

haemophilia.ie

Magazine of the Irish Haemophilia Society

Edition: September 2014

Representing people in Ireland with Haemophilia and related bleeding disorders.



The Society at a Glance

IHS Social Media Sites
5

Followers on Facebook
621

Educational Grant Applications
19

IHS Volunteers
57

Website Hits (Jun - Aug)
4,360

WHAT'S INSIDE:

- * Information on the Long Term Illness Scheme
- * An Update on Fundraising
- * The Daly Edition with Rosemary Daly
- * A Report from the PEP Programme



IHS Noticeboard



MEMORIAL SERVICE

A 'Memorial Service' in memory of all deceased members of the Irish Haemophilia Society will take place in the offices of the Irish Haemophilia Society in Cathedral Court, New Street South, Dublin 8 on Sunday 2nd November from 1.30pm to 4.30pm.

The service will start promptly at 1.30pm, with refreshments following.

As space is limited to the first 60 members who respond, we would ask you to R.S.V.P. to Fiona Brennan or Nuala McAuley by calling 01 657 9900 by Friday 24th October.

For those who are unable to attend, please be assured that your loved ones will be remembered at the service.



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HEPATITIS C INFORMATION DAY

The Consultative Council on Hepatitis C are hosting their annual Information Day on Hepatitis C in the Ashling Hotel in Dublin on Saturday 18th October.

The Information Day will include a "meet the experts" session as well as workshops on the new hepatitis C treatments, relationships, HAA cardholder entitlements, women's health, living with a chronic condition and many other interesting topics. The Information Day will be officially opened by the Minister for Health, Dr. Leo Varadkar.

There is no fee for attending the day, but as places are limited we would advise people to book early. This will be a very beneficial event and we would strongly encourage members to attend.

For further information, to view the programme in full or to register for the event, please go to www.consultativecouncilonhepc.ie



CONTENTS

- 4** CEO's Report.
- 8** Information on the Long Term Illness Scheme and Hospital Charges.
- 9** Calendar of Events.
- 10** Cubs Club!
- 11** Kidlink Page!
- 12** A PEP in their Step!
Read all about the Parents Empowering Parents Programme!
- 14** Find out about all the Fantastic Fundraising that has taken place by our Fantastic Fundraisers!
- 16** The Daly Edition -
Learn more about Rosemary Daly, one half of the A Team & a Forever Friend of the IHS!



*Debbie Greene,
Administrator*

A Note from the Editor

Hello everyone,

Welcome to the Autumn edition of haemophilia.ie. This edition is packed with some excellent articles and information.

Another excellent PEP (Parents Empowering Parents) Conference took place over the weekend of 15th to 17th August in Dublin. Read all about this event and the excellent programme, which is designed to promote effective parenting skills to parents of children with haemophilia, on page 12.

A Memorial Service will take place in the offices of the Society on Sunday 2nd November. For those who are unable to attend the service, please be assured that your loved one will be honoured during the service.

During the course of the summer months Nuala McAuley and I have been working on upgrading the current website (behind the scenes) and it is hoped that we will be in a position to have the new improved website go live sometime in December, so watch this space! You may also have noticed that the Society recently signed up to Twitter, LinkedIn, Google Plus and You Tube, so why not take a look and let us know what you think.

Keep yourself updated on everything there is to know about the 'Long term illness scheme' on page 8. Update your diary with dates for upcoming events on page 9. Check out what's happening with fundraising on page 14, and read all about the IHS Christmas Cracker Fundraiser!

On page 16 you will find a fitting article on Rosemary Daly who worked for the Society for many years. Rosemary was empathetic, supportive and cared for so many members in their hour of need. Nuala has written a lovely piece and I hope you all enjoy reading about this compassionate lady.

And finally, please contact the office on 01 6579900 if you have any questions, would like to talk to somebody in confidence, if you have a fundraising idea, an article for the magazine, or a suggestion for a publication. And don't forget you are all very welcome to drop into the office at any stage for a chat and a cuppa! We are always delighted to see members dropping in.

**Debbie Greene
Administrator**

CEO'S Report

Hepatitis C Treatment

The treatment of people with haemophilia with hepatitis C has been a major priority for the Society over the past two years.

Since 2012, a total of 20 people with haemophilia have been treated with a combination of three drugs (Telaprevir or Boceprevir with Interferon and Ribavirin). Prior to the commencement of these treatment regimes, the expectation was that there would be a sustained virological response (or effectively a cure) in 70% - 80% of people who were treated after either 24 weeks or 48 weeks of treatment.



Brian O'Mahony,
Chief Executive

A definition of a sustained virological response or cure is when the individual is clear of the virus six months after the end of treatment. The results to date have been very encouraging. Of the 20 individuals treated, 15 to date have achieved a sustained virological response with one person not yet at the six month's post treatment stage. Three members did not achieve a sustained virological response as the treatment did not work for them and unfortunately a fourth member passed away during the course of the treatment. This means that the success rate of this treatment in people with haemophilia in Ireland was 75% - 80%. However, the treatment regime was very harsh, with many side effects and the majority of people had to take this treatment for a full course of 48 weeks.

You may ask why there is a necessity for another new generation of hepatitis C treatments when the previous generation looked to be so successful. There are a number of reasons why this is the case. Firstly, for those individuals who failed treatment with an Interferon based regime and those who cannot tolerate Interferon based regimes there is a need to try a different regime. Secondly, for individuals who have very severe liver disease, it is now recognised that the Interferon based regimes may actually contribute to hastening liver failure and they carry significant risk of mortality in some cases. Thirdly, many of the new regimes have a success rate in excess of 90% for a twelve week course of treatment with little or no side effects. Of course, these new treatments come at a significant cost. The first of these new treatments to be licenced – Sovaldi® - was released in the United States earlier this year at a cost of \$84,000 for a twelve week course of treatment. The cost of this treatment in other countries, including some European countries and probably Ireland, will be lower than the US price.



Dr. Diarmuid Houlihan, Consultant Hepatologist and I at a press conference held in the IHS Office to highlight the need for an early access programme for people with Hepatitis C.

The Irish Hepatitis C Outcomes Research Network (ICORN) headed by Professor Suzanne Norris, will be defining treatment protocols for each genotype of hepatitis C using the new treatments. These protocols will be both Interferon containing and Interferon free regimens and options will be dependent on clinical need.

In addition to Sovaldi®, a number of other drugs including Olysio® (Simeprevir) and Daklinza® (Daclatasvir) are now licenced in Ireland for treatment. Olysio® is being reimbursed for use with Interferon only at the moment and a similar result is expected for Daklinza®. Decisions have not yet been taken in relation to the cost of these drugs and the reimbursement of these drugs for the Health Service in Interferon free regimens. This is being looked at now by an expert group established by the Department of Health and the HSE and includes the Irish Haemophilia Society. It is our view that the decision on the broader availability of the new treatments on a planned basis over the coming months and years needs to be made on an expedited basis to ensure that as many people as possible with hepatitis C who require these new treatments can avail of these

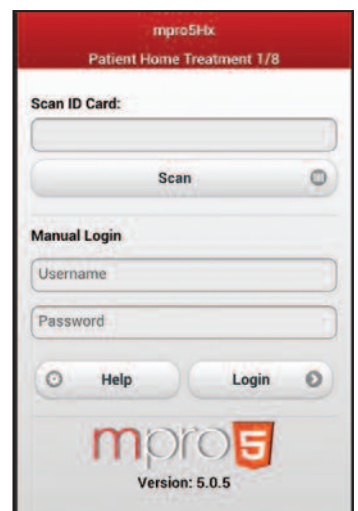
treatments. However, even more importantly there are a group of patients in the country with hepatitis C who cannot wait for any length of time for treatment. These include individuals who are currently in danger of liver failure through decompensated liver disease and with severe cirrhosis in danger of liver cancer or who may require a liver transplant. For these individuals, treatment with the new therapies is imperative without delay.

The Society, in early September, were very active in advocating for the initiation of an early access programme for these individuals. This included media advocacy and a meeting with the Minister for Health. By the time you are reading this article, the results of that advocacy programme should be clear and I hope that the early access programme will already have been agreed and initiated.

Outcome Data

A new smartphone app for the reporting of home treatment has now been in use for a number of months. This app (mpro5Hx) can be used with either Apple or Android smartphones and allows people with haemophilia who are on home treatment to scan the barcodes from their factor concentrates and report their prophylaxis or bleeding episodes in real time before taking an infusion. This allows for better clinical management of each person's haemophilia or bleeding disorder as the Centre will have a full and complete record of the use of factor by each individual and an accurate record of the number of bleeding episodes per year. In addition, if there are serious bleeds it will ask the individual to contact the NCHCD immediately for particular types of life or limb threatening bleeding episodes.

It is possible over the coming months and years that additional features will be added to these apps including a request to complete a short quality of life questionnaire with 5 questions. Most people normally do not like completing surveys. However, in the case of the collection of quality of life data in haemophilia, this is going to become increasingly important in the future in order to maintain and improve access to treatment and care.



The home treatment app allows for better clinical management of haemophilia.

Haemophilia is a success story, haemophilia treatment works and the child or adult who is on prophylaxis can lead a normal life and will have a normal life span. Bleeding episodes for those who are treated on demand, can be treated aggressively and promptly. However, it is no longer enough just to state that treatment works. It is necessary to be able to demonstrate that treatment works by the collection of good accurate data on the use of factor concentrates, on treatment patterns and on improvements in the quality of life of people with haemophilia. It will assist the doctors in optimising treatment regimens and it will assist the Society and the doctors in advocating for better access to better products on an ongoing basis. If we can demonstrate that treatment works and is beneficial then it makes it much easier to make a strong case for better treatment and improved treatment in the future for people with haemophilia and bleeding disorders. This is worth remembering when you are asked to fill out a quality of life survey or are asked by the Society to fill out a survey at a conference or return a survey either by mail or online.

New Children's Hospital



During the months of August and early September there were a significant number of articles in the media, questioning the decision on the location of the new children's hospital. Some of these articles were advocating for the decision to be changed, yet again, so that the new hospital could be situated on a green field site or in Blanchardstown in West Dublin.

It is worth reviewing how the decision to locate the new children's hospital in the grounds of St. James's Hospital was made. This decision was made in late 2012 by the Cabinet following a review of the expert group chaired by

Dr. Frank Dolphin. This expert group invited proposals from the six Dublin teaching hospitals, five of those hospitals submitted proposals, with St. Vincent's Hospital choosing not to submit. In addition to this a proposal from the Coombe Hospital was submitted. The group also received a large number of unsolicited site offers including several green field site options. In total, 32 site offers were examined. The group examined in detail the proposals from the teaching hospitals; The Mater Hospital, Beaumont Hospital, St. James's Hospital, Tallaght Hospital, The Coombe Hospital and Connolly Hospital, Blanchardstown. The criteria they examined included the degree of co-location with an adult teaching hospital, the critical mass of sub specialist care, the opportunities for adolescent care, and the extent of consultant linkages with existing Dublin children's hospitals and the depth and breadth of clinical and academic research. They also looked at the site's suitability in terms of building, access to the site, planning and design including parking, project delivery and timelines and value for money.

In examining the relative importance of the various selection criteria, the group and indeed all previous expert reports into possible sites for the new children's hospital, agreed that co-location with a major adult academic teaching hospital was essential and tri location with a maternity hospital would be even better.



There has been much debate on whether St. James's Hospital is the right location for the New Children's Hospital.

A lot of the media coverage in recent months in relation to questioning the decision has come from vested interests or from groups who advocated for a site which was not chosen. Indeed some of these groups had a formal hearing before the Dolphin Group and had their opportunity to make their case. There has been a lot of noise and wind generated with regard to the parking difficulties in St. James's Hospital and the fact that it would be better to locate the hospital in a green field site or indeed in Connolly Hospital in Blanchardstown which is a larger site. In fact, there will be more parking available in St. James's compared to the parking provision in the planned Mater Complex and indeed this parking will be underground which will be safer and will allow parents to bring the children directly into the hospital without exposure to the elements. There is no ideal site for the new children's hospital, but when we look beyond the self-serving media coverage generated in recent months it is apparent that the correct decision was made in choosing the site at St. James's Hospital.

The overriding consideration in the location of the new National Children's Hospital must be that it should be the site which will give the best health outcomes for children. This indisputably means co-location with a major adult teaching hospital. This is absolutely essential to allow for continuity of care from childhood to adolescent years to adulthood. It is essential to give access to all the adult specialities. It will be cost effective because of all the major equipment that will already be in place and it is ideal to have the research and education expertise on campus which would be there with a major adult teaching hospital.



When located in a major adult teaching hospital, children get the benefit of access to many specialists who treat high volumes of complex cases. When we look at the National specialities in relation to adult medicine, which could be of major use to children in a new children's hospital, there are 14 specialities. St. James's Hospital has twelve of these specialities, the Mater Hospital has six, Beaumont Hospital has five, Tallaght Hospital has one, the Coombe Hospital (in conjunction with St. James's Hospital) would have twelve, but most of these are in St. James's. Blanchardstown Hospital, which has now been proposed as a potential site by some campaigners has none of these National specialities and in fact Blanchardstown Hospital is not a level 4 major academic teaching hospital.

If the hospital was to be sited in Blanchardstown it would mean massive investment over many years in a new adult academic teaching hospital at that site at huge additional cost. It would take many years to get this up to the required standard in relation to the provision of a coordinated National service. The same problem would apply if the new National Children's Hospital was built on a green field site. Clearly from a point of view of aesthetics and perhaps even access, it would be wonderful to have a new National Children's Hospital on a pristine green field site, but only if you could build a new major academic adult teaching hospital on the same site at the same time. Even if this was to happen, at enormous additional cost, it would take years to build up the clinical and research expertise required in the major new academic adult teaching hospital. This is already available in St. James's Hospital.

There has been concern expressed that the hospital should not be sited in Dublin and perhaps it should be sited outside Dublin somewhere on the M50 because it is a National hospital not just a Dublin hospital. It is worth repeating that this will be a National Tertiary Care Children's Hospital and most of the normal routine children's admissions will still be in local or regional hospitals. It is anticipated that 70% - 80% of the admissions to the new National Children's Hospital will be from the greater Dublin area. Indeed at present, for the existing three paediatric children's hospitals in Dublin, 70% - 80% of the patients are from the greater Dublin area and the new hospital will treat those with complex conditions who will require hospitalisation in a major national expert centre. Most health conditions for children will be treated in the local or regional hospitals. It is also worth pointing out that the decision to site the new children's hospital in St. James's Hospital has been supported by the three existing children's hospitals in Crumlin, Tallaght and Temple Street.

This decision was made objectively by an expert group. They heard many submissions including submissions from some of those who are currently complaining about the decision. The original decision to site the hospital at the Mater Hospital site was rejected on planning grounds, because the site was so small that the building would be too high in terms of the impact on the city skyline. The St. James's site available is three times the size of the site available in the Mater.

This process has been ongoing since 2006. The initial decision was turned down on planning grounds. A new objective decision has been made. It is now time to move on, to start building this hospital and give children the future they deserve in relation to healthcare. We should not back track or be endlessly mired in indecision based on individual views, preferences or interests.



From the haemophilia point of view, St. James's Hospital has 40 years of experience in dealing with haemophilia and related bleeding disorders. The new children's hospital will integrate the experience of Our Lady's Children's Hospital Crumlin, which is currently a comprehensive care haemophilia centre. People with haemophilia have travelled to St. James's Hospital from all parts of Ireland for 40 years. They have received excellent clinical care and excellent transition care from childhood to adult services.

One of the issues in relation to the location of the new children's hospital and the new proposed maternity hospital at the St. James's site is that the existing NCHCD building would have to be demolished, probably in 2016. We have been in discussion with the Chief Executive of St. James's Hospital and Dr. Barry White and they have confirmed that the new NCHCD will be sited on the floor above the new H&H Haemophilia in-patient ward. This is ideal as it will mean that the haemophilia in-patient and out-patient facilities will all be located in one building. We will be working closely with St. James's Hospital to ensure that the new facility is ideally suited for haemophilia care for the coming years and decades.

Brian O'Mahony
Chief Executive

Long Term Illness Scheme & Hospital Fees



Long-Term Illness Scheme

If you or your child have certain long-term illnesses or disabilities, you can apply to join the Long Term Illness Scheme. Haemophilia is one of the conditions that is covered under the scheme. To qualify for the scheme the requirements are that you must be a resident in Ireland, have a PPS number and have one of the conditions on the list. There is no income requirement or means test. (We would also recommend that if you meet the criteria for a Medical card or a GP Visit Card that you apply for these as well.)

You can apply through your Local Health office or you can download the form from the HSE website (www.hse.ie). When your application is processed, a Long-Term Illness book will be issued to you. This book contains the type and quantity of the drugs or medicines you need for haemophilia. Your doctor will sign it and you can then bring this book to the pharmacy when you need any of the items. If your doctor or an occupational therapist prescribes a medical or surgical appliance, it can be supplied to you from your Local Health Office. There is no separate application form for medical or surgical appliances - your doctor simply lists the type of appliance in your long term illness book and signs it.



Hospital Fees

Under Department of Health Guidelines there is a daily hospital charge of €75 subject to a maximum payment of €750 in any period of 12 consecutive months. The charge is also applicable to all semi-private patients without exception.

All patients attending the Emergency Department are charged an attendance fee of €100.

The long term illness scheme **does not** cover any hospital fees, but there are some statutory exemptions to these charges including, if you have a Medical Card, a child up to the age of 6 weeks, a GP referral accompanied by GP letter to the emergency department and the one that is most important is for children with certain conditions including haemophilia. This exemption applies only to treatment for haemophilia. It is through these exemptions that children up to the age of 18 with haemophilia should not have to pay for in-patient and emergency department fees. Once an individual becomes an adult this no longer applies to any of the conditions under the exemption including haemophilia and the patient is liable for the charge.

The HSE has the discretion to reduce or waive the charges in certain cases so we recommend that you contact a social worker who may be able to assist you in these situations.



If you would like further clarification or for support & advice please contact Anne or Declan in the office on 01 657 9900

Calendar of Events

OCTOBER

Dates: 18th October

Event: Hepatitis C Information Day *

Venue: The Ashling Hotel, Dublin

* See page 2 for more information on this event.



OCTOBER

Dates: 30th October - 2nd November

Event: Haemophilia Camp

Venue: Barretstown



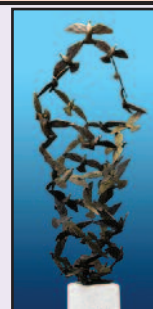
NOVEMBER

Dates: 2nd November

Event: Memorial Service *

Venue: IHS Office, New Street, Dublin 8

* See page 2 for further information on the Memorial Service.



SAVE THE DATES FOR 2015

MARCH

Dates: 6th - 9th March

Event: AGM & Conference

Venue: Hodson Bay Hotel, Athlone



JUNE

Dates: 19th - 21st June

Event: Parents Conference

Venue: Sheraton Hotel, Athlone



OCTOBER

Dates: 16th - 18th October

Event: Members' Conference

Venue: Portlaoise Heritage Hotel



Cubs Club

Hello and welcome to
Cubs Club. In this issue, we
are learning all about Bones!



The Slobs

by Conor Birkett

What are bones?

We all have bones. If we didn't, we would be like jellyfish!

Bones are living, growing and changing parts of our bodies. Bones make up the framework of our bodies, this is called our skeleton. Babies' skeletons are made up from more than 300 parts, but by the time we become adults we only have 206 bones! Some smaller bones join together to make one bigger bone. Bones also protect the softer parts of our bodies; one of these is the skull which is like a natural helmet protecting the brain.

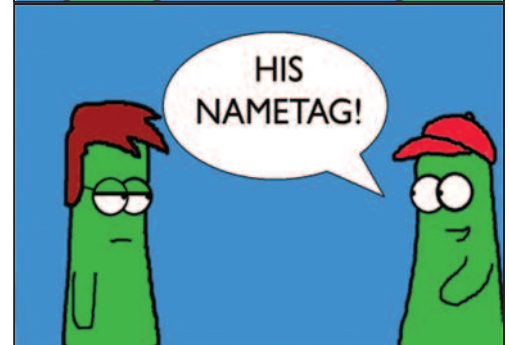
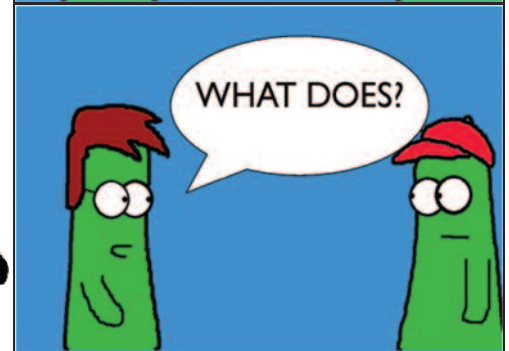
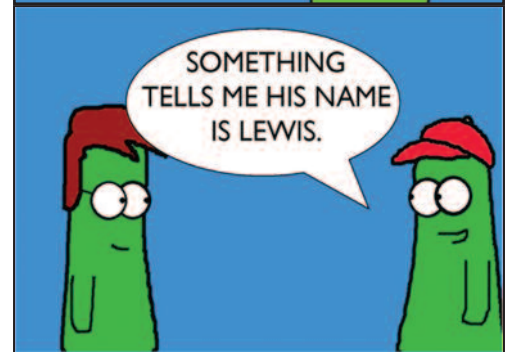
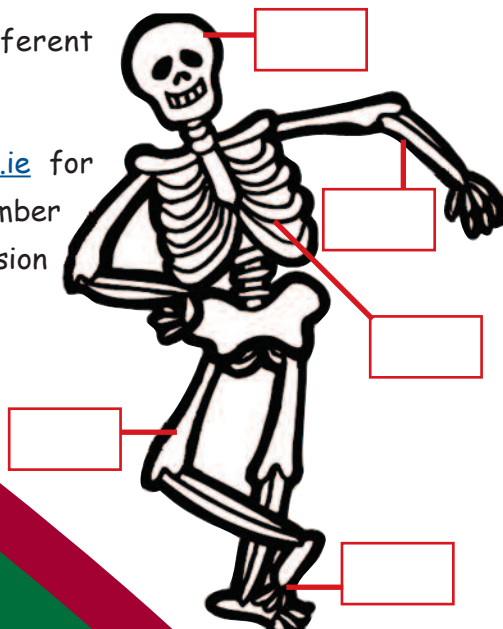
How can we look after our bones?

You need to look after your body to stay healthy. It is important especially when you have haemophilia to have strong bones and muscles! We can do this by eating healthily, getting lots of exercise and protecting our bones!!

What can you eat or drink that will make your bones healthy?

Can you identify the different
body parts on the skeleton?

Log on to www.haemophilia.ie for
the answers, but remember
to ask for permission
first!



Now that you are all back to school, you are learning lots of new things! This means that your brain is getting lots of exercise. You carry around a three-pound mass of wrinkly material in your head that controls every single thing you will ever do from thinking, learning, creating, and feeling emotions to controlling every blink, breathe, and heartbeat—yep your brain is pretty busy!

FUN FACTS!

- * The human brain is like a computer that stores our memory and controls how we think and react.
- * The brain is the centre of the human nervous system, controlling our thoughts, movements, memories and decisions.
- * The brain contains billions of nerve cells that send and receive information around the body.
- * The human brain is over three times as big as the brain of other mammals that are of similar body size.
- * Each side of the brain controls just one half of the body, the right side of the brain interacts with the left side of the body, and vice versa.
- * The human brain is protected by the skull (cranium), a protective casing made up of 22 bones that are joined together.
- * Did you know that your brain does not stop working, even when you are asleep?



Let's give your brain another workout! Find all of the following words in the word search below, all of these words are areas or parts of the brain!

S	V	N	M	C	L	A	R	B	E	R	E	C	U	S
E	B	K	E	E	C	Y	S	F	Y	Z	E	G	V	P
G	W	R	F	R	T	U	T	U	E	N	M	V	N	E
A	X	U	K	E	V	S	J	O	M	W	W	X	C	C
S	V	H	V	B	P	E	R	C	C	A	R	P	E	L
S	U	E	U	E	Z	F	X	E	Q	N	L	R	H	B
E	S	R	N	L	I	R	P	L	M	J	E	A	R	G
M	C	J	A	L	U	L	A	L	A	B	E	A	H	V
R	D	R	L	U	A	N	X	S	R	B	I	Z	H	T
S	D	S	V	M	I	I	Z	U	I	N	N	T	C	X
H	J	B	A	P	I	A	M	T	E	J	R	Y	K	J
B	Z	C	S	C	O	R	T	E	X	B	T	Q	H	O
M	H	Y	X	P	O	Q	O	T	W	K	K	D	L	Y
D	R	O	C	K	M	L	Y	O	U	O	U	U	Z	N
K	L	Y	I	J	S	T	D	K	P	I	W	W	X	A

BRAIN, CELLS, CEREBELLUM,
 CEREBRAL, CORD, CEREBRUM,
 NERVE, SPINAL, THALAMUS,
 MESSAGES, CORTEX, STEM

Solution is available on
www.haemophilia.ie

A PEP in Their Step

My name is Deirdre, I am the mother of four boys one of whom has severe haemophilia.



Three years ago I was invited to attend a new programme being given by the IHS called Parents Empowering Parents. I had no idea what to expect other than it was a programme specifically aimed at parents of children with a bleeding disorder and of a certain age.

I didn't need any persuading to attend as I was going through a very tough time, my son was being bullied in school, he was angry about his haemophilia, and we were all feeling very stressed and unsure how to deal with things. Children don't come with a how to operate manual, and things certainly don't get any easier as they get older, and so I put myself forward for the PEP programme, any help was welcome, I felt like we were drowning.

As a family we had not gone to many of the weekends the IHS organise. This is partly because I didn't want to be reminded of the terrible tragedy that had befallen the haemophilia community, but by doing this I was isolating myself and my son from the support available at these amazing events.

Time to get back on board!

I went along and all I can say is the programme has completely changed how I parent my children. I no longer get anxious about my own capabilities, I know I can do a good job. On that first weekend I was full of apprehension and my guard was well up, then I met all the other parents, all with similar stories, concerns, anxieties, and feelings. Gradually the guard began to drop and a feeling of sameness replaced apprehension. We all had lots of questions and plenty of very qualified people on hand to answer them including nurses, social workers, counsellors but most important were the parents themselves, who shared experiences, such as what to do when a vein tissues, different ways to distract the younger ones, how to tell teachers what they need to know, and for a lot of parents how to let teachers know how much their child CAN DO.

After completing the first PEP programme I jumped at the chance to train as a facilitator, as I feel there is so much to gain for both parents and children. Our lives since the programme have become more positive, we parent from a more sure and confident place.

Being a facilitator on the programme has been such a privilege. To be able to help other parents of children with bleeding disorders is an amazing feeling. A lot of the skills learned are easy to adapt to everyday life and with some patience, practice and consistency will lead to a happier home, more confident children and parents who feel good about the job they are doing.



In 2012 I took part in the PEP Programme and PEP Leadership Training. In 2013 myself and the fellow facilitators from Ireland (pictured above) led our first PEP Programme.

Being present as the new brave parents arrive unsure of what to expect is a reminder of how I felt, hopeful but full of doubts. To be there over the weekend and experience all the learning and new concepts, how we see haemophilia now as compared to treatment in previous years, how we want our children to grow and not let their bleeding disorder define who they are or dictate who they become, it's a powerful weekend with a lot of old beliefs left where they should be, in the past.

Getting to talk to the parents at the end of the final session is hard to explain, friendships have been made, but there is also a bond. We have all shared our fears, asked questions about things we thought were unique to us, only to find someone else has gone through the same thing. We all laughed and cried together, people who had met each other only two days before hugged, exchanged emails, and were all in agreement that taking part was a decision they were very glad they made.

I could enthuse about the PEP programme until the cows come home. I believe so much in the positive lessons the programme teaches. I can understand people's reluctance to get involved, to look at how we parent is hard especially if we feel guilt or lack strength in certain areas. That's what makes this Parents Empowering Parents programme so valuable. Nobody feels judged about how they parent. It is about taking the time, which we rarely have, to look at things we like in our families and things we might want to change or improve. Everyone is there for the same reason, to learn more about themselves and in turn be the best parent they can and want to be to their child with a bleeding disorder.

To be a part of PEP is such a great and worthwhile experience, and one which my children are going to benefit from for the rest of their lives. I would encourage any parent who might be interested to contact the IHS, it is a decision you won't regret.

Deirdre Mc Quail



Pictured are just some of the parents who took part in the 2014 PEP programme.

Since the PEP programme began in Ireland in 2012, over 50 parents have taken part.



Fantastic Fundraising!

Well done to everyone who has fundraised in aid of the I.H.S., you have done a fantastic job and we really appreciate such wonderful support. The last time you heard from us we told you about our Mini Marathon ladies, so here are a few other fundraisers that have taken place as well.

The **'Blue Lights Fight Night'** fundraiser took place in May and was a great success. The event was held in Jacksons Hotel, Ballybofey, Co Donegal and our sincere thanks to Declan Meehan and everyone involved in organising this fantastic fundraiser. Everyone's commitment and teamwork really paid off and just over €6,000 was raised on the night, which is amazing. We were delighted to be chosen as one of the charities to benefit from this event along with the MS Society of Ireland and the Little Angels School for children with special needs in Letterkenny.



Far left: The ladies show their strength in the ring as they prepare for their fights.

Left: There were some heavy blows on the night as ten matches took place. Fighters on the night included paramedics, fire fighters and police.

The event was a complete knock out as over €6,000 was raised for charity!

Without a doubt the real stars on the night were the fighters themselves, 16 men and 4 women, who were brave enough to step into the ring all in the name of a good cause. The fighters consisted of 2 firefighters from Ballybofey, 3 ambulance crew from Donegal and 15 Gardaí based in Donegal. While this brave bunch were out serving the public by day they were training by night, our heroes! None of the fighters had ever boxed before, but they were truly committed and spent ten weeks training in Blue Stack Boxing Club in Ballybofey leading up to the event, that is true dedication. Boxing is not for the faint hearted, our thanks to the men and women who fought on the night, it was no mean feat.

Thank you to everyone involved for their great efforts to make this such a successful fundraiser. By all accounts a great night was had and a staggering four hundred people attended to give their support, which is fantastic. The MC on the night, Paddy McMenamin from the Conal Gallen Show kept the evening flowing from the ten bouts of boxing to the raffle that took place later in the evening. There were some great prizes to be won including a hotel voucher for a weekend in Clanree, a signed Everton jersey donated by Seamus Colman and a signed Ireland jersey donated by the FAI. Then to round the night off, DJ Michael 'Mitty' Kilcoyne played into the wee small hours of the morning.



Just some of the 20 fighters who took part in the fundraiser, including organiser Declan Meehan, front left!

More recently a **'Bucket Collection'**

which was organised by Pat Clohessy, took place in the Crescent Shopping Centre in Dooradoyle, Limerick on the 30th and 31st August. Pat, his wife Sarah and son Aiden spent their family time together fundraising over the course of the weekend and raised an amazing €300 for the I.H.S. We would also like to thank the management, staff and customers of the Crescent Shopping Centre for their support and generosity.



In Limerick, the fundraising was a family affair as Aiden, Pat & Sarah Clohessy organised a bucket collection which raised €300!

Fundraising can be taking part in an organised event or organising your own fundraiser, whether it's a fun run, mini marathon or you would like to arrange a coffee morning, bucket collection or table quiz, remember we are here to offer practical help and advice every step of the way. We can organise Garda permits if required, provide posters, tickets, sponsor cards and I.H.S. t-shirts etc. Want to know where to start or what might be involved, just give me a call on 01 657 9900 or email nina@haemophilia.ie and I will be happy to help.

Nina Storey

IHS CHRISTMAS CRACKER

We are delighted to announce that the Society are running a winter fundraiser 'Christmas Draw', and take a look at some of the amazing prizes we have.

- **First prize – 7 night stay for 2 at the Sunset Beach Club, Costa Del Sol, Spain, including flights.**
- **Second prize – A weekend away for 2 at the Lake Hotel in Killarney.**
- **Third prize – A weekend away for 2 at the Castleknock Hotel in Dublin**

Tickets cost €10 each. Enclosed in this magazine you will find a book of 5 tickets which we hope that you will be able to sell. If you would like to sell more tickets or would like more information about the draw please contact Debbie or Nina in the office on 01 657 9900. Tickets will also be available for sale on our website www.haemophilia.ie. The closing date for receipt of counterfoils is Friday 12th December, and the draw will take place on Monday 15th December.

Thank you for your support.

The Irish Haemophilia Society would like to thank Castleknock Hotel in Dublin and the Lake Hotel in Killarney for their very generous sponsorship of prizes. It is very much appreciated.



The Daly Edition

Since joining the Society, I have heard a lot about Rosemary Daly and the contribution she made to the I.H.S. so it seemed only fitting that she should be the focus of the next newsletter feature. Making my way to meet Rosemary I will admit I was slightly nervous, but those nerves quickly left as I was greeted with a smile and warm welcome from the woman herself. What transpired over the next few hours was an eye opening experience as Rosemary relayed me with stories so heart-breaking and honest, you wouldn't believe. This feature will never capture the full essence of Rosemary Daly, but I hope it will give you an idea of the woman behind the name.

Rosemary Daly was one half of the I.H.S.A Team, supporting people with haemophilia who had been infected with HIV and / or hepatitis C and their families. Rosemary was volunteering with a group called Gay Health Action when she was approached about the role of Aids Coordinator with the Irish Haemophilia Society;

"It happened that I was very interested in HIV and Aids. While working with Gay Health Action someone told me about the job with the I.H.S, they had read about it in their magazine and that's how I started off. Obviously not knowing where it would end up."



Rosemary and two young members of the IHS launching the first ever non uniform day for the Irish Haemophilia Society,

Prior to working with the Society, Rosemary had no direct connection with haemophilia so I was keen to find out what drew her to the job and discovered that haemophilia and HIV had crossed her path before while working in a previous role;

"As a youth worker in Coolock, I decided to run a programme in the school for the students so that they could be educated on HIV and Aids, which was an issue that was in the media a lot, but that nobody really understood. I got medics and the Department of Health involved and then I went to find people who were in fact HIV positive at that time and one of those people was a gentleman with haemophilia. He came to the programme and spoke about his own circumstances and I was just struck by his story. I ran the programme to educate the students, but the impact it had on me was immense, from the outset I was just outraged at what was happening."

In the 1980s HIV was prominent in the media. People did not know much about HIV and Aids and there was an immense fear among the public and in particular in the haemophilia community when the contaminated blood scandal became apparent. Fear of the diagnosis, fear of people discovering their status and fear of dying.

At a time when the haemophilia community was shaken and fearful, I assumed it must have been difficult for Rosemary coming in to the role as a new staff person. However, this was not her experience;

"I had an amazing tool and that was Margaret King. She knew these people, she nursed these people as children so that was my introduction. So I had a very good person at my side and I was actually working on the back of their trust and love for Margaret King."

The fear of their diagnosis being discovered stemmed from a lack of awareness. There was very little information on HIV at the time, people believed you could catch HIV from a teacup. With this lack of awareness, came a fear and unfortunately a stigma. This was something Rosemary experienced herself and she told me of a time her son was not allowed to play with another child, because the work Rosemary did with people with HIV was well known.



Left to Right: Jennifer Ross, executive director of the Haemophilia Foundation Australia with Rosemary Daly, Theresa Mulvey and Margaret King of the IHS.

However, as the campaign for recompense began and the Society became involved in advocacy, the plight of people with haemophilia became known publicly and there was a lot of support from the general public.



Rosemary worked alongside Brian O'Mahony, current IHS CEO, on various advocacy campaigns for people with haemophilia.

Unfortunately, recompense and support was just a minor part of a HIV diagnosis. At that time there were no treatments for HIV, it was a death sentence and this was the harsh reality affecting people with haemophilia, both adults and children. Soon, the Society began to lose members to the disease and Rosemary's role changed from just supporting people with HIV. Following the death of a person with HIV and / or AIDS, there were restrictions on the care of the body following death which meant that families were being denied the opportunity to have a wake for their loved ones. Not only that, families were afraid that the lack of a wake would arouse people's suspicions about the cause of death. Rosemary and Margaret King decided they would help alleviate this problem. They began going to the homes of members who were dying and once they passed, they would lay them out for a wake.

"This was a decision Margaret and I made ourselves, it was totally intolerable and was adding to the families' suffering. However, when we made the decision, I didn't anticipate my part in this process. As Margaret was a nurse, I assumed she would take on the role and I would be there to lend her support, but she brought me in very naturally and made no big deal of it so to me it wasn't a big deal."

However, it did and still does carry some painful memories;

"The toughest part of my job was laying out the children. It was just absolutely horrendous. I knew all the football strips of all the clubs that were popular at that time. It just didn't make any sense. The anguish and the grief of a mother in particular, burying her child. That used to just tear the heart out of me and still does when I see them."

Having Rosemary and Margaret care for their loved ones in their final hours and indeed after death must have been a huge comfort and support, but there was a downside to this pivotal role that they played;

"Margaret and I would know when people were deteriorating and we would approach them and ask them if they would like us to make arrangements to bring them home. However, we then became associated with death. A mother said to me, long after her son had died "I hated seeing you coming, because I knew what it meant". It was a double edged sword."

Listening to Rosemary, it struck me as to how ordinary she made the task seem, but in reality it must have been so hard as these were not just people, they were her friends;

"I didn't have any family member who was infected or who died, but I had a huge amount of friends that became that way. I remember every anniversary of those that died, it is engraved in my brain."

The secrecy that people with haemophilia infected with HIV kept was not just to the community, but indeed within families. Children were unaware of their parent's condition, parents unaware of their adult children's diagnosis, siblings had no idea why their brother was ill. Having to face such grief, but remain in control to keep a secret must have been overwhelming. The lie perpetuated every part of their lives. Indeed this secrecy is something that is still present today. Rosemary explained that she keeps in touch with a lot of families who faced this immense tragedy and indeed those family members who were unaware of the cause of death at the time.

"With such a massive secret there is bound to be anger. Many family members are angry that they didn't know and were unable to be supportive, they would have liked to have supported the person and their family. But you don't know how people

will react until you tell them and again this was a time when people were living in fear and couldn't talk about it."

As is the case with the Society now, the support the I.H.S. provides is for the whole family, not just the person with haemophilia. When a member had passed, Rosemary continued to support the family both individually and as part of the organisation.

"Some people withdrew from the Society following a death. But for a lot of people the Society was place where they could go and talk about their experiences and meet people who knew their loved ones."

During the campaign for recompense, Rosemary was there to support individuals living with HIV and families of those who lost someone to HIV. Rosemary recalls about that time:

"It was tough, trying to bring two or three hundred people down a road that is trying to get one size fits all in compensation or a tribunal report everybody is not going to be happy with and everybody wasn't happy. The first time with the recompense, the parents of the children who died got a much lesser sum than anybody who was alive. And I remember being in that room and trying to explain this to parents. How do you explain it to them that your child is worth less because they are already dead? I'll never forget that, that stays with me, that room, that day, that hour."

The haemophilia community was still regrouping when the hepatitis C contaminated blood scandal came to light;

"I just couldn't believe this was happening. This was just a nightmare in so far as that hadn't these people and these lovely families, men and children, wives and sisters got enough to deal with. It brought everything back up"

The Society again began a campaign for advocacy and began supporting the members as they had previously with peer support meetings and educational conferences. However, through all the challenges facing people with haemophilia, Rosemary wanted to make one thing clear to me, the community was strong.

"It wasn't all doom and gloom, there was a lot of laughter. Some people will say that those HIV and hepatitis C weekends we had were the best craic ever. You could have looked into a room on a Saturday night in any of the hotels we used and heard the most fantastic sing song, the greatest craic, people standing on stools singing and dancing and no one would ever know what was going on for that group of people. Because they were allowed to have a laugh and they were among people who they knew were in the same boat as themselves and they could trust, at the same time as receiving information that was vital to them. So there was all of that, but there was a lot of messing, laughter and a bit of madness thrown in as well."



The former staff of the Irish Haemophilia Society including Margaret King, who along with Rosemary became known as The A Team!

Rosemary supported people with haemophilia and their families through times of extreme grief. Often away from home for several days at a time when a member was dying, I wanted to know how it affected her and indeed who supported her during those dark times.

"At that stage, I was younger. It didn't impact on my life then as far as I felt. As I got older and have more time to reflect, I would do it all again, but I do realise now I did miss an awful lot of important events in my own children's lives and it potentially could have affected them and in some instances they really would have preferred I was at home, but they realised what was happening for somebody else."

In 2002, having worked with the Society for over 13 years Rosemary left the I.H.S. A decision she admits was hard, but was vital.

"I had to leave, I was absolutely mentally and physically exhausted. I went to France, and for about five or six weeks, my husband will tell you, I just sat there and cried, I just cried and cried and cried and cried. It was an outpour of all the grief."

Although the right decision to leave, Rosemary admitted she missed the Society;

“Yes, I miss it like a family member who has just gone away. There is something missing in my life, that is the god honest truth. There is part of me that was never made whole again since leaving.”

It is worth noting that the I.H.S. is never far from her mind, she keeps up to date with the Society’s newsletter, keeping a special interest in the advancements of treatment for hepatitis C. She may not work for the Society, but she is still putting the members first;

“I don’t tend to go to functions or events, because I have this strong feeling that, rightly or wrongly, my popping up is just bringing back too many bad or sad memories. That’s the reason why I don’t go, not because I wouldn’t enjoy it or wouldn’t like to meet people. I just want to give people the freedom to be without me popping up and bringing back painful memories.”

Indeed, Rosemary still thinks of and worries about the haemophilia community;

“I do worry about the affect all this had on the children whose fathers died, I see first-hand that they have lost their Daddy who can never be replaced and who was and will continue to be missing forever in their daily lives and all the special occasions. For girls who are carriers this is particularly poignant as they seek medical advice from the very hospitals where their fathers received the contaminated blood products. As for the parents who lost their children and their grown up sons, many now in their old age it has been a long lonely road of what if... it never happened.

For the brothers and sisters of those who were taken before their time, the loss of the love and friendship of a brother and the uncle for their children remains. For the wives and partners, the loss of sharing the joys and woes of childrearing, or just having them there to grow old with, the pain continues.

Thankfully advanced treatment means that many of our men are living well, treatment can be tough of that there is no doubt, but for all who love them, we are so glad that they are still here.

For the children with haemophilia the future is bright, that is music to my ears, however we must never forget, that the sound of loneliness, grief, and fear is often silent. In the efforts to embrace and ensure a bright future for the children, let us keep our ears and arms open for all those whose suffering and loss paved the road to this bright future.”

It says a lot about a person to put the needs of a community before yourself, but for Rosemary it is just her nature. This was never more apparent than when I asked her what she felt her biggest contribution to the Society was;

“Well I hope more so than I think, that they felt I was just there for them. That’s it, just there, as a human being at the same level that they were at, just to be there.”

A woman, a mother, a friend, a support, an inspiration. There are so many words that could be used to describe Rosemary Daly that not even a dictionary could contain. I sat with Rosemary for over an hour just listening. There were tears as she recalled some of the hard times, laughter as I discovered her unique sense of humour and shared recollections of friends no longer with us such as Fr. Paddy who we both agreed gave the best hugs.

The contribution Rosemary made could never be summed up in words, but two words that are needed and fitting are Thank You.



Rosemary still keeps in touch with many members of the Society.



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