Magazine of the Irish Haemophilia Society

haemophilia.ie

Representing people in Ireland with haemophilia and related bleeding disorders.

The Society at a Glance

1019	46	74	6028
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OCTOBER CONFERENCE

Dates: FRIDAY 20th to SUNDAY 22nd OCTOBER, 2017
Venue: Hodson Bay Hotel, Athlone
Preliminary Adults Programme

Friday 20th October

17.30 – 19.00	Registration
19.00 – 20.00	Buffet Dinner
20.00 – 21.00	Members Forum

Saturday 21st October

09.30 – 10.00	Registration
10.00 – 11.30	Lecture: New developments in haemophilia treatment
11.30 – 12.00	Coffee Break
12.00 – 13.30	Interactive Workshop: New developments in haemophilia treatment
13.30 – 14.30	Lunch
14.30 – 15.30	Port-a-caths / Vein Care
15.30 – 16.00	Coffee Break
16.00 – 17.00	Tattoos and Piercings
19.15	Dinner & kids entertainment

Sunday 22nd October

10.00 – 11.30	Mothers Peer Support Group / Fathers Peer Support Group / Members Peer Support Group
11.30 – 12.00	Coffee Break
12.00 – 13.45	Wellness Workshop
14.00	Lunch

A Note from the Editor

Hello everyone,

Welcome to the summer edition of haemophilia.ie.

In this edition on page 4, our Chief Executive gives an update on what is happening in relation to new developments in haemophilia treatment.

On page 6, you will see dates and venues for all of our events for the rest of 2017 and for some of 2018. Members, don't forget that next year is the 50th anniversary of the I.H.S., so we will be organising special events and activities to mark this event, including a really special AGM and conference in March.

Debbie Greene, Administrator & Office Manager

Parents, if you are interested in sending your child/children to Barretstown this year, you will find all the information you need on page 7.

Applications are now open for our educational grants. If you go to page 12 you will find out about the criteria and any other information you might need.

Our Father and Son event in Lilliput Adventure Centre took place in early May. If you would like to find out more about how it went, go to page 14 and you will see an article written by member Ken Byrne.

Go to page 18 for our noticeboard which gives little snippets of information about various items of interest.

I hope you enjoy reading this edition and don't forget, we are always delighted to see members dropping into the office to say hello. If you need assistance, support, advice, information, a home visit, a hospital visit or just a chat, call Lyndsey, Nina, Brian or myself in the office on 01 6579900 and we will be more than willing to help in any way we can.

Debbie Greene
Administrator & Office Manager

Contents

CEO's Report

Brian O'Mahony,
Chief Executive

At the recent 'Ageing' (and haemophilia) conference in Kilkenny, Dr. Michelle Lavin from St. James's gave an excellent overview of the challenges ahead for people with haemophilia. This cohort of members will be the first generation of people with haemophilia to have survived long enough to be able to confront the challenges of ageing. Specific haemophilia related risks including ongoing joint damage, bleeding, surgery and an increased risk of inhibitors for those over the age of 60 was discussed. General ageing complications such as cardiovascular health, high blood pressure, kidney disease and the risk of bowel or prostate cancer was also discussed. The National Coagulation Centre (NCC) is now including checks on bone health for all severe and moderate haemophilia A and B patients. This includes a DEXA scan for bone density and blood tests including checking Vitamin D levels. The majority of Irish people are deficient in Vitamin D due to our lack of exposure to sunlight. It is worth checking with the NCC or with your GP to see if you should be taking Vitamin D supplements. It is important for people with haemophilia to have their bone health assessed as we want to avoid osteoporosis or osteopenia in addition to the existing risk of arthropathy from joint bleeding. In a recent UK study, 5% of people with haemophilia had osteoporosis (porous bones) and 24% had osteopenia (where the protein and mineral content of the bone is reduced - less severe than osteoporosis). People with haemophilia may have lower than average bone mineral density, perhaps, in some cases because their peak bone mineral density was never achieved due to bleeding or lack of exercise in childhood. Dr. Lavin also stressed the benefits of appropriate diet and exercise for good cardiovascular health and the risks of diabetes from being overweight. (Dr. Lavin's lecture can be found on our website in the conference reports section.) It was perhaps appropriate that this session followed after an excellent presentation on diet and nutrition and changing the eating habits of a lifetime. The importance of having your blood pressure checked regularly was emphasised as were participation in the national bowel cancer screening programme for those over the age of 60 and having your GP check you for prostate cancer annually. The conference was well attended and the evaluations showed a very high degree of satisfaction with the programme. It was clear that the members present agreed with our strategy to now hold this conference on an annual basis.

New departures for the Society this year in relation to events include a Father and Son event and a Mother and Daughter event. The Father and Son event took place in May at Lilliput Adventure Centre. It was a very active weekend and I believe everyone really enjoyed it a lot. The Mother and Daughter event will take place in late June and will be a similar activity event. These events are designed to give the parent and child time to spend together and with a group of parents and children with a bleeding disorder. The events should allow both the parents and child to participate actively in exercise by doing enjoyable activities for which haemophilia is not a barrier.

A milestone in relation to activities was reached this month when Chris Bombardier, a man with severe haemophilia A from the USA, became the first person with haemophilia to climb Mount Everest. Chris took a factor VIII infusion while on Everest, which gives a whole new meaning to a high factor level! We salute his achievement. This activity is, obviously, not within the reach of the vast majority of people with or without haemophilia, but it does demonstrate what is possible with modern haemophilia treatment.

Chris Bombardier who has severe haemophilia

On May 15th, we posted an article on the Society's website on sporadic Creutzfeldt-Jakob Disease (sCJD). Members will recall that there was a lot of concern in the past relating to variant CJD (vCJD), the human equivalent of mad cow disease that rose to prominence in the UK and Ireland in the period 1985-2000. To date, there have been over 200 cases of vCJD, mainly in the UK. There has not been a case in a person with haemophilia, but in the past, there were 4 cases linked to blood transfusion. A very large number of people with haemophilia in the UK and some 50 people in Ireland were known to have used plasma-derived factor concentrates manufactured from UK sourced plasma, from 1990 to 2001 and were placed on an 'At Risk' register which required additional precautions to be taken with endoscopies or surgery on these individuals. As reported in the last Society's magazine, these restrictions have now been relaxed. The posted article refers to sporadic CJD which occurs at random at a rate of 1.5 per million population per year. It mainly affects people in middle or older age. Approximately 100 people in the UK every year develop sCJD. The cause is unknown and has not been linked to blood products. However, it was reported in May that two females with inherited bleeding disorders (one with von Willebrand's disease and one a factor IX carrier) had died from sCJD in 2014. Both had been treated with blood products or factor concentrates in the past. This is the first time that sCJD has been reported in people treated with clotting factor concentrates anywhere in the world. At this stage, it is not known if this is a coincidence. Active surveillance continues for both vCJD and sCJD both in the UK and internationally.

A significant number of people with haemophilia B in Ireland were recently tested for antibodies for a specific Adeno Associated Virus (AAV) to assess their suitability for a clinical trial on factor IX gene therapy. AAV functions as the vector or delivery system for gene therapy. Approximately 30% of people tested will have existing antibodies to this virus and therefore will not be eligible for possible participation in the clinical trial. We expect progress to be made in the coming months leading to the probable participation of some people with factor IX deficiency in gene therapy clinical trials here later this year. Further opportunities for participation in other factor IX and indeed factor VIII gene therapy trials should be available to Irish people with haemophilia in the coming two years. In addition, a number of people with factor VIII deficiency have now commenced weekly subcutaneous injections with Emicizumab as part of a clinical trial. This bi-specific antibody mimics the effect of factor VIII and allows the individual to be treated subcutaneously instead of having to take regular intravenous factor VIII prophylactic injections. We will, of course, continue to monitor developments with interest. It is exciting to see several of the concepts we have spoken about over the past number of years now come to fruition and to see people with haemophilia here in Ireland, having the opportunity to participate in these clinical trials. Separately, Shire and Xenetic Biosciences have announced that they are discontinuing development of a polysialylated factor VIII. This was to be an extended half-life factor VIII which they had hoped would require only a once per week infusion. This dosing criteria was not met in the Phase 1-2 study. Shire continues the development of their other extended half-life factor VIII, Adynovi, which is expected to be licenced for use in Europe later this year.

It was also very encouraging in May to see the then Taoiseach and Minister for Health lay the foundation stone for the new National Children's Hospital on the St. James's Hospital campus. The pace of building work has clearly increased in recent months and we eagerly await the completion of this long planned and badly needed facility.

Brian O'Mahony,
Chief Executive.

Calendar of Events for 2017/2018

2017

October

Members Conference
Dates: 20th to 22nd October
Venue: Hodson Bay Hotel, Athlone, Co. Westmeath.

Haemophilia Camp Barretstown
Dates: 28th to 31st October
Venue: Barretstown, Co. Kildare.

November

Memorial Service
Date: Sunday 26th November
Venue: I.H.S. Office, Dublin 8.

December

Christmas party for kids
Date: Saturday 9th December
Venue: Grand Hotel, Malahide, Co. Dublin.

2018

March

50th Anniversary AGM & Conference
Dates: 2nd to 4th March
Venue: Royal Marine Hotel, Dun Laoghaire, Co. Dublin.

October

October Conference
Dates: 19th to 21st October
Venue: Radisson Hotel, Sligo.

Barretstown

For those of you who have never been to Barretstown, or for those of you with children younger than 7 years old, you can still experience the magic of Barretstown. Even better, you can experience this together with your family! There are several family camps throughout the year in Spring and Autumn.

The element of surprise is one of the best things about Barretstown and without giving away too much of the fun, we have decided to give you a glimpse of what a typical day at camp looks like.

A TYPICAL DAY AT CAMP

09:00 - 11.00	Breakfast & Cottage Time
11:00 - 13.00	Family Challenge
13:00 - 15.00	Lunch & Rest Hour
15:00 - 17.00	Activities (Age appropriate groups)
17:00 - 18.00	Cottage Time
18:00 - 20.00	Dinner & Cottage Time
20:00	Evening programme
21:00	Cottage for younger children or adult or teen lounge
22:00	All back in cottages

Check out the remaining dates for camps in 2017 below and if you and your family are interested in attending or indeed have any questions about Barretstown, please contact Fiona on 01 657 9900 or you can email her at fiona@haemophilia.ie

SUMMER		AUTUMN	
Summer 3	10 July - 16 July, Age 7 - 17 Sibling	Autumn 1	15 September - 17 September, Family
Summer 4	21 July - 28 July, Age 13-17	Autumn 3	29 September - 1 October, Family
Summer 5	3 August - 9 August, Age 7-13	Autumn 4	6 October - 8 October, Family
Summer 6	14 August - 20 August, Age 11-15	Autumn 5	13 October - 15 October, Family
Summer 7	24 August - 27 August, Family	Autumn 7	28 October - 31 October, Haemophilia
		Autumn 8	3 November - 5 November, Family
		Autumn 9	10 November - 12 November, Family

Living with Factor V Deficiency

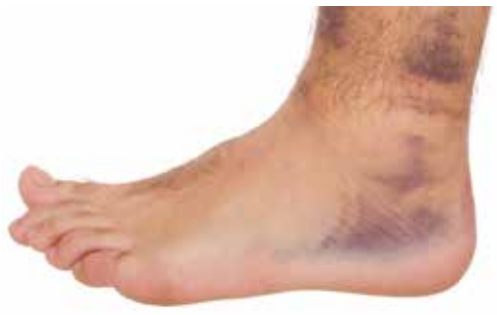
To discuss living with factor V deficiency, I must first give a brief history of my family and where it all started.

There are five siblings in the family, two boys and three girls. Both my older sisters and I have factor V deficiency, the rest are unaffected. When my older sister was six months old she bumped her head against the side of a coffee table. She was brought to hospital and did not respond to the treatment given. Blood tests were completed and it was then found that she had factor V deficiency. When I was born I was checked and also found to have factor V deficiency. Subsequent tests revealed that both my parents had low levels of factor V in their blood. Needless to say this was a great shock to my parents who had never heard of factor V.

I remember my sister and I received treatment at the same time. Joint bleeds, biting our tongues, bumps which would turn into bleeds were common for us at the time.

We were living in Chicago, Illinois and it was common practice for hospitals to pay for blood from anyone who would walk in off the street. My parents organised 'blood drives' for us inviting friends to donate blood to us. This blood would then be stored and used for us when required. This was very progressive thinking for the 1960's. Even though we had a good quality of life in Chicago, the medical bills for the two of us were crippling my parents and they decided to return to Ireland in 1973.

I don't remember my parents telling us not to do certain activities but I do remember being told to 'be careful' always. My mother would say that we would only learn through experience in other words if we did something and got a bleed then we would not do it again. I think this was very good as we tried everything and knew what we could and could not do. The simple things like riding a bike, gymnastics and basketball were a risk for us. I spent more time with my fingers taped together due to bleeds in the



finger joints with basketball. Eventually, I gave up. Gymnastics the same, too much pressure on the joints resulted in bleeds. The bike was a necessity so I learnt to be more careful.

The teenage years brought many challenges, especially the onset of puberty and having periods. Despite having identical diagnoses, both my sister and I had very different experiences with periods. The answer in those days to heavy periods was the pill and cyclokapron. Professor John Bonnar was my gynaecologist at the time and he was excellent. My parents were horrified that their 13-year-old daughter had to be put on the pill and there was often heated discussions between my mother and Professor John Bonnar about this. The first ten years of having periods were hell for me regardless of being on the pill. The majority of my hospital visits at this time were for heavy periods. I often received blood as my haemoglobin was so low. I was never encouraged or allowed to stay at home from school with heavy periods. I would just have to get used to it and if I got a job I wouldn't be able to stay at home! This time also coincided with a transfer from Harcourt Street Children's Hospital to Top Floor Hospital 1 in St James's. Gone was the relaxing carefree environment of Harcourt Street to the absolute depression of Top Floor Hospital 1 in St James's. I can still remember my first in-patient stay, being in a ward with older and very sick people. Even though the wards were depressing the care was good and the matrons kept everyone on their toes!

I was doing my Leaving Certificate when testing for HIV became available. We were not aware at the time that we were being tested but on a subsequent hospital visit, I was told that I was negative. I was on my own at the time and this just slipped into the conversation when I was speaking to the doctor. There was a lot of ignorance regarding HIV at the time and this is just how it was done. I would hope that this would not happen today! Did my parents' blood drives save me from HIV? I don't know but I am truly grateful to them.

Starting a family brought its own challenges. It was not a question of my husband and I making a decision to have a family but a whole team of people were involved. Private decision be damned! I was initially referred to a consultant who told us that due to the bleeding disorder the only way forward was IVF and that there were no other options available. This did not sit well with me as I could see more bleeding problems with IVF than anything else so I changed gynaecologists to Dr. Hugh O'Connor in the Coombe. Another great man which put us at ease! A plan was agreed upon and hospital visits, scans and treatment followed every month. Thank God when I was pregnant all went well and I went the full term to 40 weeks. We have a lovely healthy daughter so all the hard work was worth it in the end.

Looking back on what I have written, I may have given the impression that factor V deficiency is a doddle. This is not and was not the case. I had many trying times throughout my life with my bleeding disorder. With great family support and a good medical team, the hard times were bearable. I would advise any person with a bleeding disorder to protect their mental health during the hard times. A bleed can be rectified easily but the mind needs gentle care. Take care and thanks for reading!

Ann Marie McCabe

Cubs

Self-Infusion

Growing up with haemophilia means that when the time is right you will learn how to self-infuse!

Self-infusion means you can treat a bleed from home or from school, or even when you are on holidays and you don't have to go to the hospital! When you are young your Mam or Dad gives you your injections until you are big enough to learn how to self-infuse, but you can be a big help too!

Do you know what you can do to help?

Picking the area where you will get your injection – Maybe you could pick a nice comfy chair. Just make sure there is lots of light to see your big juicy veins and enough room for everything you will need for your injection!

Clean your hands – It's really important to make sure that you and whoever is giving you your injection has washed their hands. This could be your job! You could remind your Mam or Dad! You could also clean the factor bottle – ask an adult to show you how!

What do you do to help?

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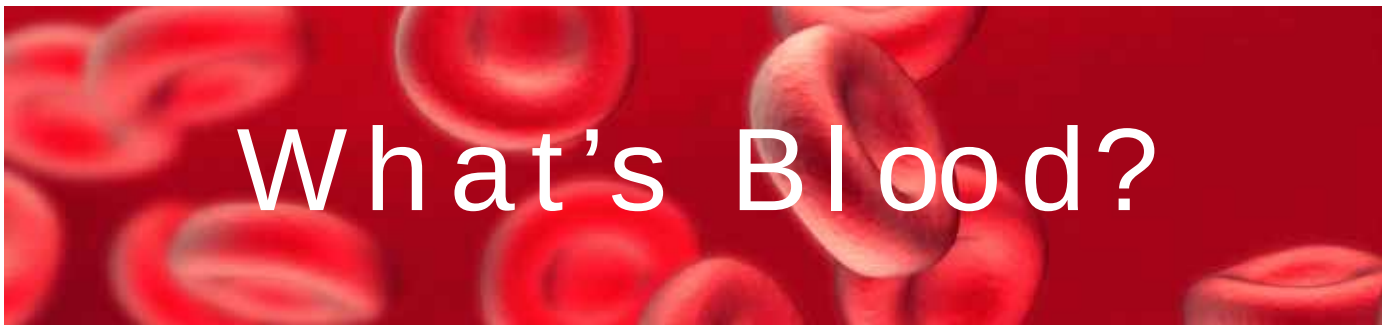
Mix the factor – This is a very grown up job and it's really important to know how to do this. Maybe ask your Mam or Dad next time you get an injection why you have to mix your factor!

Finding your veins – You could help put on the tourniquet and find a good vein. Some people have big juicy veins other people have smaller veins! You could even have a look at your Mam or Dad's veins. When you pick a vein, remember to use the swab to clean the area before you get your injection!

So even when you are not doing your own injections there are lots of things you can do to help.

Kidlink Club



What's Blood?

We often talk about haemophilia being a clotting factor deficiency and how important clotting factors are in our blood. Do you know what else is in your blood? Let's find out!

What makes up my blood?
Blood has several different 'ingredients' which are:

Red blood cells – These cells carry oxygen throughout the body.

White blood cells – Made up of several different types of white blood cells, white blood cells fight infections.

Platelets – These cells work together to help you stop bleeding.

Plasma – This is a yellowish liquid that carries nutrients, hormones and various proteins around the body.

Where do all of these 'ingredients' come from?

Your bone marrow, which is inside your bones, makes your red blood cells, your white blood cells and your platelets. Plasma is mostly water, which is absorbed from the intestines from what you drink and eat!

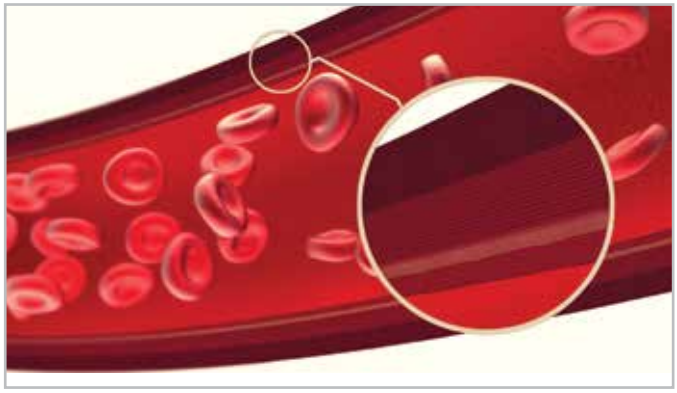
I have haemophilia, what happens when I get a cut or a bang?

If you hurt yourself and you get a bleed or a cut, platelets go to where the bleeding occurs and cover the hole by plugging it up. This is the first step in the clotting process. When the platelets plug the hole, they release chemicals that attract more sticky platelets and also activate various clotting factors, which are proteins in the blood.

A person with haemophilia is missing one of their clotting factors either factor VIII or factor IX which is why they bleed for longer after a bump or bang and can get spontaneous bleeds!

Fun Facts

- Your blood is filtered by your body around 300 times a day.
- There are around 250 million red blood cells in just one drop of blood.
- The cornea in the eye is the only area of the human body that has no blood supply.



Educational Grants 2017

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

Are you going to college?

Do you have haemophilia or a related bleeding disorder?

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

If so, why not take the time to apply for an I.H.S. educational grant?

Applications are now invited for the 2017 Educational Grants. You can apply online on our website www.haemophilia.ie, or you can also download the application forms from our website, complete them and post them into the office.

What types of Educational Grants are available?

There are two categories of grants available as follows:

- Educational Grants for people with haemophilia or related bleeding disorders.
- Educational Grants for immediate family members.

How much are the Educational Grants for?

The grants are broken down as follows:

Maureen & Jack Downey Educational Grant

- First prize €4,000
- Second prize €2,000 *(This is called the Father Paddy McGrath Educational Grant)*
- Third prize €1,500

Margaret King Educational Grant

- First prize €2,000
- Second prize €1,000
- Third prize €500

The Criteria for the Maureen & Jack Downey 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. The person applying must be registered at the National Coagulation Centre at St. James's Hospital in Dublin.

The Criteria for the Margaret King Educational Grant

This grant is made available to an immediate family member of a person with haemophilia or related bleeding disorder be it a spouse, son, daughter, sister, brother, mother or father. The person applying must be accepted on a post second level educational course, and the person with the bleeding disorder must be registered at the National Coagulation Centre at St. James's Hospital in Dublin.

What is the opening and closing date for applications?

The opening date is Friday 30th June 2017 and the closing date is Friday 29th September, 2017.

How are the applications scored and who scores them?

Once the closing date arrives and all the applications have been received, a subgroup of three people from the executive board (which cannot include anyone with a family member applying for any of the grants) meet to consider and score the applications, and make recommendations to the rest of the executive board regarding recipients. The successful applicants are then notified at the end of October by letter.

Applications are scored on the following:

- The quality of the application.
- The information given on the application form.
- Involvement in the Irish Haemophilia Society.
- Financial need.
- How many in the family are going to college.
- If the application is a first time application.

Can I apply every year?

Yes, you can apply every year, even if you have already been successful, but remember even if you are eligible to apply for both grants you can only apply for one of them.

Take some time to complete your application, as the more complete and detailed your application is, the higher your chance is of being successful. And please do fill out the application yourself! Good luck to everyone who applies.

Debbie Greene
Administrator

Father and Son Overnight

So with a little trepidation, we pulled into the car park. Adam was really looking forward to this weekend. Me, well, not so much but it's a great idea and super for the kids to chill with the other kids and their dads, which is more than likely something that does not happen all that often in today's world with everyone so busy. One rule for me! No phone or at least only use it for photos and to let the wife know we arrived fine.

The sun was out and we were ready for the fun and games that lay ahead. After meeting up with everyone and grabbing a coffee we all gathered in the courtyard and the first activity was a treasure hunt.

We were all split into teams, Adam was our map reader and not a bad one as it turned out. We were to find 14 items all spaced about in the grounds. It was a timed challenge and the race was on. We were to come back and record the score and time, then wait for all the teams to come back. (I think there might be one team still out there!) Anyhow, our team finished second and I was blamed for not being quick enough which seemed to be a typical blame for the weekend!

The second activity was the climbing wall. All the kids had a few goes on this and in fairness to them, they were all very good with a number getting to the top. A few dads gave it a shot and I think it would be fair to say the sons may have won this one!

Next was lunch which was good as the sun was replaced by cloud and a lot of wind. It was quite cold but it was a welcome break from the sun.

After lunch, we all hit the woods for a few games. We also all took a shot of archery, some were better than others. There was also a screaming challenge, to run up a hill and scream out loud with the same breath. Jay and Paul got furthest and there was a tweaked hamstring and a few close to passing out. Adam made it furthest from the kids.

Next on the list was onto the lake for a bit of canoeing. Once everyone got out into the lake there was a lot of water fights and fun, even with the wind doing its best to blow everyone back onto the shore.

The final activity of the day was the famous Bogs! Wow, the kids just loved it (and the big kids too, Paul and Jay). It's a boy's ideal activity, water and dirt. Walking, crawling and bombing! The bogs allow you to do it all, oh and say goodbye to your clothes cause they ain't getting clean (ever). As you walk through the fields with the bogs you see piles of shoes and trainers piled up from people who lost them in the bogs and they have been thrown out to the side by others. ..It's quite a sight!

Freezing but happy we headed back to the warmth of the shower room where everyone spent ages trying to get the muck and dirt off themselves. My guess is they will still find dirt weeks later, especially in that beard Jay!

Then it was dinner which was hoovered up by all. A bit of time to chill and then back out into the woods for another game. A reverse game of hide n' seek where when you find the team hiding, you hide with them and then the last team to find all hiding out are the losers. It was fun and took a while before we all got this one done. Then, a few final games of sniper and it was back to the lodge. There was a movie for some and for others, there was the best game of the weekend, the simple task of kicking a rugby ball into the bin.

A gang of us spent a good few hours taking turns at landing the ball into the bin. Adam Byrne was the only one to get it in, 3 times, in fact, left footed, right footed and from the ground! He well and truly put the rest of us in the bin!

Later a few of us played some cards then we hit the beds for some well-earned sleep.

Up early the next morning, the sun was out and it was a beautiful morning. The activities were to start about 10am so everyone was kind of doing their own thing and chilling in the sun.

The first activity of the morning was the building blocks. We were told the record was 27 crates which is very impressive, however, not to be outdone by this the lads set out to beat this and managed a new record of 35, which was pretty awesome indeed.

The final activity was the trampoline game which was a very close competition. All the kids loved having a bash at this game and seemed to really enjoy it.

Then it was time to head home, worn out but happy out too. It was a deadly weekend, both kids and dads met some really nice people and had fun together which was the main thing.

A big thanks to Paul and Jay for making sure it all ran smooth and that all the kids were looked after from the time they arrived to the time to head home.

Until the next one!

Ken and Adam Byrne

Photos from the overnight were taken courtesy of Ken Byrne

Ageing Conference

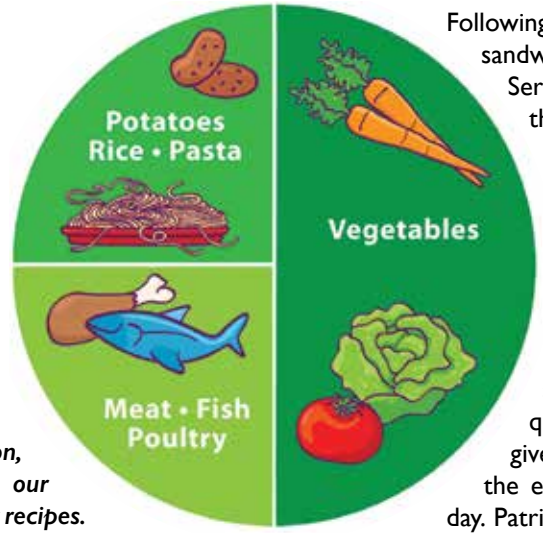
Our third Ageing Conference took place over the weekend of 19th to 21st May in Hotel Kilkenny.

Saturday morning began with a talk from dietitian Ms. Ellen Roche. Ellen gave an excellent presentation entitled 'Is it too late to change the habits of a lifetime?' and the simple answer is 'NO'. With small changes in our diet, we can make huge changes. Ellen gave those in attendance excellent information and advice and as expected our members had many questions. Ellen provided samples of various brands of products like yogurts, sweeteners and portion size which was very helpful. Ellen gave some good tips as follows:

- Use olive oil for salads and rapeseed oil for cooking.
- Use full-fat butter and super milk.
- Use Greek yogurts.
- Use natural sweeteners.
- For dinner, half your plate should be vegetables, quarter protein and quarter carbohydrate.

Take Vitamin D regularly (The recommendation is to take 10ug daily during the months from September to May. However, it is advisable to speak to your consultant or GP about this)

If you are interested in diet and nutrition, you can find Ellen's presentation on our website along with some lovely healthy recipes.



The next session was on physiotherapy. Mr. Gerrard King, Physiotherapist from Cork University Hospital gave a presentation on various aspects of physiotherapy and after his talk, he was hands on accessing members with various issues that they asked him about. Gerrard was very good but I felt that he needed more time for practical demonstrations and perhaps going forward we could ask members to come to a similar session dressed casually to do some physiotherapy exercises.

Following a fairly healthy lunch of soup and sandwiches, Ms. Ger Kane from the Health Service Executive updated members on the Health Amendment Act (HAA) Card. There were lots of questions and interaction from the audience and some follow ups to be done.

The last talk on Saturday was from Mr. Patrick Stagg from Citizens Information who gave an excellent talk on benefits and entitlements. Patrick is so well informed and answered all the questions and queries so well. We had given Patrick a list of questions prior to the event so he was well prepared on the day. Patrick spoke about the state pension and PRSI contributions. Did you know that you need a minimum of 520 PRSI stamps/contributions or 10 years PRSI stamps/contributions to obtain the minimum state pension? You learn something new every day. I also learned that this can be checked online on the social welfare website. In fact, I tried it myself today and this is correct.

Mr. Gerrard King giving his presentation

Dr. Michelle Lavin

(If you go to www.welfare.ie and click on the online services there is a section there called 'Request copy of social insurance record'). Patrick had lots of different individual queries from members, so he very kindly hung around for a while afterwards to talk to members individually in confidence.

The group joined up again for dinner on Saturday evening in the restaurant which was really nice. It was lovely to catch up with people I hadn't seen in a good while and nice to see lots of interaction amongst members.

On Saturday morning, Dr. Michelle Lavin gave a presentation in relation to 'Ageing, Pain Management & Treatment Protocols'.

This was an excellent presentation and included a discussion on the ageing process around joint damage, bleeding risks, pain management, surgery, inhibitors, bone health, cardiovascular disease, high blood pressure, poor kidney function and prostate issues. Again, some great interaction came from the audience and it was good to hear Michelle encouraging people to stop smoking. We finished the morning with a short discussion around support services with some very good ideas coming from members for the future.

What a great conference. I think members really enjoyed it. We had great attendance at all of the sessions, the hotel worked well for our group and the food (although not as healthy as it should be) was good. With it being a less demanding conference for staff it's also great to have more time to actually talk to members and to catch up and I even learned a thing or two myself.

Debbie Greene
Administrator.

Noticeboard

Outreach

Please contact Lyndsey in the office on 01 6579900 if you need support in any of the following areas.

- A hospital or home visit
- Support in relation to HAA card entitlements
- Support in relation to social welfare entitlements
- Educational talks to schools
- Information in relation to travel

Ezine

If you would like to sign up for our monthly electronic Ezine magazine, please contact Aoife in the office on 01 6579900. (Email: aoife@haemophilia.ie). This electronic magazine gives reminders of events, articles of interest other up to date things that are happening in the I.H.S. (Please note that this is not replacing our quarterly printed magazine.)

Planned Giving

We are asking members to consider committing to planned monthly or annual donations to the Society at a level which they can afford. Of the funds raised, 75% will go to defray the cost of purchasing the apartment and 25% will go to our overseas development fund.

We hope that you will consider participation in this planned giving campaign to allow us to work for a better future for you and for those with haemophilia in developing countries.

Brian O'Mahony Award

Dr. Beatrice Nolan recipient of the 2016 award

Nominations are now open for the 'Brian O'Mahony Award for outstanding contribution to haemophilia care in Ireland'. Nominations can be proposed only by members of the Society. Members of the current board or staff cannot be nominated. If you would like to nominate an individual who, in your opinion, has made a real difference in haemophilia care in Ireland, please send your nomination to: info@haemophilia.ie by 29th September 2017.

Leave a Legacy

We are asking you to leave a donation or legacy to the Society in your will. A strong active and effective Haemophilia Society is essential and will continue to be essential in the future if we are to optimise the quality of life for people with bleeding disorders in this country. We hope that you will support our endeavours by positively considering leaving a present for the future and leaving a legacy to the Society.

Irish Haemophilia Society Hoodies

Our comfy I.H.S. hoodies are now available to purchase at all of our events and conferences. They come in a range of different sizes and are priced from €20 to €25. If you are interested in purchasing a hoodie, please give the office a call to place your order. We can have your hoodie available for collection at the next event or conference that you attend.

Children Sizes:	3-4, 5–6, 7-8, 9-11, 11-12, 12-13
Adult sizes:	S, M, XL
Cost	Adult Hoodies: €25.00 / Children Hoodies: €20.00

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