember you must sign your children in for the Kidlink programme.

YOUNG ADULTS

Young adults will leave the hotel on Friday evening and will travel to a nearby hostel for 2 overnight stays. On Saturday young adults will attend the Limerick Adventure Centre. This programme is for 12 to 18 year olds.

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Youth Group/Kidlink Co-ordinator
Alison Daly

Contents

Parents Conference

"When parents come to the Hospital, they meet other parents, but they are in hospital for a reason and they are highly stressed – their child has a bleed or their child is in for surgery. However, weekends like the Parents' Weekend allows them to talk to one another. Here, parents meet parents and children meet children and everybody is on one level of the same experience. We have had people, both kids and parents, asking us since Christmas if there would be another Parents' Weekend."
Mary Kavanagh, Haemophilia Nurse Specialist, Our Lady's Children's Hospital Crumlin speaking on why she feels the Parent's Weekend is so beneficial.

The second annual Parents' Weekend took place on April 23rd – 25th 2010 in the Castleknock Hotel and Country Club in Dublin. After the success of the first Parents' Weekend in 2009, the Society hoped for similar interest from members this year and we were not disappointed, not only were attendances up from last year, but the weekend itself was booked out. To anyone who was unable to attend the conference, the presentations from the weekend are up the website, we hope you find them beneficial.

The weekend began, as usual, with registration on Friday night. Registration was well attended and allowed the staff to meet with some new families, some who are not members of the Society and some who are members, but had not attended any of the I.H.S. events previously.

The programme itself started at 10am on Saturday morning. The hotel reception was a hive of activity with people registering and heading off to their various groups.

The crèche base for the weekend was the Castleknock Suite, which was a perfect room for a group of 17 children. Carmel Downey was once again matriarch of the crèche with help from Sandra, Jane, Jenny and my own sister, Laura and Mam, Julie. The kids in the crèche really enjoyed themselves over the weekend, with various activities to keep them entertained including: arts 'n' crafts, dvds and a nature walk to name, but a few. Indeed at one stage the nature came to the crèche with every child having their very own parrot! Speaking to Carmel at the end of the weekend, she said she felt the weekend was a great success and the fact that the crèche was full to capacity showed how much people appreciate these weekends and how beneficial they are, not only to the adults, but to the children as well. A huge thank you to Carmel and all the volunteers in the crèche for their hard work over the weekend, they certainly had their hands full!

The adult and kidlink programmes started together on Saturday morning with a talk from Kidlink Coordinator Alison Daly. Alison informed parents and children of the changes to the I.H.S. child protection policy and the Kidlink group agreement. The Kidlink group agreement is a document which each child signs up to, witnessed by their parents, that states they understand the rules of the Kidlink programme and promise to abide by them.

Once everyone had signed their agreements, the kids left the talk to go swimming, which is always one of the highlights of the weekend. After over an hour in the pool, the Kidlink group met in reception before heading off on their bus tour to see the sights of Dublin. The first and indeed only stop on the bus tour was the Irish Museum of Modern Art in Kilmainham. After enjoying a lunch in Mc Donalds, the kids were more than happy to explore the grounds of the Royal Hospital and kept the Kidlink leaders on their toes with games of chasing and hide and seek. After a fun filled afternoon in the sun it was back to the hotel for some family time before dinner.

While the kids enjoyed the fabulous weather that Dublin was experiencing, their parents were taking part in workshops and educational sessions. The main session on Saturday, "Improving Your Child's Quality of Life", was broken down into four talks, the first by Dr. Beatrice Nolan, Consultant Haematologist in OLCHC which focused on haemophilia in the first two years of life. The talk itself was very informative and indeed was very interactive. Although the session focused on the haemophilia in the first two years of life, there were many parents of older children at the session who shared their experience with parents of younger children, which was very beneficial. Evelyn Singleton, Haemovigilance Officer in NCHCD, spoke next on the handheld devices which are being introduced at the moment. The handheld devices come with many benefits in relation to haemophilia care including: more accurate data collection, reduction of work for patients who currently fill out their treatment sheets and post them back to the centres, and easier data analysis for the centres. Evelyn updated the group on the current situation in relation to the handheld devices and explained in more detail the benefits using these electronic devices. After her talk, Evelyn gave individuals a chance to test the handheld devices and showed them how they work. The next part of the session involved I.H.S. Counsellor, Anne Duffy, giving parents a talk on "Prophylaxis Outcomes". Anne's talk featured data collected from Brian O'Mahony and Declan Noone from a recent survey they conducted in European countries on the benefits and effects of using prophylaxis. This talk was very interesting and showed in black and white the importance of prophylactic treatment. The last part of the session was titled "Getting the best from your care" and included talks from Dr. Beatrice Nolan and Traci Dowling, a mother of a young adult with haemophilia. This talk ended the session off nicely, and went down extremely well with the group.

After a break for lunch, the programme continued with Rachel Brosnan, a Clinical Child Psychologist, making a presentation on communicating age appropriate information to children. This session was very well attended and looked at not only talking to the child with haemophilia, but also siblings. This led nicely into the next session, "Parenting Skills: Impact of Haemophilia". This session took the form of a workshop as after talks from Anne Duffy, Traci Dowling and Anthony O'Connor, a father of a child with haemophilia, people opened up to each other about their different experiences and how they have dealt with various issues including siblings, sports, needle-phobia and hospital visits. In such a supportive environment, it was great to see that everyone in attendance felt comfortable enough to share their feelings. This was the last session on the programme for Saturday and as it had been such an emotional and informative session it brought the day to a very successful end. After dinner the entertainment for the evening began when Rondo the Magician took the microphone and dazzled everyone with his magical skills and unique sense of humour. The children really enjoyed the magic show and the adults, although they may not admit it, were entertained also. After the magician it was time everyone went to bed, it had been an enjoyable, but long day for everyone and sleep was what everyone needed.

Sunday morning kicked off at 10am. The adults split into two groups for a Mother's workshop and a Father's workshop. The workshops were closed so I cannot really comment on them, but from the evaluations of the weekend it is fair to say they were the highlight of the weekend for everyone who attended. Credit must be given to Michael Butler and Anne Duffy who facilitated the Father's workshop and Mother's workshop respectively, with the help of Dr. Beatrice Nolan. Workshops such as these give parents the opportunity to talk openly and frankly about issues they have, not just in relation to haemophilia, but treatment, hospitals, experiences and general life issues for parents of a child with a bleeding disorder.

While the parents were locked away in their workshops myself and the other staff members attended the infusion demonstration which had been put on

Parents and children gather for an update on the Kidlink programme.

Dr. Beatrice Nolan and Brian O'Mahony speaking about the first two years of life.

Arts & Crafts at the creche

for the Kidlink group. Mary Kavanagh facilitated the session which saw Gary Butler, a child with haemophilia, give himself an infusion. Gary, who is 10 years old, has been infusing himself for over a year now and told the other children how and why he started to infuse himself and explained to them that with practice and over time, infusing yourself is not a big deal. The other children really responded to Gary and many enquired about when they could start infusing themselves. Mary Kavanagh explained about veins and Gary and Kidlink leader, Ciaran Dowling, showed the other children how to recognise and feel a vein. To encourage the children to start infusing themselves, Brian O'Mahony told the children of an initiative being run by the society where by if and when a child starts to infuse themselves they can contact the Society to let us know when they start infusing, and we will reward their efforts with a voucher for gamestop. After the infusion demonstration, the children and the staff watched a demonstration on how to mix up factor and then got to practice mixing the factor with dummy kits that had been supplied by the OLCHC. The session was really beneficial, from my point of view alone and from the kidlink evaluation forms it was clear to see they felt the same. Mary Kavanagh was delighted with how the session went, *"I think it went really well, the kids participated excellently. The fact that Gary was there doing it was amazing, because no matter what I say or what someone else says to the kids, we are not doing it all the time, Gary is. They saw him infuse himself, they saw that he is capable and they saw how fast it was. Also, I think showing the kids how to mix the factor afterwards was a brilliant idea. They were really interested and I think they saw that it is a step by step process. Overall I think they responded really well to the session."*

After the infusion demonstration, the Kidlink group took part in circle time and the Youth Group were treated to a behind the scenes tour of the hotel. I spoke to Kidlink Coordinator, Alison Daly to get her views on how she felt the weekend had gone; *"As always I was very pleased with the weekend, the kids are always incredibly well behaved and I think that the activities were great that we had lined up. I will admit that I was over ambitious in my plan to visit three stops on the Dublin bus tour, but the one stop we did was brilliant, because it had an outdoor area where the kids could run around and play games. The infusion demonstration was brilliant, it ran over on time, but we decided to just let it run as the children were enjoying it so much. The leaders as usual were fantastic over the weekend and have some fantastic suggestions for future activities!"*

A huge well done and thank you must be given to the leaders and volunteers who helped out over the course of the weekend. In particular, Alison Daly who put on great activities for the children to keep them entertained.

As is customary, the weekend ended with a group lunch. Once everyone was fed they went on their way. I must say congratulations to my colleagues who ensured that the weekend went off without a hitch.

I think the weekend was a huge success and from the evaluations it was clear to see that everyone who attended felt the same. From speaking to members over the duration of the weekend, I asked them what they had thought of the weekend and why they found it so beneficial and here are some of the answers I got:

"You gain from hearing other people's experiences and how they have dealt with what you are going through at that point".

"All the talks are going to be either something that has happened to you or will happen to you. Just getting to meet all the other parents and getting to know everyone is the major thing, it really is just a fantastic weekend".

"It gives less experienced parents a chance to hear stories and get a better idea of what to expect and what other people are doing".

"This is my first time attending a weekend by the I.H.S. and I found it fantastic, so interesting and everyone is so welcoming".

"It makes people realise they are not on their own, they have this support group around them. It is good for the parents to meet other parents, children to meet other children and siblings to meet other siblings so they realise they are not on their own either".

"My son is much more confident about his haemophilia, he is amazed that there are older people with the same condition as himself and he is delighted to have friends the same age as himself who have the same condition".

"These weekends allow you to hear the other aspects of haemophilia, hear positives as opposed to always hearing the negatives".

"This weekend last year was the first weekend run by the I.H.S. that my family and I had attended. It is the first time we got involved, I didn't want to be a Society mammy, but we haven't looked back since and to me it was the biggest enticement to become properly involved with the Society".

"If you are reading this and have never been to an I.H.S. event before, I would greatly encourage you to become involved. I cannot stress enough how informative and beneficial these events are, not to mention fun, but don't just take my word for it, take the people quoted above too. I hope to see you at a conference soon".

Until the Members Weekend in October…

Nuala Mc Auley

Parents' Weekend Picture Gallery

Society Conference on Hepatitis C & HIV

Helena Irish, Gillian Farrell & Niamh Larkin from St. James's speaking at the conference

A conference / workshop was held in May for members who are living with HIV and / or Hepatitis C. Many members of the Irish Haemophilia Society who are affected by these viruses work hard to ensure that they remain updated in relation to current therapeutic options and future possible developments in this area. These conferences are very useful in helping the members to get the most information in a short period of time. In addition, the conferences assist members in developing their coping skills and in managing their lifestyle.

Helena Irish from the Hepatology Centre in St James's Hospital gave a broad overview and an update on Hepatitis C treatment. In the coming years, there are potentially exciting therapeutic developments with the initiation of clinical trials with protease inhibitors such as tealprevir. Protease inhibitors, a class of drugs commonly used as part of combination therapy for HIV, may in conjunction with Pegylated interferon and Ribavirin offer a greater chance of successful treatment for Hepatitis C than the current dual therapy. We are also aware that an increasing number of people with haemophilia are being referred to the Liver unit at St. Vincents Hospital in Dublin for pre liver transplant assessment. We want to ensure the maximum co-ordination and co-operation between St Vincents and the haemophilia centres in St James's and Cork University Hospitals. To this end, the subject of liaison between the services was addressed by Yvonne McGarry, Liver Transplant Co-ordinator from St. Vincents Hospital. Yvonne gave a comprehensive talk on what people could expect during a liver transplant assessment and demystified the process for those present. The conference was also an opportunity for members to meet Niamh Lavin, the Clinical Nurse Co-ordinator for Hepatitis C services from the HSE. Niamh is responsible for developing and overseeing the home nursing service for persons with Hepatitis C when required, and for assessment of home support service requirements. Sarah Jamieson, who until recently was the Senior Psychologist at the NCHCD in St. James's Hospital facilitated a discussion on maintaining a balanced and positive approach. (We wish Sarah all the best in her new post and we are delighted that she is maintaining her links with our community.) Anne Duffy from the Irish Haemophilia Society facilitated a workshop on communication and Helen Shiel, Clinical Nurse Specialist from the NCHCD facilitated a discussion and demonstration session on stress reduction.

The weekend conference was a fine balance between updating members on the clinical and scientific progress and practical lectures and workshops designed to assist them in improving their coping skills and balance their lifestyles. One participant stated that "the weekend was an enjoyable and informative conference which gave all of us present an opportunity to share our experience and concerns and learn more about new therapies and ways of coping". This, we believe was a sentiment shared by all who attended.

Brian O'Mahony

Niamh Lavin, Anne Duffy & Helena Irish facilitating a workshop at the conference

Noticeboard

MINI MARATHON

A huge thank you to everyone who took part in this year's **Women's Mini Marathon** on behalf of the Irish Haemophilia Society, particularly when the weather was so bad on the day.

The Mini Marathon is an important fundraiser for the Society, and our numbers taking part this year significantly increased from last year.

We hope everyone enjoyed the day. It was great to see everyone and hopefully we will see you all again next year.

Thanks for your support.

ATTENTION KIDLINK CLUB MEMBERS

Hi everyone, its Debbie here. What are you all doing for your summer holidays this year? Maybe your visiting your cousins in the country, maybe your going to summer camp, maybe your going abroad, maybe your just having fun with your friends. We would love to hear from all of you how your summer holidays went.

Drop me a line and we might just publish it in the next magazine! See you all in October.

FUNDRAISER

Garda Band Concert

Date: Thursday October 7th 2010

Venue: Glencarn Hotel, Castleblayney, Co. Monaghan.

Tickets: €10

Doors open at 7pm

For more information please contact the office on 01 657 9900.

A huge thank you to Vincent Jackson and Susan Clarke for organising this event.

I.H.S TEXT SERVICE

Would you like to be kept updated by text in relation to our various events and activities. If you are interested please contact Nuala or Fiona in the office on 01 6579900.

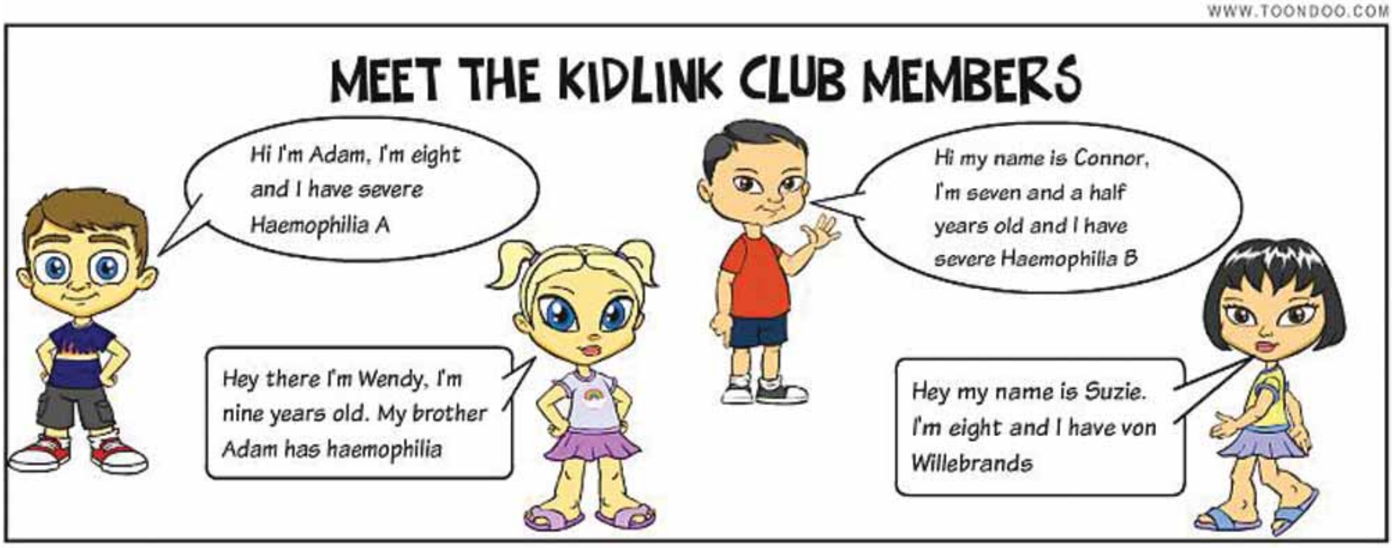
FACEBOOK

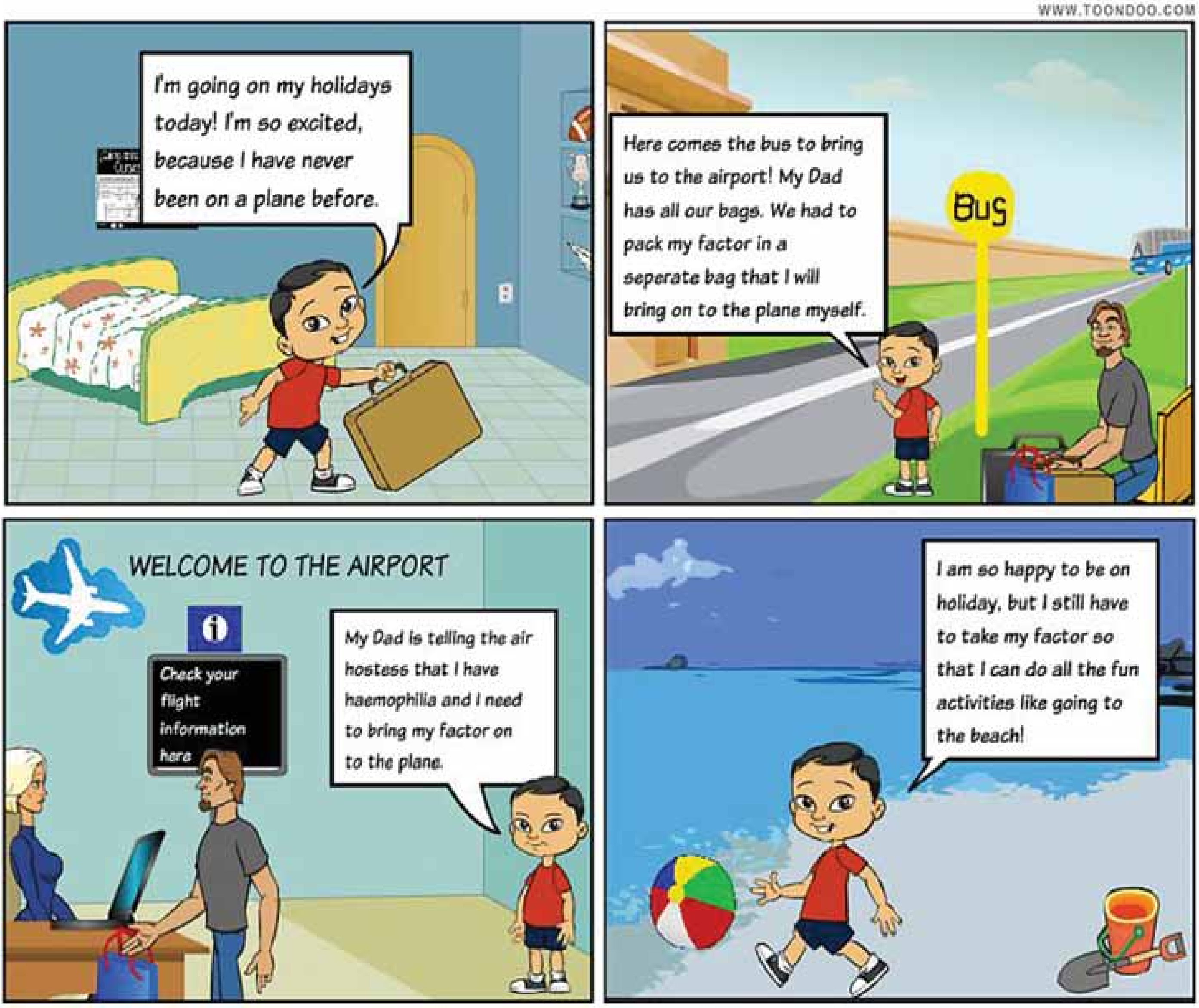
Are you a fan of facebook? The Irish Haemophilia Society is now on facebook, simply log onto our website: www.haemophilia.ie and click on the link at the bottom of the page.

Important Message

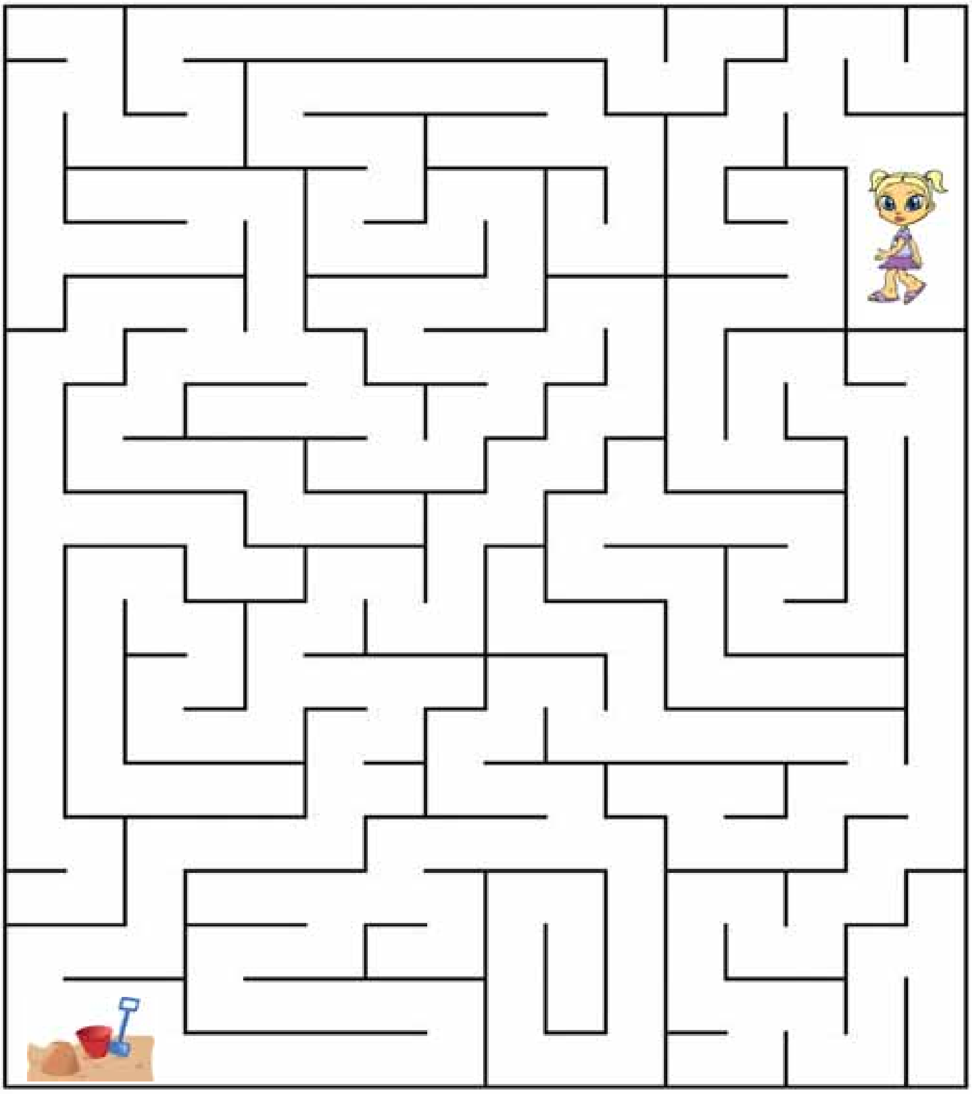
To enhance our magazines and website, we use photographs that have been taken at our events and activities. If you would prefer not to have your photograph included in our publications, please contact Debbie Greene in the office on 01 657 9900.

Kidlink Club





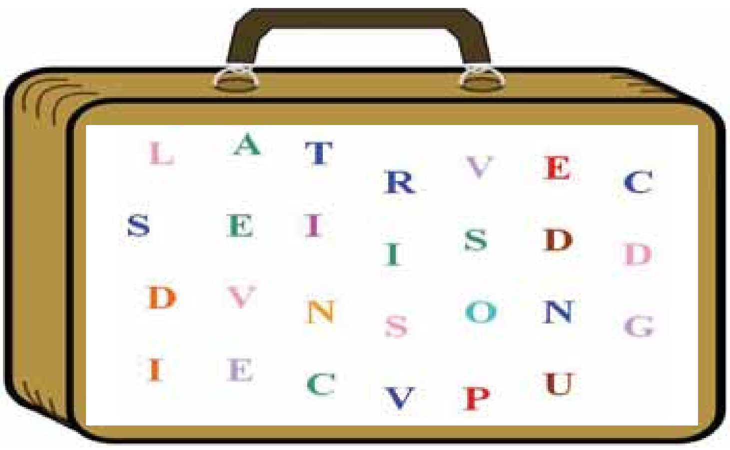
"All cartoon images and icons are from www.toondoo.com"



Can you help Wendy find her way through the maze to the beach?

Can you unscramble the letters below and help Adam reveal words associated with summer?

Suzie is off on holiday, cross out the letters that appear on her suitcase more than once to reveal where Suzie is going on her holidays.



HECAB

AYHOLDI

PANEL

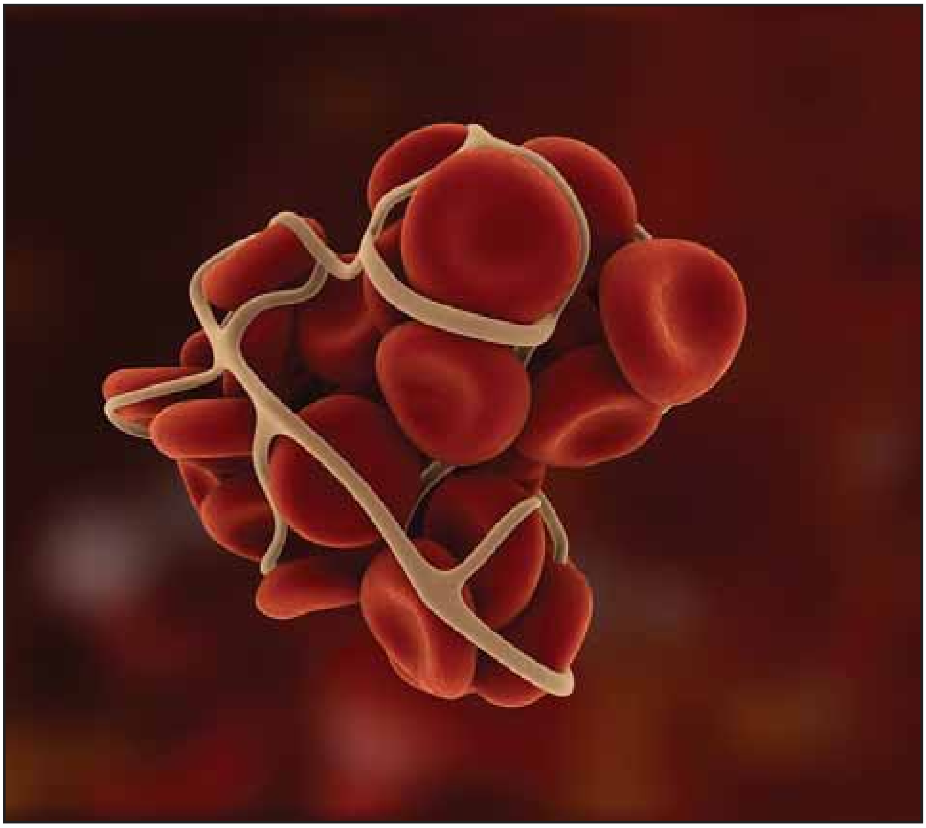
ASCUTIES

HENNINSUS

EASEDIS

Answers to Adam's Anagrams: Beach, Holiday,
Plane, Suitcase, Sunshine, Seaside.
Suzie is going to Portugal on her holidays.

Safety Supply & Availability update



Continued Vigilance in Blood Safety

At the recent conference of the International Plasma Fractionation Association, a wide litany of blood borne viruses, bacteria and agents was discussed. People with haemophilia and von Willebrands Disease, who use plasma derived clotting factor concentrates are relatively fortunate compared to those who rely on frequent transfusions of fresh blood, plasma or other labile components. Plasma derived concentrates are subject to various techniques which are very effective in inactivating dangerous viruses. This is evident from the fact that such concentrates have had an excellent safety record globally since the early 1990's in not transmitting HIV, Hepatitis C or Hepatitis B.

Other viruses which have caused concern in relation to blood transmission in recent years including the agents responsible for SARS, Avian flu, Swine flu, West Nile Virus are known to be inactivated and therefore not transmitted by plasma derived Factor concentrates. Agents which can theoretically or practically be transmitted by blood but are not a concern for factor concentrates include the viruses or bacteria causing diseases such as Dengue fever (prevalent in Asia), Chagas disease (prevalent in South America and a concern for transmission by blood in the USA because of immigration), Babesiosis, Q fever (originally transmitted by goats but can be transmitted by blood transfusion) and Chikungunya virus.

XMRV

A relatively new virus 'XMRV' is the subject of a lot of discussion and speculation as it has associated with (but not proved to cause) Chronic fatigue Syndrome and Prostate cancer. This virus, however like HIV, Hepatitis C and B, has an outer lipid coat and is therefore very susceptible to inactivation by the current methods used. Again, it may be of concern in relation to blood transfusion, but should not be of concern for those with haemophilia. Less we become complacent however, it is worth remembering that there are several viruses which lack an outer lipid coat and are therefore more difficult to inactivate in plasma derived Factor concentrates,. These include Hepatitis A (dealt with by vaccination), B19 parvovirus (thought to be relatively harmless) Parvovirus 4 and Hepatitis E both of these not associated currently with known disease) . In addition we must not forget vCJD. The major concern however is not any one of these viruses but rather if and when a new virus emerges which is difficult to inactivate (similar to B19 parvovirus) but causes serious disease (unlike B19). To conclude as I started, continued vigilance is vital.

XMRV Donor deferrals

As a precaution against possible transmission of XMRV (see above), a number of countries including Canada, Australia and Belgium have begun deferring blood donors who have symptoms of chronic fatigue in case they may transmit XMRV. (It would surely be assumed in any case that if an individual is chronically fatigued he or she should not be donating blood or plasma)

vCJD Screening test fails

A Canadian company 'Amorfix' have stopped any further development of their potential screening test for vCJD as the test lacked the required sensitivity (it did not give positive results when 3 samples known to have come from individuals with vCJD wer tested using the proposed test). Their remains the possibility that a screening test for vCJD will become available in the near future. This will have ramifications for blood donors. It will also be of interest to people with haemophilia and to other persons who amy have used blood or blood products extensively in the past.

The countries with the highest number of cases on vCJD per head of population are the United Kingdom, France and Ireland. The Irish Haemophilia Society wish to prepare for the eventuality of a screening test being available. Therefore, we have organised, in June, a meeting of key leaders from the irish , UK and French Haemophilia societies together with key clinicans form all3 countries and experts including Dr. Bruce Evatt. The meeting will take place in mid June and we hope it will assist us in developing a comprehensive, realistic and practical policy to assist all of our members when and if the subject of a screening test becomes a reality.

MSM Donor issue continues to generate Controversy

Men who have sex with men (MSM) are currently permanently deferred as blood and plasma donors. This policy, which was put in place due to the higher risk of transmission of blood borne viruses by this group of potential donors, continues to be challenged as discriminatory in several countries. The issue has attracted the attention of the US Senate and is also being re-examined in Australia. The World Federation of Hemophilia and the European Haemophilia Consortium have clearly stated their opposition to any change in this current lifetime deferral unless the science justifies this change. Many groups of people are deferred as donors on a precautionary basis (including those who have lived in the UK for defined periods of time due to vCJD risk, those who have travelled to malarial zones) but none of these groups of people see fit to protest at what is a public health measure.

Let me be absolutely clear, we would welcome a change in the permanent deferral of MSM if, and only if, it was justified by the science. We will not accept that decisions should be made by blood transfusion services, activists or politicians courting public popularity which place recipients of blood and blood products in danger in order to allow them to pander to any group or non scientific decision process. Blood safety is too important to our community both nationally and globally to be a political football.

Home Treatment Monitoring

The new electronic devices which will be used to record home use of Factor con centrates have begun use in the first group of 30 persons with Haemophilia. This is a great leap forward (to paraphrase Mao Tse Tung). I do not believe we will have to endure pangs of nostalgia for the distinctly 19th century pink home treatment forms.

The new devices will allow people with Haemophilia to scan the product into the device at the time of infusion and transmit real time data to the National centre. Obviously it will be a real improvement in facilitating a product recall if required. However, the real advantage will be in allowing the person with haemophilia to send the information immediately, the centre to have access to real time data which will allow for more timely and optimal clinical management of treatment regimes and management of individual bleeding episodes.

Now, if I could only find the on button!

Brian O'Mahony

Grants & Scholarships 2010 / 2011

It's "Grants & Scholarships" time of year again. We were delighted with the amount of interest and applications we had last year, and we are hoping that we will get an even bigger response this year. Below you will find two articles we received from the recipients for 2009/2010. These articles clearly show that it is well worth applying for these grants and scholarships and they really do help a lot. So if you are eligible why not apply?

Hello, my name is Christina O'Sullivan and this year I was the grateful recipient of the Margaret King Educational Scholarship. I am currently in my first year of Applied Psychology at University College Cork, and this reward has truly helped to make my first year at university enjoyable and enriching. The money from this award meant that I was able to afford all the necessary college text books and materials without having to get a part-time job. This meant that I had more time to prepare for assignments and to study for exams and this made the transition from secondary school to university a lot easier. It also meant that I could engage fully in the social aspect of university. This year, I decided to take up debating and was lucky enough to travel to Turkey to represent UCC in the World Debating Championships. As part of my preparation for the championships I had to travel to competitions in Galway, Dublin, Oxford and Durham. The money from this award allowed me to travel to these competitions. This scholarship has helped me to experience all aspects of university, both academic and social and for that I am very grateful.

Christina O'Sullivan

I write this letter to extend my upmost gratitude to everyone at the Irish Haemophilia Society. I have been very grateful to accept the Maureen Downey Educational Grant. This grant has made a very positive impact on my university life. With the aid of the grant I have been able to purchase the essential text books necessary for my course work. As well as most importantly to me, I have been able to afford the transport to go home to see my family more often. For these things and many others, I would like again to thank the Irish Haemophilia Society.

Daryl Butler

Background

Up to the 1970's effective treatment for haemophilia was not widely available in Ireland. One result of this was that many people with haemophilia lost a lot of time from school due to recurring bleeds which left them incapacitated for long periods of time. This in turn meant that a large proportion of them did not go on to college. When treatment improved and home treatment became available this made a huge difference not only to their quality of life, but they no longer had to miss so much school and the percentage of those going on to college was comparable to the general population.

In response to this the Society in the late 1980's decided to offer an Educational Grant each year to a person with haemophilia or related bleeding disorder, going on to post second level education. This is called the **'Maureen Downey Educational Grant'.** Currently the award is in the amount of €4,000. Applications are invited from any person with haemophilia or related bleeding disorder, who has been accepted on a course at any post second level educational institution.

Since then, the Society has introduced a second grant in 2004 which is called the **'Margaret King Educational Scholarship'**. This scholarship is made available to an immediate family member of a person with haemophilia or related bleeding disorder, who has been accepted on a post second level educational course. Currently the award is in the amount of €2,000.

Applications are now invited for both awards. You can apply by downloading the application forms on our website www.haemophilia.ie in the 'Young Adults' section, you can also complete the application forms online, or alternatively if you would like for us to post you out an application form please contact the office.

When all applications are received and the closing date arrives a sub group of three people from the Board, (which can not include anyone with a family member applying for the grants) meet to consider the applications and make recommendations to the Board. The successful applicants are then notified by post of their award at the end of October, and an official announcement and presentation is made to them at the following AGM.

THE CLOSING DATE FOR BOTH AWARDS IS FRIDAY 29TH SEPTEMBER 2010

SOME TIPS FOR APPLYING

When applying we would like to encourage you to sit down and take some time to complete the application forms, as the more complete and detailed your application is, the higher your chance is of success.

Some applications in the past have been poor due to some basic errors, such as:

- Not doing a spell check
- The Irish Haemophilia Society spelt incorrectly
- The name of the grant/scholarship spelt incorrectly

So remember:

- Always do a spell check
- Be sure you have the name of the Irish Haemophilia Society spelt correctly
- Be sure you have the name of the grants and scholarships spelt correctly
- Answer all questions, do not leave any questions unanswered
- Give as much information as possible even if it means attaching a back up sheet
- Make sure you apply on time

And please do fill out the application yourself!
Good luck to everyone applying.

Debbie Greene

Women's Mini Marathon

"Go I.H.S. Team"

"Not even the constant rain could dampen my spirit"

"It's a walk in the park"

"I was surprisingly enthusiastic"

Some comments from I.H.S. staff Nina Storey and Fiona Brennan who participated for the first time this year in the Flora Women's Mini Marathon which took place on Monday 7th June in Dublin. We had an excellent turn out on the day even though the weather was so bad, so a very big thank you goes to everyone who took the time to participate in the Mini Marathon on behalf of the Society. Numbers this year far exceeded last years which is fantastic, and we are hoping that next year we will have even more members and friends take part on behalf of the Society. I hope you enjoy the following two article from an I.H.S. staff perspective!

Debbie Greene

I don't know what people are talking about – 10K in the heat, 10K in the crowds, 10K at a steady pace?! I'll have it done in 90 minutes at the most I thought, it's a walk in the park, but clearly a walk in the city is different.

Getting on the Luas in Stillorgan, I realised just how much us ladies talk. Amongst the crowds stood one young man and I'm pretty sure he got off well before his stop! There was a buzz of excitement and despite my thoughts over the past few days of how to take myself out of action I was surprisingly enthusiastic. Walking down to the hotel I couldn't believe how much preparation goes into organising this event. Water stations aplenty, physiotherapy tents placed strategically en route and people to guide you to the right area for your athletic capabilities.

On reaching the hotel I was met by my supposed walking partner Nuala with a long face. She had injured her already temperamental ankle the night before (the cause of this "accidental" injury is still unknown!) and unfortunately had to count herself out, but luckily she was there to help out in the hotel with Debbie, Carmel, Ann and Michael. Five of us set off from the hotel together Nina, Sandra, Deirdre, Aisling and I with a cheer and made our way to the starting line. On the way I hoped this trek would be knocked off our 10K but sadly that did not happen.

Seeing the "elite athletes" taking their slip road to the top of the line I must say I envied their effortless glides – if only I could be that graceful! As five of us approached the starting line a giddy air was beginning to set over us. I was amazed at the sheer volume of people out together for a great cause. I seem to have forgotten to mention that Dublin suffered monsoon season type weather on June 7th – I may be exaggerating ever so slightly but the torrential rain didn't dampen anyone's spirits and the atmosphere was upbeat for the entire 10K. We took off at a decent pace and by the time we reached the 5K mark I was surprised that I hadn't felt it go by at all, I think the momentum of the crowd can make the journey appear shorter. Plenty of men dressed up as wonder woman, nuns and ballerina's kept us entertained along the way and if there was a fear of you starting to dry off between the torrential showers the firemen and their hose from the 7K to 8K marks sorted that out. It really didn't matter anyway we were already like a 40,000 pack of drowned rats!!

When we turned the last corner and saw the 10k finish line, a sudden and albeit false burst of energy came over us and we ran the final 300 metres to the finish. We obviously decided there and then that because we did it in 98 minutes, next year we have a good chance of running or even winning – the delirium had taken over us at that stage! We were welcomed back to the hotel with a cheer and some very creative banners completed expertly by Nuala, congratulating us on our triumphant return!

A special thank you to all those who raised money for the Society and thanks to the gang in the hotel for organising towels, food and drinks for us when we finished. As a rookie to the marathon world, I am shocked that I am looking forward to next year!

Fiona Brennan

Wet and miserable, but far from a washout, 40,396 lovely ladies plus myself (for the first time ever) took part in this year's 28th Flora's Mini Marathon on the 7th June. To date the race is the biggest of its kind in the world and the biggest single day charity event in the country. Now that's what I call Girl Power……

As this was my first time to take part in the Mini Marathon, not even the constant rain could dampen my spirit, and as if I was not wet enough from the rain, my sisters decided I should have an official baptismal and made sure I got a complete soaking from the fireman with their water hoses (they owe me a new mobile phone) Even this did not discourage me and I crossed the finish line with a smile on my face and a kiss from my two gorgeous sons, Luke and Adam.

It was wonderful to have so many people take part on behalf of the I.H.S including a few staff members who wouldn't even run for a bus (myself included), except for our wonderful motivator Nuala, who due to a previous ankle injury could not take part on the day. However, Nuala hobbled into Buswells Hotel on the day and was there to greet everyone with a big cheer as they arrived back from the race.

Women from all corners of the country ran, jogged and walked to raise funds for so many worthy causes. Well done to everyone for their hard work fundraising for the Society, especially in these times when fundraising is harder to do, but is needed more than ever.

You have all done great work, thank you so much, it is really appreciated and hopefully we will see you all again next year.

GO TEAM I.H.S

Nina Storey

Calendar of Events

JULY

WORLD FEDERATION OF HEMOPHILIA CONGRESS 2010

Dates: 10th to 15th July

The World Federation of Hemophilia Congress 2010 takes place in Buenos Aires, Argentina. The Congress provides the largest international meeting place for members of the global haemophilia and related bleeding disorders community. Renowned international treatment and research experts from around the world will participate in the Congress along with our very own Brian O'Mahony and Anne Duffy. The I.H.S. have 9 poster displays at the congress along with a seperate stand/booth.

Keep an eye out for the next issue of the magazine in which there will be a special World Federation of Hemophilia Congress Supplement with lots of interesting and informative articles.

SEPTEMBER

RELATIVES' INFORMATION SEMINAR

Date: Friday 10th September 2010
Venue: Rochestown Park Hotel, Douglas, Cork
Time: 7pm to 9pm

Date: Saturday 11th September 2010
Venue: Irish Haemophilia Society Office
Time: 2pm to 5pm

We are pleased to announce that 'Information Seminar's' for Relatives will take place again this year. Please encourage your relatives to come along, it will give them a better understanding of haemophilia and related bleeding disorders. Whether it be grandparents, aunts, uncles or any other relatives this is a great opportunity for them to learn and to ask all those questions they have.

No charge is applicable for these seminars, and if any of your relatives would like to attend please contact Nuala in the office on 01 6579900 to register no later than 27th August 2010. If you go onto our website www.haemophilia.ie you can also register to attend in the 'Register for Events' section.

OCTOBER

MEMBERS' CONFERENCE

Dates: Friday 15th October to Sunday 17th October
Venue: Castletroy Park Hotel, Limerick

The venue is confirmed, the dates are confirmed, the programme is nearly there so its all systems go for our ever popular Members' Conference in October.

Information and booking forms will be going out to members during August. Further updates will also be available on our website www.haemophilia.ie. And members please remember if you are booking your child in for the creche, kidlink or young adults programmes we would ask you to make sure your child does attend the programmes they are booked in for.

OCTOBER

OFFICIAL OPENING OF HAEMOPHILIA CENTRE IN CORK UNIVERSITY HOSPITAL

Date: Wednesday 6th October

NOVEMBER

SOCIETY CONFERENCE ON HEPATITIS C/HIV

Dates: 13th & 14th November
Venue: Cork (T.B.C.)

MARCH 2010

AGM & CONFERENCE

Dates: 4th to 6th March
Venue: Slieve Russell Hotel, Ballyconnell, Co. Cavan.

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