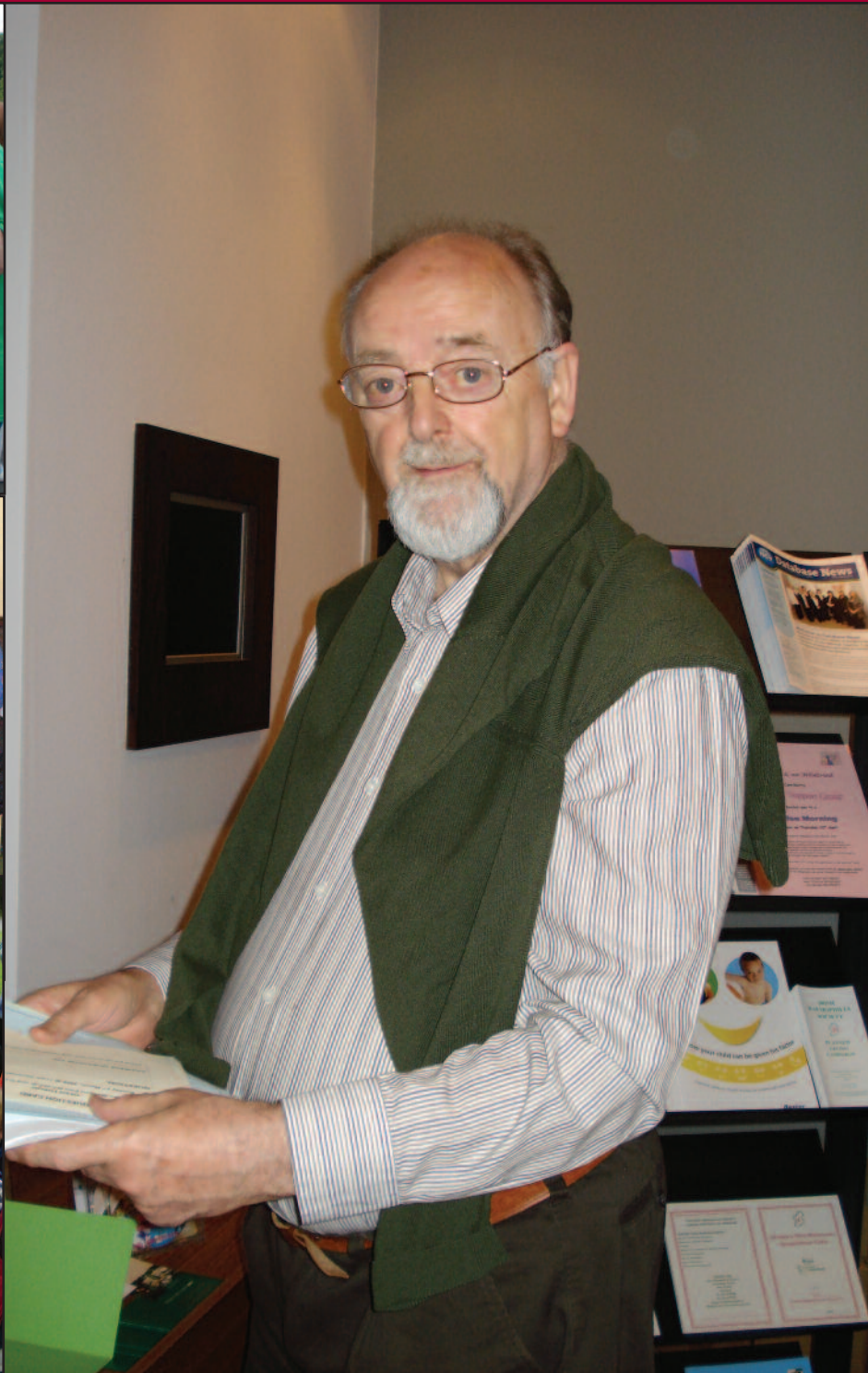


haemophilia.ie

Magazine of the Irish Haemophilia Society



Edition: June 2011

HIS I.H.S.

An information meeting for men with haemophilia or a related bleeding disorder aged 18 - 35

Date: 10th & 11th September 2011

Venue: The Clarion Hotel Liffey Valley, Co. Dublin

The Irish Haemophilia Society are holding a conference specifically aimed at young men with haemophilia or related bleeding disorder. This conference will focus on key issues for this age group and will allow you to receive up to date information from speakers as well as other people with bleeding disorders.

This conference is not an annual event so we would encourage all members to attend. For more information see our website www.haemophilia.ie or contact Nuala, Fiona or Declan on 01 657 9900.



PROGRAMME

Saturday September 10th

12.00pm - 1.00pm	Registration
1.00pm - 2.00pm	Lunch
2.00pm - 3.30pm	Travel and your Bleeding Disorder
3.30pm - 4.00pm	Coffee Break
4.00pm - 5.00pm	College / Work Life
7.00pm	Dinner & Pool Tournament

Sunday September 11th

10.00am - 11.30am	When your Bleeding Disorder Becomes Part of your Relationship
11.30am - 1.00pm	Open Forum
1.00pm - 2.00pm	Lunch

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A Note from the Editor

Welcome to the June edition of haemophilia.ie and what a packed magazine we have for you. For those of you who don't already know we have a new Chairperson. Michael Davenport after being Chairperson for 8 years has decided to step down from his position, and we are delighted to announce that Traci Marshall-Dowling is our new Chairperson. Wishing Traci all the best in her new role, I have no doubt she will be excellent. Traci introduces herself to you all on page 4.



This edition includes reports, articles and photos from our recent Parent's Conference in Killiney which was an astounding success. Thanks to everyone who took part. From evaluation forms received back it was fantastic to see parents get so much out of the weekend, and we were delighted to welcome members from Northern Ireland to this conference. You will also find reports in this edition from our Women with Bleeding Disorders Seminars in Cork and Dublin that took place recently.

It's that time of year again! Applications are now invited for grants and scholarships. For more information please see pages 20 to 22.

An information meeting for young men with haemophilia and related bleeding disorders takes place in September which is a new initiative for the Society, you will find more information on page 2.

We were all very saddened when Father Paddy McGrath passed away in April, we will miss him so much. On pages 7 to 11 you will find a deserving tribute to Paddy who did so much work for the Society over the years. May he rest in peace.

Don't forget members, if you would like to write an article contact Nuala or myself on 01 6579900. Finally members don't forget to keep us in mind if you are planning any fundraising activities in the near future. Hope to see you all soon, and remember pick up the phone if you have any questions, queries or require support, that's what we are here for.

Debbie Greene,
Administrator

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Chairperson's Welcome

Dear Members,

For those of you that I haven't had the pleasure of meeting, my name is Traci Marshall-Dowling. I am a mother of two children and in my professional career I work within the Adult Education Sector, working with young adults with mild learning difficulties, mental health difficulties and/or disabilities.

I have been an active member of the Irish Haemophilia Society for 18 years (coming up to nineteen this July!). Although, my parents were members since the Society was first established over 40 years ago, as we have a long family history of Haemophilia. I am a Haemophilia Carrier and have a son with Severe Haemophilia A (less than 1% clotting factor).



*Traci Marshall-Dowling,
Chairperson*

I have been Vice Chairperson of the IHS board for the past 3 years. Following the recent election at the AGM in March, I was surprised that Michael Davenport, the excellent Chairman of the IHS for eight years, had decided to step down from his role. I was even more surprised, but very honoured to be nominated and elected as the New Chairperson of the IHS. If I do half as good a job that Michael has done over the past eight years I will be doing ok.

I really enjoy my work with the IHS and have participated in Advocacy workshops, Carrier workshops, Members' weekends and often liaise with parents of children living with Haemophilia. I believe that the excellent work the IHS staff; volunteers and Board members carry out on behalf of its members is of vital importance. The advocacy, lobbying and services the IHS provide ensures the continuation of safe, effective and efficient products, assists parents adapt to a new and often difficult situation in a supportive environment and encourages people living with Haemophilia to make their disorder part of their lives rather than becoming their life. I am proud and honoured to be part of it all.

I think going forward that we will face many challenges and opportunities as a Society but I have every confidence that we, the members will work together to overcome those challenges and make the best of the opportunities provided and will only strengthen further as a Society in the process.

Traci Marshall-Dowling
Chairperson

MEMBERS' CONFERENCE

The Carlton Shearwater Hotel, Ballinasloe
14th - 16th October 2011

PRELIMINARY PROGRAMME

Saturday 15th October:

- | | |
|---------------|-------------------------------------|
| 10.00 – 11.00 | Taking charge of your health |
| 11.30 – 13.00 | Taking charge of your mental health |
| 13.00 – 14.00 | Lunch |
| 14.00 – 15.00 | Making exercise a part of your life |
| 15.00 – 17.00 | Exercise – Yoga/ Wii Fit etc |

Sunday 16th October:

- | | |
|---------------|-----------------------|
| 10.00 – 11.00 | Healthy Eating |
| 11.00 – 13.00 | Cooking Demonstration |



CEO's Report



Brian O'Mahony,
CEO

The Extended Journey

There has been a remarkable transformation in Haemophilia care over the course of the last 50 years. From a time when a diagnosis of severe Haemophilia was inevitably associated with constant bleeding episodes, certain joint damage and poor life expectancy, to the children with Haemophilia today who have access to prophylaxis and as a result have an excellent quality of life, adults can aspire to education, employment and full integration into society. The safety issues of the past with replacement therapy are largely behind us and the treatment options for those with HIV and Hepatitis continue to improve. There are more treatment options for those with inhibitors and there are exciting potential developments with longer acting factor concentrates. For the first time, we will have a generation of people with severe Haemophilia who will live long enough to confront the normal diseases and medical complications associated with ageing.

The full benefit of these exciting changes require an educated and informed patient population who take the time to educate themselves about Haemophilia, about the current treatment and care available and about future prospects for improved treatment and care. The doctors and staff at the Haemophilia Treatment

Centres have a responsibility to provide optimum treatment and comprehensive care and the patient or parents have an equal responsibility to fully engage with their care and assist in outcome measurement and data collection by attending the centres for review and for returning their home treatment records in a timely and complete manner.

There are exciting potential areas of progress. Clinical data from Germany suggests that starting prophylaxis earlier (before 1 year of age) with lower doses may have a beneficial effect on reducing the risk of developing inhibitors in young children with Haemophilia. I know that the team in Our Lady's Children's Hospital, Crumlin are acutely aware of this research and are looking at the models of prophylaxis being used. The long term benefit of prophylaxis is clear. Children with severe Haemophilia can grow up with a far lower number of bleeding episodes, far less joint damage, less disruption to their life and to the lives of their parents and siblings. A paper shortly to be published in the journal *Haemophilia* by Declan Noone and I examines the impact of a lifetime of prophylaxis on young men with Haemophilia. Sweden introduced prophylaxis as standard therapy for severe Haemophilia in the late 1970's (whereas other countries including Ireland, UK and France introduced prophylaxis in the 1990's). Therefore, Sweden is the only country where the quality of life of the young men with Haemophilia reflects the reality of a lifetime to date with prophylaxis and is a realistic picture of what Irish children on prophylaxis can look forward to if they continue with prophylaxis. The outlook is very good. Young men with severe Haemophilia surveyed in Sweden have an average of 3 bleeds per year. Only 1 in 4 has any joint damage. They missed an average of half a day per year from college or work and their quality of life was

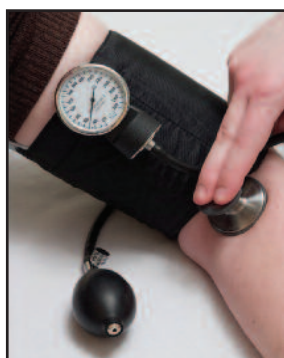
designated (by themselves) as close to perfect. If children persevere with prophylaxis into early adulthood, they should face the future as young adults with excellent joints and the same quality of life and prospects for further education and employment as their peers. There is more debate about the merits - clinical and economic - of continuing prophylaxis into adulthood.

Published data demonstrates a remarkable effectiveness for secondary prophylaxis (for defined periods of time) in adults with specific bleeding patterns. It appears that the question of continuing prophylaxis into the future for adults will ideally be individually assessed on a case by case basis with the individuals bleeding history and bleeding pattern, activities and lifestyle and their individually assessed response to doses of factor (specifically how long it lasts in their blood) may be used to determine the optimum treatment regime and dose for each person.



We are also seeing the first generation of adults with severe Haemophilia who can reasonably expect to live long enough to be concerned with the normal health concerns of older males - heart disease, cancer and hypertension among them. There is no doubt that developing these health complications will have an impact on an individuals Haemophilia as indeed Haemophilia will have an impact on the treatment of any of these other conditions. Interventions such as anti coagulant therapy or insertion of stents in cardiac disease will be more complex and problematical in a person with an underlying bleeding disorder.

Every effort should be made to avoid these complications by promoting a healthy and active lifestyle and encouraging regular medical checks. People with Haemophilia have built up a relationship with their treatment centre which, in most cases, greatly supersedes or entirely replaces that which they may or may not have with a general practitioner. I firmly believe that the Haemophilia Treatment Centres should include regular checks for diseases of ageing as part of the comprehensive care review for all with Haemophilia. Ongoing monitoring of blood pressure, cholesterol, blood glucose and other parameters could assist in prevention of complex diseases which would be difficult to treat. This would be both effective and cost effective.



We are seeing an increased attendance at our weekend conferences. This is very welcome and demonstrates the thirst for knowledge, for education and for peer and community support. Our conferences this year will cover the entire extended journey of a person with bleeding disorders from birth to ageing. Birth and childhood issues were covered at our recent parents' conference. Ageing was a topic at the annual conference last March and lifestyle and healthy living will be topics for our October members conference.

The journey continues to an age where no people with severe Haemophilia have journeyed before. As they say in Star Trek.... Live Long and Prosper.



IHS at Haemophilia Clinics in Cork

We are delighted that the new Haemophilia Treatment Centre is now open for business at Cork University Hospital. Out-patient clinics are being held on a weekly basis with children and adults being seen on alternate weeks. The Irish Haemophilia Society will have a staff member at the Centre for the Comprehensive clinics in the coming months. The Society staff member will be there with information on our events and meetings and copies of our publications and information materials. We will also be there to assist with any queries you may have about benefits or entitlements, information for travelling or any relevant issue. If you would like to meet or speak with our staff member there, please mention this to the doctor or nurse when you are at the clinic and they will send you in to see us. We look forward to seeing you in Cork and we share in your delight at the opening of this wonderful new facility.

IHS Elects new Chairperson

At the meeting of the IHS Board in March, Traci Marshall-Dowling was elected as the new Chairperson of the IHS. Traci has served on the Board for the past 3 years and as Vice-Chairperson since 2009. Traci is the mother of a young man with Haemophilia and also has a brother with Haemophilia. I wish Traci all the best in this challenging and vital role and I look forward to working with her. I know she has the energy, ideas

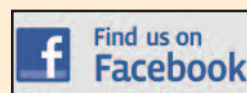
and enthusiasm to be a very successful Chairperson.

Michael Davenport stepped down as Chairperson in March. Michael had served as Chair for 8 years. He made an extraordinary contribution. He gave selflessly of his time and energy and his commitment was even greater given the fact that he also, during that time, served a 5 year term on the Haemophilia Product Selection and Monitoring Advisory Board and a total of 7 years on the National Haemophilia Council. Michael was a very effective chair. His unassuming style brought the best out of many people and his real engagement with the issues and the members was always evident. He spoke in public on many occasions despite a strong dislike of having to do so. He preferred to engage with members individually or in small groups. His jokes were legendary (in a bad way) and his constant talk of golf, which he saw as an analogy and metaphor for everything, will be missed in a strange sort of way. Michael will continue on the Board and is now Vice-Chairperson.

Brian O Mahony
Chief Executive

Make sure you keep up to date with all the I.H.S. news by logging onto the website
www.haemophilia.ie

You can also follow us on facebook!



For additional support, join the IHS Discussion Forum
www.haemophilia.ie/forum



Farewell to a Friend of the I.H.S.

The entire Haemophilia community in Ireland were greatly saddened at the death of Fr. Paddy Mc Grath on Easter week after a long illness. Paddy was the unofficial chaplain of the Irish Haemophilia Society, the friend, the counsellor; the source of consolation in times of despair for many. Paddy first got involved with the Society in the late 1980's. This was a deeply troubling time. The country was emerging from recession. Health spending was savagely cut. Resources for Haemophilia care were limited. We were beginning to fight the first of many battles to secure health care, assistance and support for the 106 people with haemophilia who had been infected with HIV through contaminated blood products. I gave a talk to a group of priests and nuns on the situation. Paddy was present. He approached me after the meeting and offered his support and involvement in helping people with haemophilia. His compassionate and practical Christianity was an enormous help to our members who were struggling with devastating diagnosis, the prospect of developing AIDS, an imminent or early death and the fear, anger, guilt and stigma wrapped up in the diagnosis of HIV at that time. Paddy offered comfort, consolation, unstinting support and practical help. His softly spoken voice carried an air of authority, of knowledge, of consolation. He always found the appropriate words no matter how difficult the situation was for the person or family he was engaging with. For our members and community, he presided at many – too many – funerals and also more joyous occasions such as weddings and baptisms. At funerals, his personal involvement and knowledge of the individual who had passed away meant invariably that his words were appropriate, often poignant and always succeeded in capturing the essence of the person's humanity and a distillation of the real meaning of their life.



Paddy was also intensely practical. His work on the AIDS housing project benefitted many people. His work on the Haemophilia HIV Trust was of great benefit to our community. The mass he would celebrate at each of our conferences became an integral part of the weekend for the members and community. The occasions were a reflection of Paddy – warm, informal and inviting to all. The memorial services he helped to organise and officiated at for our members at the lovely church in Dominic Street and later at the Society's office were profoundly moving and greatly appreciated. Indeed Paddy even went Global as he officiated at the memorial service at the World Federation of Hemophilia Congress in Seville, Spain in 2002.

Paddy was part of the Haemophilia family. He was close to many of the members and staff. He frequently joined the staff for meals, for outings, for coffee and cake in the office. His warmth permeated the most frustrating day. He had a great sense of humour and fun. He hated long meetings and short coffee breaks. He loved playing poker with the monopoly money we used on Friday nights at conferences, mainly because he nearly always won. He loved to socialise with our community and I know that many of our members looked on Paddy as a real friend and almost a member of their family.

The esteem in which Paddy was held was evident by the long and constant stream of visitors who spent time with him in his final months, weeks and days. He had friends who sat with him 24 hours a day and who deemed it a privilege to be there. He was the best living advertisement for Christianity and Catholicism I have ever met. He was a friend, a mentor, an inspiration and a profoundly good man and priest who was a credit to his order, his family and his God. He will be greatly missed.

Brian O'Mahony
Chief Executive

We were very sad to hear of the death of Fr. Paddy. He was a lovely, kind man, always willing to help anyone in trouble. We loved meeting him at the I.H.S. conferences and have fond memories of his Saturday evening masses with Joe Rabbette singing and playing the guitar.

May his gentle soul rest in peace,

Michael & Ena Loughnane

Slán, Anam Cara

The recent death of Fr. Paddy McGrath filled me with great personal sadness. Fr. Paddy was Chaplain to the Irish Haemophilia Society for many years. He was a great source of strength and comfort to many members over the years, particularly the years that brought such trial and tribulation to many. Paddy was a quiet man, not given to lengthy conversation or discussions, but that quietness belied great personal strength. Paddy was first and foremost a listener. He listened with great attention to whoever was talking to him. He listened without judgement or censure no matter what the speakers' views were. He was saint-like in his ability to reach out and communicate to people from many different levels of society. And he had the ability to say just what people needed to hear in any given situation.

My association with Fr. Paddy goes back over many years and he was very kind to me and my husband George in times of great personal stress and heartbreak. No matter how angry or unreasonable I felt, he just listened and allowed me to rant or vent my frustration without interruption. Paddy and I had great debates regarding the existence, or not, of God. He listened as I spoke, without contradicting me in any way, but for him there was never any doubt about God's existence. God existed for him in a real and meaningful way. His whole life was a testament to his faith. God's goodness shone out of him in the way he lived his life and served the people around him.

For many years Fr. Paddy attended the Annual Conference of the Irish Haemophilia Society and he celebrated Mass on the Saturday night for the members. Paddy always made this Mass feel special, an intimate occasion and for many it was the highlight of the weekend. In the last few years, due to illness, Paddy was unable to attend the conference and celebrate our Saturday night Mass, and for many of us our weekend was diminished because of it.

When my husband George also became ill, Paddy phoned me several times to comfort us both. Just after George died he contacted me again explaining that he was sorry he could not attend the funeral because he was in hospital. He told me that as soon as he was able, the first Mass he would say would be for George. This was so typical of the man, always thinking of other's needs before his own.

I know that each member of the Irish Haemophilia Society will have their own stories of Paddy McGrath, but these are the memories I have of someone who for me was always a soul friend and whom I will miss very much. May you enjoy the company of Angels Paddy.

Cora Marshall

Our Thoughts on Fr. Paddy

He was there for us when we were going through very difficult times. I know he shared our pain, he was one of us. We were so sad to hear of his passing. We have many fond memories of him but one that stands out for me was when I was waiting to go into the tribunal and was petrified, Fr. Paddy was with me. He started to tell me a very funny story which helped to get rid of the tension.

Somebody speaking about their mother at her funeral said "To those who knew her, no words are needed. To those who didn't know her, no words are adequate". That applies to Fr. Paddy as well.

Sleep in peace, dear friend.

Paddy & Breda Owens



Fr. Paddy Mc Grath with IHS staff member Anne Duffy and member Joe Healy.

A True Gentleman

I feel privileged to have known Paddy. I will miss him a lot. I always looked forward to his visits into the office (he always brought in lovely cakes), and I have to say he was truly a compassionate, kind hearted, hugely amusing and witty gentleman. He was a pillar to members of the Society for so many years and will be hugely missed.

Debbie Greene
Administrator



Back row: Alison Daly, IHS Chairperson Michael Davenport, Fr. Paddy,
Front: IHS Staff; Nina Storey, Margaret Dunne, Anne Duffy and Debbie Greene



Fr. Paddy receiving his Honorary Life Membership for the Irish Haemophilia Society

My Fondest Memory

I will never forget the first time I met Paddy, I was watching my P's and Q's and making sure not to curse, but I needn't have worried. Paddy had such a dry sense of humour; all we did was laugh. I smile every time I think of this, and then I laugh again. I will really miss him. Love,

Nina Storey

A Thieving B.....!!/?

When I first met Paddy, in Iceland House over ten years ago, we had a difference of opinion over the ownership of an umbrella whereby he accused me of being a 'thieving b****d'! On our travels around the country, to visit I.H.S. members, apparently I was a poor driver in a hopeless car who was taking us the wrong way! Would I put up with these insults for much longer.....? Absolutely! I loved travelling with Paddy. He was a great companion with many humorous stories and a fountain of knowledge on many subjects. Despite the amount of good work he did he was a very humble man and never boastful. It was a privilege to know him.

Michael Davenport



Fr. Paddy with Justice Roderick Murphy at the opening of the IHS office in New Street in 2007



Fr. Paddy with IHS staff Margaret Dunne and Nina Storey

THE FULL NINEYARDS

There are some things missing from my life, a beard, a bald head and laughing eyes between. Yes I'm thinking about Paddy McGrath.

Paddy was an honorary member of our family for more than twenty years. He was our rock of strength when times were bad, our happy laughing friend when things were good.

At the last AGM before Margaret retired from the I H S Paddy said some nice things about her in his homily at the evening Mass. He concluded by saying he had always felt comfortable in our home. Comfortable, he could not have picked a word which would have pleased me more.

I have many memories of Paddy McGrath. I remember a crowded hotel room in Seville, Paddy celebrated mass and Ursula sang the hymns.

I remember a happy day when Paddy officiated at the wedding of our daughter Joan.

I remember a sad day when Paddy presided over the funeral of our little granddaughter Emma.

I remember an evening in our home as Paddy sat surrounded by our friends and his, a glass of red wine in his hand, as he sang the complicated song "I'm my own Grandpa".

Paddy was my friend, he was often at the receiving end of my somewhat irreverent sense of humour. We were drinking companions and downed many a pint together, he was the voice of reason in our often heavy philosophical discussions. We both had a love of odd or quirky facts, mostly historical. As an extension of that we had an interest in the derivation of words and phrases. A couple of weeks after Paddy died I came across the origin of the expression "The full nine yards" and as I was thinking I will have to share this with Paddy I realised I would never be able to share these little gems with Paddy again. Right then and there I knew how much I will miss Paddy McGrath.



Fr. Paddy officiating at the wedding of Joan and Ken Byrne

I can only hope when my time comes to pass on I will be greeted by a beard, a bald head and laughing eyes between.

See you later Paddy.

Your friend,

Jim Dunne

The full nine yards refers to the length of the ammunition belt of the World War One Lewis Gun. When you fired the full belt you had given it everything you had, coincidently that is how Paddy lived his life. He always gave it the full nine yards.

Dear Paddy,

Your patience and humour meant a lot to me over the years. Your poker playing was heaven sent (unlike mine). I loved having a pint and a chat with you.

May you always look after us,

Noel O'Leary

The Late Fr. Paddy McGrath

During my too few and all too brief encounters with Fr. Paddy, I always had the urge to paraphrase Oscar Wilde and think to myself that "The days are long gone when Christ walked with men, but Paddy who is His image takes His place."

I still hold that view.

William Murphy

Thinking of Fr. Paddy the words which immediately spring to mind are gentleness and strength - two attributes which wouldn't be regarded as common bedfellows, but in this case they worked beautifully - plus a mischievous sense of humour. To me he was the person who came the closest, as far as it is humanly possible, to being "all things to all men" that I've ever known; he truly lived his life through other people, giving it everything he had, no doubt at great personal cost to himself. Right now I'm sure that the Master is putting the "finishing touches" to his creation and will soon introduce him to the unimaginable joys that are in store for him.

May his good soul rest in peace.

Cepta Cooney



Joe Healy, Fr. Paddy Mc Grath and Lily Healy



Ena Loughnane, Fr. Paddy Mc Grath and Siobhan O'Leary

Father Paddy was one of the gentlest people I have ever known. He reminded me of Padre Peo in both looks and the way in which he lived his life.

I first met Father Paddy in my Aunt's house twenty years ago, when he offered Mass for my brother, Donal. He was so kind and gentle, making everyone feel welcome. Father Paddy and Irish Haemophilia Society staff were present at many a similar Mass. I never could understand how Father Paddy and the IHS staff dealt with so many deaths in the 80s and 90s and still continued on with the work of the Society, helping families deal with their loss, phoning up members when something was about to be published in the newspaper, answering phones and organising events. How they got through the Tribunal I will never understand, I could not even read the reports not to mind being present.

When my Aunt, Mary O'Leary died, her sister Siobhan and I were very grateful for Father Paddy's presence. Father Paddy visited Siobhan on a number of occasions after Mary's death and he would sit and listen to Siobhan talk about Mary's life.

Not that it matters, but what age was Father Paddy? He never seemed to age, to me he looked the same twenty years ago as he did the last time I saw him.

Father Paddy, may you rest in peace and I sincerely hope your Housing Project will continue.

Nuala (Twomey) Mc Donald

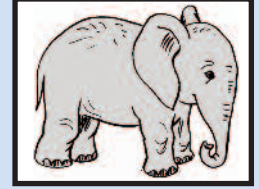
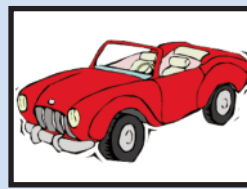
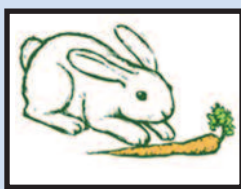
HAEMOPHILIA IN FOCUS

Q. I have a bleeding disorder, can I play sport?

A. Yes, you can play non-contact sport. It is good to learn skills and how to play safely. Also, sport and exercise are good for you because they help to make your joints and muscles stronger, helping stop bleeds. Swimming - it is good exercise while the water acts as a cushion for your limbs.

TREATING BLEEDS

Name the picture. Use the first letter of each word to fill in the 5 spaces below.



Now re-write the letters in the boxes below. Use the letters above to help you identify five ways after infusing to recover from a bleed. A clue has been given for each.

To shield from harm

To relax and take it easy

To make cold

To apply pressure

To raise up high

J
O
K
E
S

C
O
R
N
E
R

How do you spot a modern spider?

He doesn't have a web, he has a website.

Why did the rooster run away?

Because he was a chicken.

What do you call a dog with no ears?

Anything you want, it can't hear you.

Youth Group

WHICH FACTOR?

When you have haemophilia, one of your 13 clotting factors is missing or doesn't work properly. All of your factors must work together to form a clot. Factors are named by roman numerals.

Write the number that goes with each of these roman numerals.

Circle which factor you are missing if you have haemophilia A.

Or draw a square around which factor you are missing if you have haemophilia B.

I = _____ XIII = _____ X = _____ XI = _____

VI = _____ III = _____ VII = _____ V = _____

IX = _____ XII = _____ II = _____ IV = _____

VIII = _____



Well done to Youth Group members Niamh Birkett and Demi Moore on winning the Superhero Arts 'n' Crafts Competition at the Parents Conference. They may not be real superheroes, but they sure are Superstars!!

ANSWERS:
Treating a bleed: P.R.I.C.E.
Which Factor: I=1, II=2, III=3, IV=4, V=5, VI=6, VII=7, VIII=8, IX=9, X=10, XI=11, XII=12, XIII=13

Parents Conference Report

They say third time's a charm. After the first two Parents Conferences went so well, we thought we knew what to expect, we were wrong. It was fair to say that after disappointing attendance at the Women with Bleeding Disorders Information Days we in the office were a bit worried that attendance at the Parents Conference would also be affected. However, as it turned out we had no need to worry as attendance was not only great, but it was also the highest it had ever been!

On Friday May 20th myself and the other staff packed up the bus and headed for Fitzpatrick Castle Hotel in Killiney. After a spot of lunch and a quick tour of the hotel the work began – first was the set up, we may make it look effortless, but a lot of work goes on to ensure the weekend runs smoothly. With four rooms and a registration area to set up we cracked on, even surprising ourselves by getting everything set up ahead of schedule. While some of the fitter members of staff headed to the swimming pool and the gym, I headed for a nap, I had a feeling it was going to be a busy weekend.

As is the norm, registration took place on Friday evening. As a lot of new families attended the weekend this gave them a chance to introduce themselves to the staff and other families. Getting to meet other families in similar circumstances is, in my opinion, one of the main benefits from this conference.

Saturday morning was very busy indeed with kids being registered for their different groups, delegates checking in and speakers setting up their presentations. It was a good thing we all had an early night the night before!!

The adults' programme was the most informative I have seen since I began working with the Society, with talks on everything from bullying to pregnancy, every aspect of life, not just life with a bleeding disorder was covered. The programme began with a talk from Dympna Cauley, the Assistant Director of Nursing in Crumlin Hospital, who explained the role of the Community Haemophilia Nurse and how it can benefit parents. Dympna told parents that the nurse is not only there for post-op patients, but for all families *"Whether you are a parent starting home treatment or you would just like a nurse to come out to your house for support, advice or education that is what we are here for"*. Dr. Beatrice Nolan commented that the Community Nurse is a great resource for parents and encouraged all to use this service, but she was also keen to point out that the nurse will not replace the services provided by clinics in the hospital and that the parents and child will still need to attend their scheduled appointments.

The next talk was on Coping with Bullying and was presented by Maria Ruane from Barnardos. This talk was extremely rewarding, but I have to say some of the figures that Maria highlighted were disturbing to say the least. For example, did you know that there is a one in three likelihood of being bullied and that 31.3% of primary school students and 15.6% of secondary students reported being bullied (O'Moore et al, 1997), and that is only the figure reported. Maria highlighted that many people experience bullying, but never report it so the figures could be considerably higher. Indeed the culture of secrecy and "not telling" is what bullying thrives on. So how can you recognise signs of bullying? The truth is it is not easy, as Maria explained every child is different – some children withdraw into themselves where as some act out. Worse still with cases of cyber bullying increasing there are more ways for people to be targeted. It was interesting to hear about the difference in bullying when it comes to gender, girls tend to use emotional abuse where as boys have a tendency to use physical abuse. Maria was quick to address the myth for boys when it comes to bullies, that if you're a real man you will stand up for yourself and handle things alone. Bullying is a terrible ordeal and nobody should go through it alone. Although, the session was scary it was very informative and beneficial. Maria gave examples of how to talk to a child about bullying and what parents can do to help the situation. It was very encouraging to see parents who attended this session discuss their own experiences with this subject, it really is a credit to all involved within the society, the hospital teams and the delegates themselves that people feel they can open up about such personal matters.



After such an informative morning, a much needed coffee break was in order, but as the parents took some time to mingle and chat, I accompanied Maria from Barnardos to the Kidlink group where she continued to highlight the issue of bullying. Maria had worked closely with Anne Duffy, Counsellor with the I.H.S. and Fiona Brennan, Children Programme's Co-ordinator to accommodate the Kidlink and Youth groups in receiving talks on bullying. Maria started the session with the kidlink group by

asking if anyone knew what bullying was and I have to say even I was surprised that the first answer she got summed it up so perfectly, *"Making other people feel bad to make yourself feel better"*. The session covered everything from the different types of bullying, to the different types of bully and even included a few movie references!! It was great to see the children all work together and allowing time for each other to speak, it is hard to believe that a lot of these children only meet each other at the I.H.S. weekends. The friendships and respect shown amongst the group really is a credit to Fiona and her team of volunteers.



Following on from the Kidlink session I made a quick dash back to the Adult's programme where the team from Our Lady's Children's Hospital Crumlin were discussing self infusion. The session, which ran for an hour and a half, was jam packed with information. Bridin Brady, Clinical Nurse Specialist, started the session with a presentation on hand-held devices. Bridin gave a clear and informative description of how the device will work and the benefits this device will have not only for the patients and their families, but also for the hospital. Diarmuid O'Riain, Clinical Specialist Physiotherapist, was next to speak in a very interactive session titled *"First Aid for Muscle and Joint Bleeds"*. The session reiterated the importance of P.R.I.C.E. (Protection, Rest, Ice, Compression and Elevation) and with the help of his glamorous assistant IHS staff member Declan Noone, Diarmuid demonstrated the different types of ice packs available.



Although, Diarmuid did have to scold his assistant for not leaving the ice pack on for the recommended time, he said this is something he himself, as well as the parents, would be used to! Diarmuid and Bridin then gave a joint presentation on a leaflet they are working on with the IHS. The *"Treatment of Bleeding Episodes"* leaflet will include the information on the home treatment prescription, but will also have diagrams and basic advice for treatment of various bleeding episodes. Imelda Kelly, Haemophilia Clinical Nurse Specialist was up next with a presentation on self infusion. For this talk, Imelda focused on the three requirements for self infusion – patience, support and teamwork. Imelda said it was important to start self infusing as soon as your child expresses an interest. Fingers crossed that some of the kids who attended the self infusion workshop are interested!! Remember, once a child self infuses, contact the IHS and we will send them out a €30.00 gift voucher.



Earlier in the day Imelda had met with the Kidlink and Youth group to lead a self infusion workshop. Following on from the success of the workshop at last year's Parents' Conference, this year more children were invited to self infuse. The workshop once again proved very successful, it allowed the children who were self infusing to discuss the process with others and gave the children who were not self infusing a bit more confidence in their own ability. Everyone seemed to enjoy the session, although one or two of the volunteers did seem to turn a funny colour with all the talk about veins and needles, although the boys in the group with haemophilia soon had them feeling back to normal!

After lunch, the adult programme split, parents could attend either a talk on von Willebrands by Dr. Mary Gleeson, Haematology Registrar or a talk on Developments in Prophylaxis by Dr. Beatrice Nolan, Consultant Haematologist. Unfortunately, I was unable to attend either of these talks as I had a critical role to play as head judge in the Kidlink / Youth superhero competition, of which I will speak further about later. However, having looked at the presentations and from the feedback on the evaluations these were excellent talks.

I.H.S. CEO, Brian O'Mahony then addressed the full group on

the issue "Future Developments in Factor Concentrates". The talk was very interesting and while it was very positive and listed all the improvements that have been made and continue to be worked on, it also highlighted the difference between haemophilia in the developed and developing countries. "There are 400,000 people with Haemophilia globally. The World Federation of Hemophilia estimates that 70% still receive no treatment".

The final talk of the day was "What to Expect When you are Expecting" by Dr. Beatrice Nolan. Although the attendance at this session was less than at others, the presentation itself was outstanding. This time it was my turn to lose some colour from my cheeks as Dr. Nolan spoke about delivery plans! Luckily, I seemed to be the only one phased and those in attendance seemed to take a lot from the talk.

The children's programmes for the weekend were just as busy as the adults. For the crèche there was a puppet show, educational games, movie time, story time, arts and crafts and a teddy bear picnic! With 22 kids the ladies in the crèche had their hands full at the weekend, but I know they had as much fun as the kids.



The Kidlink and Youth groups had a mixture of educational sessions and fun activities. As mentioned previously the groups took part in a self infusion workshop and workshops on bullying. During the weekend they also, Journeyed Around the World with the new WFH educational game, enjoyed not one, but two swimming sessions and created their own superheroes. Congratulations to Demi Moore and Niamh Birkett on their winning superheroes. As a judge, I could not officially enter the competition, but I didn't want to miss out on the fun so created my own superhero alter-ego named Enigma, but that is all I can tell you about her, the rest is a mystery!

All programmes finished at 5.00pm which was just in time for me to watch Leinster pull off a spectacular victory in the Heineken Cup Final. Then it was time for dinner and some outstanding entertainment as Silly Billy stunned and amazed the

adults (ok me) and children alike with his quick wit and magnificent magic! When the act was over and the magician had disappeared all the children were tired so it was early to bed for all again.

There was no time for sleeping in on Sunday morning as the programmes started at 9.30am with mothers' and fathers' workshops. To allow the workshops to be as informal and open as possible, staff did not attend so I cannot review these sessions, but they were the highest evaluated session from the weekend so I think that speaks for itself.

The final session of the weekend was by Ed Keubler, a Social Worker from Houston, Texas. Ed spoke about the PEP (Parents Empowering Parents) Programme. The programme originated in 1996 in America and is about promoting effective parenting skills through educating and supporting parents. Using various techniques such as role playing, discussions and teaching exercises PEP has proved successful with over 700 nurses, social workers and parents trained worldwide. Ed was at the Parents Weekend, because the Irish Haemophilia Society are facilitating the PEP programme next year. This is a great initiative and we look forward to seeing the results of the programme in the future.

And just as quickly as it began, the weekend was over. I hope that everyone who attended got something from the weekend, I know we here at the Society were delighted with how things ran and from the evaluations so was everyone else. For those not able to attend, the talks from the conference are available on the I.H.S. website www.haemophilia.ie. A huge thank you to all the volunteers who helped out at the conference, of whom there are too many to name individually, without you the conference would not have been possible.



No rest for the wicked though, we've already begun planning for the Members' Conference in October – to view the programme or for information on future events visit www.haemophilia.ie

Nuala aka Enigma over and out!

Right: The mothers and fathers workshops were one of the highlights of the weekend.

Bottom Right: Attendance at the Conference was the highest ever. Ed Keubler gave an excellent presentation on the Parents Empowering Parents Programme.

Bottom Left: Children of all ages were entertained by Silly Billy the magician, overall everyone had a great weekend!



Women with Bleeding Disorders

The Society organised two information days for Women with Bleeding Disorders. The first was on Saturday 16th April in The Rochestown Park Hotel in Cork and the second was on World Haemophilia Day Sunday 17th April in The Hilton Hotel Kilmainham in Dublin.

Professor John Bonnar, Chairperson of the National Haemophilia Council kindly chaired the seminars, and we were delighted to have Dr. Paul Giangrande, Consultant Haematologist from Oxford in the UK attend. Dr. Giangrande gave excellent talks on "Women and Bleeding Disorders" and on "von Willebrands Disease". Eadaoin O'Shea, Haemophilia Nurse Specialist from the National Centre for Hereditary Coagulation Disorders (NCHCD) in St. James's also gave a talk entitled "A Journey Toward a Bleeding Disorder, Diagnosis and Beyond", which was very interesting and informative. Finally our very own Brian O'Mahony spoke about the services that the IHS offer to women with bleeding disorders.

Registration and attendance was free. Attendance could have been better and we were a bit disappointed at the turn out, as we had spent a lot of time discussing our strategy to try and reach out to women with bleeding disorders, and to encourage awareness. We had contacted obstetricians, sent our publication on Women and Bleeding Disorders along with our flyer to all the maternity hospitals in the country.

We also sent a mailshot to all members and advertised the seminars in the March magazine, and we issued a press release which resulted in two newspaper articles being published. Having said that, those who did attend benefited hugely.

The seminars were excellent and ideal for any woman with a known or suspected bleeding disorder. There are 1,165 women registered at the NCHCD in St. James's Hospital, but very few are on our database or mailing list. These women suffer from von Willebrands Disease, mild haemophilia or rare bleeding disorders. In the past women with undiagnosed bleeding disorders often faced long delays before adequate treatment, frequently heavy menstruation, and all too often unnecessary hysterectomy. Concerns now can include menstrual problems, pregnancy, carrier status and menopause. So these seminars were ideal for any woman who had concerns or who was interested in learning more about their condition.

We would like to encourage any woman with a known or suspected bleeding disorder to contact the Society or a health care professional for support. Knowing about your bleeding disorder and its severity, symptoms and treatment is vital.

Debbie Greene
Administrator

My Mini Marathon Experience

Hello Everyone. My name is Mary Hanney and I have two boys with Haemophilia - Sean is 17 years and Daniel is 13 years. I have just completed my 14th Mini Marathon and I have been asked to put pen to paper and write a few thoughts about my experience doing the Mini Marathon.



*Mary Hanney,
Secretary*

To tell you the truth I never give it any thought before as I'm sure like a lot of families living with Haemophilia a lot of the time you live on auto pilot. I always just applied for my entry number, collected my number at the RDS where I enjoyed all the free samples of food and wine and then did the walk. It was only now that I was asked to write a few words about my experience doing the Mini Marathon that I have really thought about it. (I can actually think now as my mind is not as frazzled as it used to be when the boys were younger).

Anyway looking back to the very beginning when I started doing the Mini Marathon I can see that I have come a long way in terms of self confidence in dealing with Haemophilia and appreciating the feeling of achievement that I have in completing so many Mini Marathons and also giving something back to the Haemophilia Society. Before my boys were born I had completed the Mini Marathon purely for myself. It was only when my boys were diagnosed with Haemophilia that I started walking the Mini Marathon with a view to fundraising for a Society that has given me so much help and support.

As I stood at the start line on the 6th June 2011, I thought back over previous years and started to see comparisons in getting from the start line to the finish line of the Mini Marathon and in getting from the start when Sean was first diagnosed with Haemophilia to now, age 17 years. I feel that at the starting line you look ahead to the finish and wonder how you will get on. Will you get tired? Will you trip up? Will you be able to get to the finish line? How long will it take? I compare that to when Sean was young. How will I cope? Will I be able to inject him? Will I be able to protect him? How will I manage? As the horn blows and I cross the start line I realise that I am really looking forward to this walk. The atmosphere is electric. Everyone is in a wonderful mood

and as we pass certain points along the way a band is blasting out music. As all the ladies pass the bands the talking stops and everyone raises their hands clapping along to the music. It is truly an uplifting experience. Everyone walks it as their own pace, some are trying to run, some are walking very fast and others like myself are just enjoying walking at a steady pace. We pass the Fire Brigade Station where the hoses are spraying water high in the air. Nobody wants to get wet so everyone speeds up trying to avoid the water. And as I reach the 10km mark I look back and see that I have reached this 10km mark many times in my life. When I managed to get my first vein, when I gave my first infusion, when I balanced injecting two boys with a full time job, when I trained my eldest boy to inject himself. What fantastic achievements all of these were and I never really thought about them before and as I crossed the finish line and beat my time from last year by eight minutes I was feeling very happy.

I collected my medal and I celebrated with my very good friend Adrienne who I walk the Mini Marathon with every year. We returned to Buswells Hotel where we met up with all the other ladies and had a very welcome cup of tea and a sandwich which is provided by the staff and volunteers of the Irish Haemophilia Society every year who do a fantastic job. I was then presented with a scroll from the Irish Haemophilia Society recognising my achievement. My friend Adrienne walks the marathon for the DSPCA but she is still very welcome for a cup of tea and a sandwich by all the staff. Good friends are so important to have to help you along your path in life. You know every one of us ladies in Buswells that day had every right to be proud of our achievements. We really don't applaud ourselves enough for what we achieve in life and especially in dealing with Haemophilia so I ask all you mothers dealing with Haemophilia to think back on your achievements - no matter how big or small - and give yourselves a big pat on the back.

I would encourage you all to take part in the Mini Marathon at least once. It does wonders for your self fulfillment and it also helps raise much needed funds for the Haemophilia Society - plus it is a fantastic fun day out with all your friends. I will sign off now hoping that next year I will see you all strutting your stuff on Leeson Street.

**Mary Hanney,
Secretary**

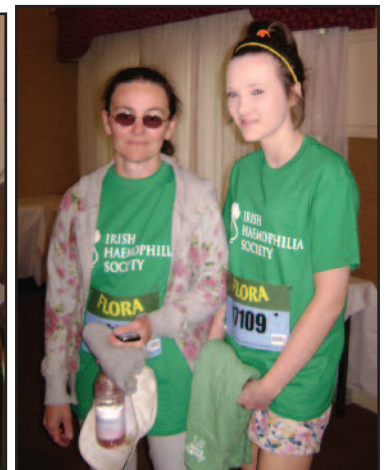
A Big Thank You!

This year's 29th Women's Mini Marathon took place on the 6th June 2011 and as usual the atmosphere on the day was fantastic. To date the race is the biggest all-women's event of its kind in the world. The camaraderie among everyone taking part on the day is a wonderful experience. The day is definitely focused on fun, it does not matter if you run, jog or walk. During the race you have a good laugh and when you read the names on all the t-shirts you reflect on how peoples lives are effected and the real reason that they are doing the race, to raise funds for a worthy cause. It is amazing to think of the number of charities and organisations from all over the country who benefit from all the funds raised.

Our sincere thanks to everyone who took part in this year's Women's Mini Marathon to raise funds in aid of the I.H.S., your support is really appreciated. It was lovely to see so many people in Buswell's Hotel on the day, we hope you had a great time and liked the new 'Green' I.H.S. T/shirts.

All those who registered to take part in the race either through the Evening Herald newspaper or on online received a commemorative medal, so the feeling of achievement is great, on a personal level as well as helping others through fundraising. So if you want to make a difference, keep the date in your diary for next year.....

Nina Storey



WELL DONE LADIES!!



Grants & Scholarships

ARE YOU GOING TO COLLEGE?



Have you been accepted on a post second level educational course?



Do you have haemophilia or a related bleeding disorder?



Are you a family member of a person with haemophilia or related bleeding disorder?

APPLICATIONS ARE NOW INVITED FOR THE 2011/2012 GRANTS AND SCHOLARSHIPS

You can apply online on our website www.haemophilia.ie . You can also download the application forms from our website, complete them and post them into 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.

Educational Grant

This grant is made available to a person with haemophilia or related bleeding disorder, who has been accepted on a post second level educational course. Currently the award is €4,000.

Recipient for 2010 / 2011 - Ciaran Dowling

Educational Scholarship

This grant 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 €2,000.

Recipient for 2010 / 2011 - Sarah Gilgunn

For 2010 - 2011 we were also delighted to be able to make further smaller payments to a number of applicants, and we are pleased to announce that in total the Irish Haemophilia Society made payments totalling €23,000 for the period 2010/2011.

So as you can see it is well worthwhile applying. These grants really do help a lot and we would like to encourage you to apply. And don't forget even if you are a recipient of a payment this year, you can still apply again next year.

Grants & Scholarships

**Opening date for applications for Grants and Scholarships is:
1st JULY 2011**



TIPS FOR APPLYING

When applying, please 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 grant / scholarship 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 everyone!

**Debbie Greene
Administrator**

www.haemophilia.ie

**Closing date for applications for Grants and Scholarships is:
16th SEPTEMBER 2011**

Granted & Grateful

I am delighted to be writing this article to extend my gratitude to the Society having been awarded the sum of €2,000 for the Margaret King Educational Scholarship at the start of this college year. In 2009 I was keen to further my interest in Scientific Research, so I decided to return to University to complete a Masters of Science in Molecular Medicine. A big part of me just wanted to go back to being a student again!

The grant I received from the IHS fully allowed me to return to college and was put towards the fees for the course. Originally I studied a Bsc. in Biomedical Science and then continued with an add on degree in Pharmaceutical Science. As you can probably tell I really do enjoy being a student! I spent a few years working in the Pharmaceutical Industry but still missed the books and really wanted to get more involved with research and the Masters in Trinity was the perfect opportunity for me to do this.

Starting in September 2010 I felt a little bit anxious about sitting in a lecture theatre again and found it quite difficult to get into study mode again, as all I remembered from college was the fun parts! But I hit the books and managed to get through the year, passed all my exams and still had plenty of great nights out and made lots of new friends too.

The course is one year long and the final part I have left to complete is to carry out a 3 month research project, which I am in the middle of at the moment! I got the opportunity to do my project in the haemostasis lab at the Institute of Molecular Medicine in St. James's Hospital working on the molecular basis of von Willebrand Disease under Professor James O'Donnell, whom most of you will know is one of the Consultant Haematologist's at the National Centre for Hereditary Coagulation Disorders. This is a great privilege that I have gotten to further investigate bleeding disorders and develop a more advanced knowledge of the area. This course has opened me up to so many more opportunities and I hope to continue studying and perhaps start a Ph.D in September.



If I was to give school goers and undergraduates alike any advice about university it would be to enjoy it as much as you can, don't be shy, make as many friends as possible and most importantly put in the hours of study because it is all worth it in the end!

I really can't thank the Society enough for the grant I received and would strongly encourage others to apply for the many grants and scholarships that the IHS so kindly provide.

Sarah Gilgunn

Msc. Molecular Medicine, Trinity College Dublin



I would like to express my thanks and gratitude in relation to the grant. I am very appreciative of this opportunity and to state that it will prove very beneficial to me in aiding with the costs of my studies throughout the year.

Thanks again and I look forward to seeing you all soon.

Ciarán Dowling
Biosciences, DIT



Calendar of Events

SEPTEMBER

HIS I.H.S.

Conference for men up to 35 years of age

Dates: 10th & 11th September

Venue: Clarion Hotel Liffey Valley, Dublin



OCTOBER

Members Weekend

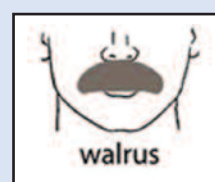
Dates: 14th to 16th October

Venue: Carlton Shearwater Hotel, Ballinasloe, Co Galway



MOVEMBER

The weather report is in and in November it will be raining Men. Yes that's right November will officially become M-ovember and we are asking all the men of the I.H.S. to take part and fundraise for the I.H.S. by growing a moustache. 30 days is all we ask. In the battle of the sexes for the fundraising crown, the ladies have taken a huge lead with a fantastic turn out for the Women's Mini Marathon. So men here is the question, are you up for the challenge?



To register to take part in Movember or for more information contact Nina on 016579900 or nina@haemophilia.ie

NOVEMBER

Regional Meetings

Date: Monday 21st November

Venue: Galway

Date: Tuesday 22nd November

Venue: Sligo

Date: Wednesday 23rd November

Venue: Letterkenny

March

AGM & Conference

Dates: 2nd - 4th March 2012

Venue: The Lyrath Estate Hotel, Co. Kilkenny





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