Magazine of the Irish Haemophilia Society

haemophilia.ie

Inside this Issue:

The Society at a Glance

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Edition: October 2015

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PARENTS EMPOWERING PARENTS

PEP Training Programme

The Irish Haemophilia Society invites all parents of children with a bleeding disorder to attend the next PEP programme which will take place on:

Friday 20th November - Sunday 22nd November 2015

Clarion Hotel, Liffey Valley, Dublin

This parenting programme was designed specifically for parents of children with bleeding disorders in 1996 by Danna Merritt, a Social Worker in the United States, to help parents become more aware of their thoughts and feelings, which may influence how they parent their children.
This awareness gives parents choices about keeping or changing their current practices. The weekend will provide a supporting environment where parents are given time to reflect on how they were parented and their own parenting skills.

Here are some comments from parents who have already attended PEP:

"I expected it to have many areas of advice in parenting and it exceeded all my expectations"

"The whole programme was very helpful"

"Definitely very enjoyable, it really hits home as it's like they're talking about your family, so we got great solutions to help us all in everyday life"

To reserve your place, please contact Fiona Brennan on 01 657 9900. The full cost (which is required at the time of booking) of the weekend is €50.00 which includes attendance at the programme, two nights accommodation and meals.
Please note that this course takes place over 3 full days and is for adults only.

I.H.S. HOODIES FOR SALE

We are delighted to announce that we now have Irish Haemophilia Society hoodies for sale in various adult and children's sizes. Hoodies will only be available for purchase at I.H.S. events and cost €25 each. Why not treat yourself to an I.H.S. hoodie at the next event.

Contact Details

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A Note from the Editor

Debbie Greene, Administrator

Hello everyone,

Welcome to the Autumn edition of haemophilia.ie. I hope you enjoy reading this edition.

You will see on the inside cover some information in relation to the PEP (Parents Empowering Parents) Programme. We would like to encourage as many parents as possible to attend this excellent programme which is designed to promote effective parenting skills to parents of children with haemophilia.

In this edition on page 4, our Chief Executive gives an update on the new National Children's Hospital, and on tenders and procurement systems in Europe which is very interesting, and shows how important it is to be involved in the whole process.

Keep yourself updated with our Calendar of Events for 2016 on page 7 where you will find dates and venues for all the main conferences next year.

Personal trainer and board member John Stack gives us an introduction to strength and conditioning on page 12. This article is the first of many articles that John has planned for the magazine and we hope you find useful and informative.

On page 19 you will find information on the genetics of von Willebrand's disease which is very important to be aware of, and on page 16 please see an update on 'alert cards' for people with haemophilia.

Finally, please contact the office on 01 6579900 if you have any questions or queries, 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

CEO's Report

In the April 2015 edition of our magazine, I mentioned that there was increasing concern about Hepatitis E. This virus is transmitted primarily by the consumption of undercooked pork. It can also be transmitted by blood transfusion or transfusion of some other blood components which are not subjected to viral inactivation designed to inactivate lipid-enveloped viruses such as Hepatitis E. Plasma-derived factor concentrates used in Ireland are virally inactivated to inactivate non-lipid enveloped viruses such as Hepatitis E. However, people with haemophilia and related bleeding disorders are more likely than many others in the general population to require blood or blood products. Therefore, we are very pleased that screening of blood donors for Hepatitis E will commence in the coming months.

Brian O'Mahony, Chief Executive

The application for planning permission for the new National Children's Hospital has now been submitted. It is our earnest hope that permission is granted and that the building of this much-needed facility can commence on the St. James's hospital site, as soon as possible. The I.H.S. has been actively engaging with the family forum group established by the development board. They are actively listening to organisations, such as ourselves, whose members will be attending the new hospital as patients. Presuming that planning permission will be granted, it will then be time to move ahead and build the hospital without further delay. Constantly second-guessing or questioning the chosen location, which has been a feature of media coverage and advocacy by some individuals and organisations, is counter-productive and self-serving. Everybody is entitled to his or her opinion. However, the fact remains that the decision on the location was a carefully considered decision taken at the end of an exhaustive and inclusive

Proposed new NCHCD.

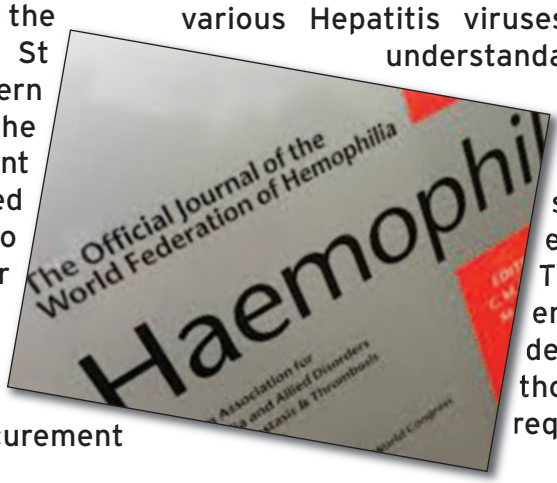

NCH Rainbow Garden.

process. The location was chosen to provide the best possible clinical care to the nation's sickest children for the foreseeable future. My concern would be that if this debate continues endlessly, it could result in the entire project being scrapped. That would be a disaster for the children of this country.

The planned building of the new maternity hospital in the St. James's campus will result in the demolition of the current National Centre for Hereditary Coagulation Disorders (NCHCD) building. The NCHCD will be re-located on a newly built floor above the current Haemophilia H&H Ward. The plans for this unit are impressive and we hope this will provide excellent out-patient services to our community for many years to come. In the last external audit of the haemophilia services, the services in St James's were correctly praised. A concern was raised by the distance between the out-patient NCHCD and the new in-patient unit. This concern will now be addressed by the new building which we expect to be completed in 2016 or shortly after that.

The Journal 'Haemophilia' recently published the results of a survey we had carried out on tenders and procurement systems for factor concentrates in Europe. We carried out an extensive survey that was answered by national haemophilia patient organisations, or in some cases by haemophilia clinicians, from 38 European countries. The results show that 19 of the 38 countries, including Ireland, use a tender system while 17 use a different procurement system and two countries use a mixture of both systems. Of the 19 countries using a tender system, the haemophilia patient organisation is involved in the process in ten of the countries. This involvement can be informal, such as observer status, involved only in the scientific and technical aspects or involved in all aspects of the process. Ireland and Serbia are the only two countries where the haemophilia organisation is formally involved in all aspects of the process. The situation is even starker when we examined other procurement processes, with only five of 19 countries having any involvement by the patient organisation. It is our view that expert haemophilia clinicians such as designated directors of comprehensive care centres and representatives of the national haemophilia patient organisation must be involved in the process of selecting and purchasing clotting factor concentrates. If this is not the case, the process is by definition flawed.

Given the tragic history of the contamination of factor concentrates in the past with HIV and various Hepatitis viruses, this community is understandably anxious to ensure that the products selected for treatment meet the highest standards of safety, efficacy and quality. This is best achieved by ensuring that the decisions are made by those who have the required knowledge and



expertise. This has to include haemophilia clinicians and appropriately selected and trained patient organisation representatives. Most countries have procurement systems in place for their general medications. However, the selection and purchase of complex and specialised medications such as clotting factors, should not be left solely to procurement officials or general procurement boards with no detailed knowledge of the products, or understanding of the underlying condition. This is not bulk purchase of hospital supplies or simple medications. These are complex and expensive medications. The majority of doctors will have little or no knowledge of these medications. The doctors with the required expertise are those who work full time or almost full time in haemophilia. They will have the time and interest to keep up to date with this complex and changing area. In many countries, the inclusion of factor concentrates in the general procurement schemes means that the products are not optimally chosen. Patient organisations are often unhappy with the products selected and at a European level. We have been dealing with their concerns on this matter over the past number of years. I have met procurement boards in European countries who knew little or nothing about haemophilia or factor concentrates, yet continue to be entrusted with the responsibility of purchasing these products. This is sheer folly.

The purchase of complex medications for a rare disease such as haemophilia requires specific knowledge and expertise. Health Ministries or authorities may have a concern that involving the patients or doctors in the decision may result in the purchase of the most expensive medications. This is incorrect. It should result in the purchase of the safest and most effective medications but our survey demonstrates conclusively that the involvement of the doctors and the patient organisation in the procurement process saves money. In countries where the patients and doctors are both involved, prices for all factor concentrates are lower. The cost of purchasing recombinant Factor VIII in countries where the patients and doctors are involved is 24% lower than in those countries where they are not involved. A similar pattern is seen for recombinant Factor IX and for plasma-derived Factor VIII and Factor IX. This bears out our experience in Ireland. The Irish Haemophilia Society and the directors of the three comprehensive care centres from St. James's, Our Lady's Children's Hospital Crumlin and Cork University Hospital are formally involved, with the contract holder, the Department of Health and other experts such as a blood transfusion expert and virologist in our Haemophilia Product Selection and Monitoring Advisory Board (HPSMAB) since 2002. Since the inception of the HPSMAB, we have always selected the safest and most efficacious product in each tender process. We have also saved the country very significant amounts of money which has also allowed access to the quantity of factor concentrates to more than double since 2002. Prior to that time, Ireland paid 26% above the average EU price for factor concentrates. The board has overseen a reduction in the cost per unit of some 60% and a removal of handling fees and other charges which has resulted in a total decrease in cost approaching 70%.

We have recently estimated the saving to the exchequer from the work of the HPSMAB to be in excess of €130 million over the past 13 years. Involving the Society and the doctors formally in the tender process was the right thing to do. It was also, clearly, the smart thing to do.

Brian O'Mahony
Chief Executive

Dates for your diary

2015

Members' Conference
Date: Friday 16th – Sunday 18th October
Venue: Heritage Hotel, Portlaoise

Barretstown Camp
Date: Friday 30th October - Sunday 1st November

PEP Conference
Date: Friday 20th – Sunday 22nd November
Venue: Clarion Hotel, Liffey Valley

2016

AGM & Conference
Date: Friday 4th – Sunday 6th March
Venue: Hotel Kilkenny

Carrier Conference
Date: Saturday 7th – Sunday 8th May
Venue: Castleknock Hotel, Dublin

Parents Conference
Date: Friday 24th – Sunday 26th June
Venue: Sheraton Hotel, Athlone

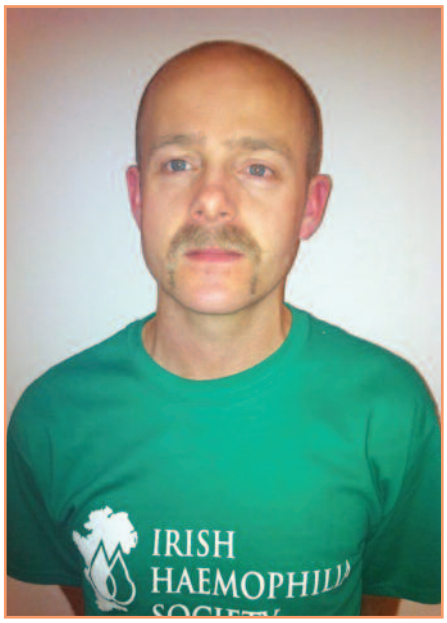
October Conference
Date: Friday 14th – Sunday 16th October
Venue: Radisson Hotel, Sligo

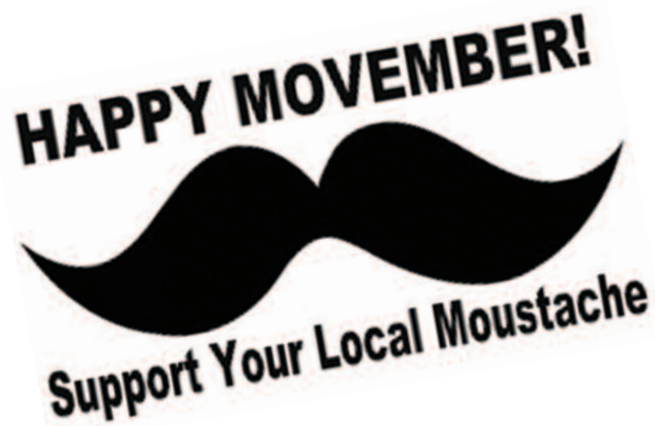
PEP Conference
Date: Friday 11th – Sunday 13th November
Venue: Clarion Hotel, Liffey Valley

Movember

It's getting close to that time of year again, November is just around the corner and with it comes 'Movember'.

Movember is an annual event involving the growing of moustaches during the month of November. So gentlemen we are asking you to grow a moustache for the month of November and help raise fundraise in aid of the I.H.S.





LEGACY
LIVING A LIFE THAT LASTS.

My Legacy

As a Society we offer support to our members, but through us our members also offer support to each other. To help us to continue to build on this community spirit into the future, we hope that you might consider naming the Society as one of the beneficiaries in your will. Legacies, however small, will give members an opportunity to contribute to a better future for people with haemophilia and bleeding disorders even after they have passed away. If you would like to include a legacy to the Society in your will, the Society will pay the solicitor's fees in relation to the drawing up of your will.

"The goal isn't to live forever, the goal is to create something that will"

MyCharity.ie

Fundraising just gets easier, the Society are registered with MyCharity.ie, so if you are thinking of organising your own fundraiser or taking part in a group event such as a mini marathon or fun run, why not set up a fundraising page on MyCharity.ie. It's so simple to set up and your page can be linked to Facebook or emailed to your family, friends or colleagues. No more chasing people up for sponsorship money, they just go online and donate any amount they like. This is a safe and secure method of payment and all funds come directly to the Society.

Planned Giving

We are very grateful to everyone who contributes to our Planned Giving Appeal. These contributions have allowed us to offer more services to our members via the apartment facility and also to support haemophilia care globally through our Twinning Programmes and the World Federation of Hemophilia GAP Programme.
To allow us to build on this support we are asking our members to consider, if possible, committing to a monthly donation. Even if it is only €10 per month, all amounts are very much appreciated.

"Life isn't about getting and having, it's about giving and being"

Thank you for your support. For more information on any of the above, please contact Nina on 01 6579900 or email nina@haemophilia.ie

Cubs Club

Welcome to another edition of our Cubs Club!!

Hi Guys, You all have met Brian before. He has severe haemophilia. At the beginning of September Brian went back to school. His favourite thing about going back to school is not the homework, but playing with his friends in the yard at break time. His favourite game to play is basketball. His Mum said that it was really important for him to take his prophylaxis regularly, so that when he is playing with his friends in the playground at lunch he has enough factor soldiers to protect him if he gets a bang. He takes his factor every second day. How often do you take your factor?
What are your top 3 favourite games to play at break time?

1. _____

2. _____

3. _____

Can you find all the hidden words in this word search?

Words can go in the following directions: → ↓

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

CATCH
TIPTHECAN
CORNERS
FOOTBALL

HIDEANDSEEK
HOPSCOTCH
BASKETBALL

FRUITSALAD
HOCKEY
REDLIGHTS

Q: What's a Mummy's favourite type of music?
A: Wrap!

Q: What do you call a witch that lives at the beach?
A: Sand Witch

Welcome to the Kidlink page!!

Keeping your smile sparkling!

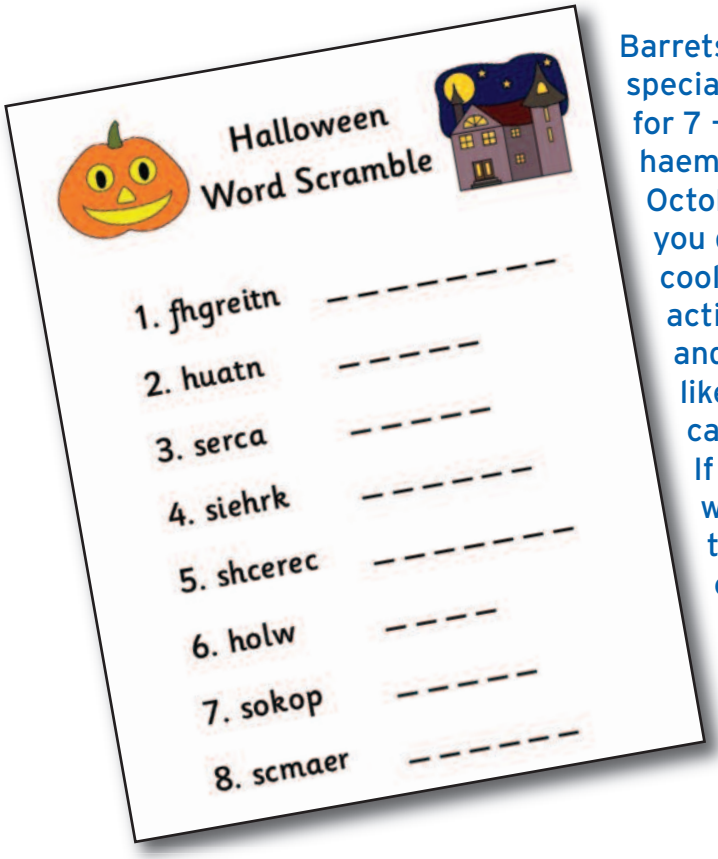
It is really important for people with haemophilia to look after their baby teeth & big teeth. Brushing your teeth everyday can help keep your teeth healthy, stop infections and your smile will be so shiny people will need sunglasses to look at your teeth. Sometimes when you brush your teeth your gums bleed. This happens to people who don't have haemophilia too. This may mean that you might need to go and visit your dentist. The dentist will clean your teeth and make sure they are strong and healthy but the more you mind your teeth the less you will see of the dentist!

Did you know:

If you keep your teeth healthy you can keep them forever!
The 1st toothbrush was invented in 1770!

BARRETSTOWN
a serioüsfun camp

Barretstown October Camp



Barretstown are having a special Halloween camp for 7 – 17 year olds with haemophilia this October. In Barretstown you get to do really fun, cool, adventurous activities like archery and high ropes. Do you like drama, fishing or canoeing?
If you think you would really like to go to this camp ask your Mam or Dad to call Fiona in the I.H.S. to talk about booking you a place

Q: What do ghosts eat for their supper?
A: Spooketi

Q: What room does a ghost not need?
A: A living room!

Strength and Conditioning Training for Teenage Boys with Haemophilia

The concept of formalised strength and conditioning training is something that, as a teenager with haemophilia, is not on your radar. In fact, you may never even have heard of it. The idea of weight training, speed and agility training, plyometrics, fitness testing, pre-habilitation, training for power and everything else that makes up 'Strength and Conditioning', has, to date not been an option for people with haemophilia. Until recently, you would have been advised to play a sport or activity that allows you to maintain good health, with very low risk of having a bleeding episode.

However, that was then and this is now. Thanks to improvements in treatment, particularly the use of prophylaxis, the sporting/recreational options that are available to you nowadays are far greater than in the past. You can now enjoy competitive sports that would have been unavailable to you previously and you can now play them at a higher level. Of course, you must be sensible with your choices.

Playing sports at a higher level, however, comes at a price. All sports carry the risk of injury, regardless of whether you have haemophilia or not, and the higher the level you play the sport, the greater the demand on your body and the greater the risk of injury. Minimising the risk of injury is an important aspect of strength and conditioning training. Becoming stronger and better conditioned for the sport you play reduces the risk of injury. Did you know that a large proportion of injuries incurred during a team sport (e.g. GAA football, hurling, soccer, basketball, etc.) are NON-CONTACT injuries? In other words, the athlete gets injured without incurring an impact by an opposing player. A classic example is an ACL tear (i.e. a tear to the Anterior Cruciate Ligament, which is a ligament in the knee). Many athletes who incur an ACL injury do so when jumping up to catch a ball and landing badly. No impact required. Teaching good landing mechanics, maintaining these mechanics under the pressure of a tackle and having very strong legs can reduce the risk of ACL tears – that is where Strength and Conditioning comes in.

However, let's take a step back and talk about physical activity itself first. Humans, by nature, are meant to be active, and encouraging physical activity is important at every stage of your life. Physical activity enhances the development of brain function, coordination, social skills, gross motor skills, emotions, leadership and imagination.

In other words, being physically active is good for you! If you are not currently playing a sport or engaged in some form of physical activity, I urge you to start. Competition is not required to reap the benefits of sport but is useful as it gives a person something to focus on and work towards.

What is the aim of Strength and Conditioning (S&C) Training?

Strictly speaking, the main objective of S&C training is to prepare people for the demands of their sport. So, a rugby player has to be strong, powerful, fast, agile and able to sustain a high level of intermittent intensity for 80 minutes. So does a GAA player, a basketball player or a soccer player for the duration of their games. Different sports have different physical demands and a well-designed S&C programme will be customised to meet the needs of individual athletes for their particular sport.

S&C does not have to be restricted to sports, however. It is also extremely beneficial for improving ordinary health and well-being. For example, far more back injuries occur during normal everyday activities than from sport. A strong, mobile body has far greater resistance to injury than a weak, immobile body. For people with haemophilia, there is research that indicates it can improve the quality of life and reduce the frequency of bleeding episodes. The table shows some research that has been done on the benefits of strength training for people with haemophilia.

Green and Strickler, 1983	Increased strength, flexibility and joint stability gained from strength training reduces the frequency of joint bleeds for people with Haemophilia
Koch et al., 1984	Exercise causes a transient increase in clotting factor levels for people with mild and moderate haemophilia
Titkinsky (2002)	Data supports the use of resistance training for reducing the frequency and severity of bleeding episodes
Souza at al (2012)	• Concluded that exercise can improve several outcomes of quality in people with Haemophilia • Referred to the improvement in blood coagulation mechanisms as a result of exercise
Gonzalez et al (2007)	Authors highlight the need for increasing muscular power through resistance training to address particular weaknesses
Pietri (1992)	Suggested that strength training be commenced early in the rehabilitation of joints after acute haemarthrosis
Hilberg et al. (2003)	'strongly' recommend that specialised sports therapy be included as an integral component of the complete training regimen of haemophilic subjects

In reality, S&C is about developing the body to suit the demands of a person's lifestyle and includes activities of daily living and sport.

I want to talk about the Youth Physical Development (YPD) Model as it is going to form the basis for future articles. It is shown in the graphic below.

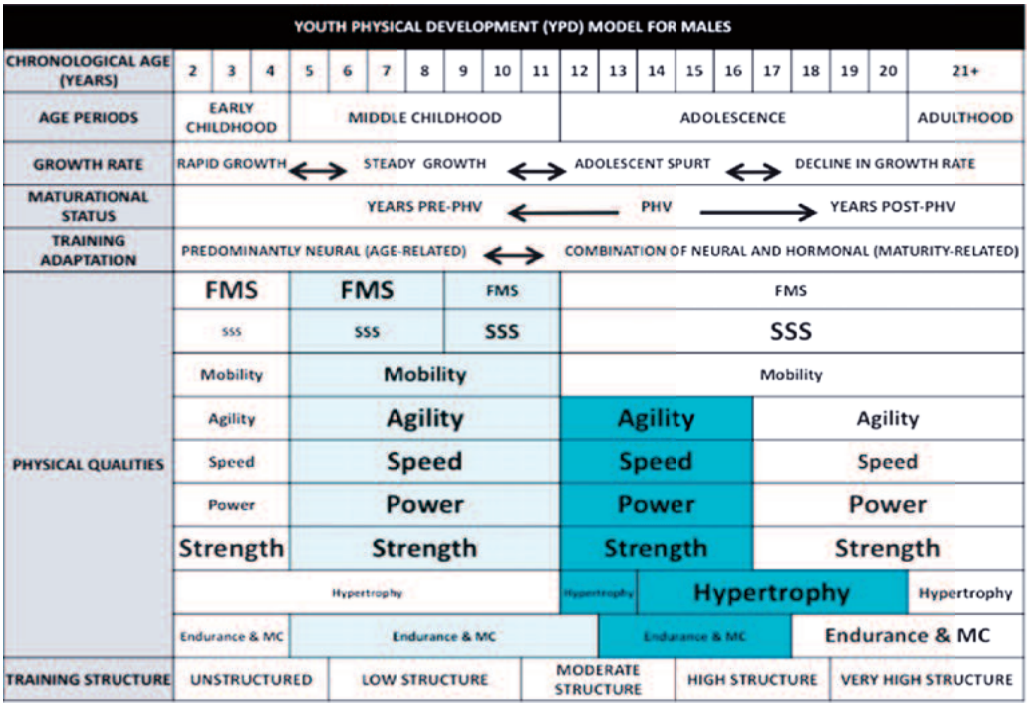


Figure 1 Lloyd and Oliver, 2012

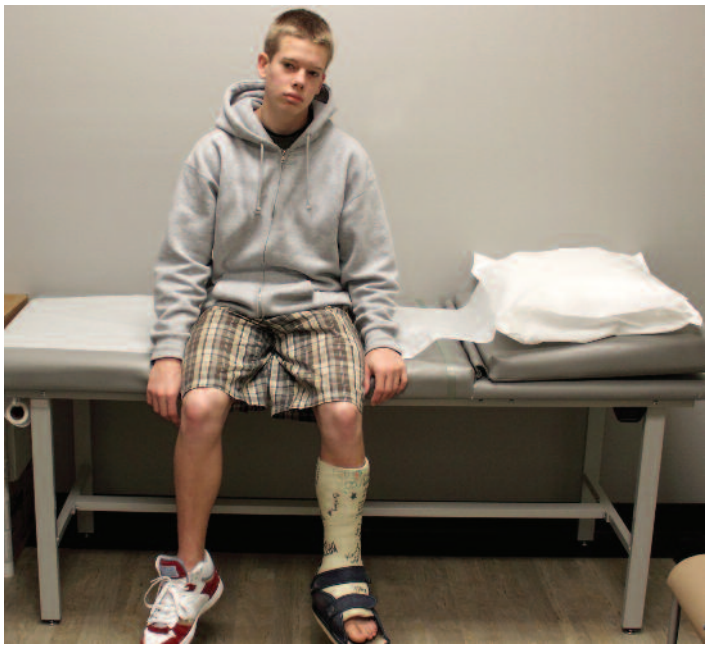
In simple terms, the YPD is a way to describe athletic development throughout childhood, into adolescence and early adulthood. In the row 'Physical Qualities' the size of the font illustrates the importance of that activity at that particular stage in your life. The bigger the font, the more important it is.

Fundamental Movement Skills (FMS) are movements like running, jumping, climbing, throwing, rolling, and so on; activities that physically active, kids will develop. These are important from a sporting perspective because they become the cornerstone of athletic development in teenagers. Kids with poor FMS may become poor athletes.

SSS are sports specific skills, which, based on the size of the font in the diagram, don't feature much before age 10. After that, however, they become more important and, by late teens become critical.

The chart shows that, as an adolescent, you need to develop agility, speed, power, strength and hypertrophy (hypertrophy after age 14).

I met some of the youth group recently at the IHS offices (thanks for your hospitality by the way; you were great to work with), for a talk on strength and conditioning. None of you had a particular sport in mind, but you were physically active in some way and interested in your physical well-being. Despite not being involved in a structured sport, we still had a great workshop on the benefits/importance of strength and what you, as adolescents, need to do to prolong your physical well-being and make some form of sport or physical activity a part of your life. You need to continue your sports or physical recreation and you need to build muscle and get strong. Muscle mass has been described as the armour you need to withstand the physical intensity of sports. Strength is what gives you the ability to excel at other aspects of physical fitness.



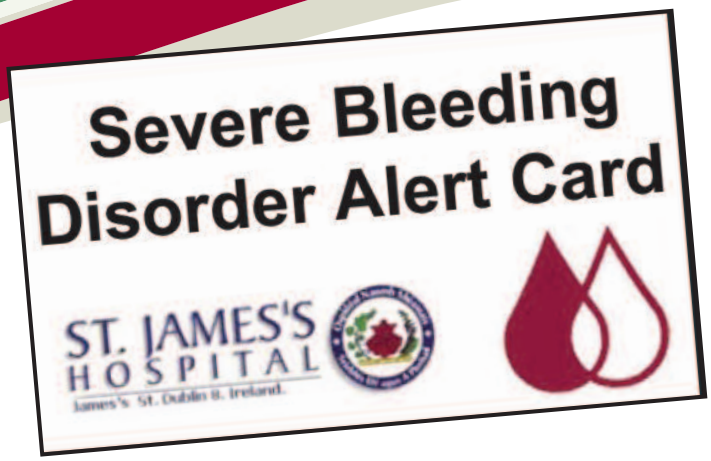
The Benefits of Strength Training

Very briefly, strength training provides many benefits to people with haemophilia. A well designed and implemented strength programme will obviously make you stronger. It will also prevent muscle atrophy (have you ever had a limb in a cast and noticed how skinny that limb is after the cast is removed – that's muscle atrophy, which is muscle wastage or loss of muscle). It contributes to motor development (this has nothing to do with driving by the way), skill mastery, feelings of competency and achievement, and athletic success. In other words, strength training makes you a better athlete. It reduces the risk of sports-related injury and there is evidence to suggest that it may help reduce the frequency of bleeding episodes.

This is a very brief introduction to strength and conditioning and the benefits it can bring you, a teenage boy with haemophilia. In the next article, I'll look at what a strength programme looks like, consists of and identify the best exercises for you to do to get the most out of gym sessions.

John Stack
Personal Trainer

Severe Bleeding Disorder Alert Cards



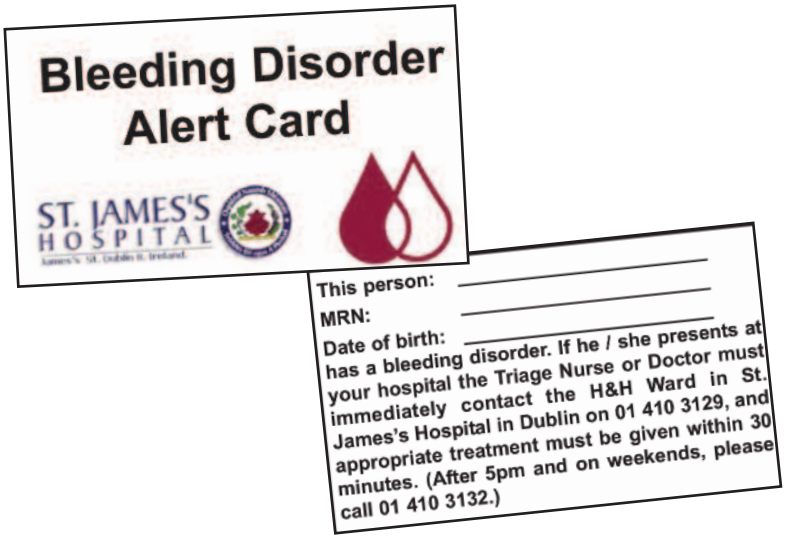
A reminder to you all to make sure that you carry with you at all times your 'Severe bleeding disorder alert card'. This is very important. Your consultant haematologist at your haemophilia treatment centre will provide you with a card. If you have not received same, please ask for one when you are next attending your treatment centre.

If an individual with haemophilia presents at an emergency department with a bleeding episode that requires treatment with factor concentrate, a number of delays can occur. Firstly, the triage nurse may not be familiar with haemophilia and may not be aware of the fact that factor concentrates should be given without delay. The doctor seen at the Emergency Department may be similarly unfamiliar with haemophilia and may order tests, x-rays or scans to confirm a bleeding episode is present before ordering factor concentrate. There may be a delay in locating the factor concentrate that is stored in the hospital. There may be a delay if a consultant haematologist in the hospital has to sign off before the factor concentrate is to be used.

In a normal scenario in an Accident & Emergency Department when a person without haemophilia attends, the person is triaged, seen by a doctor, diagnosed and then treated. The difference with a person with haemophilia is that it is necessary to treat the bleeding episode with factor concentrate without delay and then follow up with diagnostic scans or other tests required after giving treatment. The health care workers in the emergency departments may be reluctant to do this and we have recorded a number of cases where people with haemophilia have been subjected to long delays in emergency departments before receiving factor concentrate because of some of the above-mentioned scenarios. This is despite the fact that they would have asked the emergency department to contact their Comprehensive Treatment Centre for advice and information. We are aware of two cases in the past two years where individuals with severe haemophilia suffered traumatic head injury and, despite requesting treatment with factor concentrates as soon as they arrived in the emergency department, significant delays of several hours occurred. These cases could have resulted in permanent damage or even death.

Bleeding Disorder Alert Cards

In conjunction with the National Haemophilia Council, the I.H.S. have now produced an alert card for people with mild or moderate haemophilia. These cards will be distributed by the Comprehensive Care Centres to all patients with mild or moderate haemophilia in the coming months. The cards ask the health care worker in the relevant Emergency Departments to immediately contact the treatment centre for advice and information.



For the person with haemophilia, the most important piece of equipment in a non-specialist centre is the telephone and the instruction to the Emergency Department staff to call your haemophilia treatment centre immediately.

Debbie Greene

NEW LOOK I.H.S. WEBSITE

www.haemophilia.ie

The Irish Haemophilia Society's new look website will be relaunched in the coming weeks!

The structure and look of the new website has been much improved. Navigation is much easier and it looks cleaner, fresher and more contemporary.

Watch this space!

SERVICES & SUPPORT

We are aware that everyone cannot attend our events for various reasons. However, this doesn't mean you don't need support. If you would like a home visit at any stage, we can arrange this for you. The Society also can arrange to go and speak to teachers, crèche leaders and other educators to educate them about haemophilia. Please also remember if you or your child are in hospital, the staff are here to help.

The I.H.S. attempts to make contact with each member at least once a year. However, this can be a tough task as some details for members may have changed. If you have not renewed your membership, you can still update your contact details to ensure that you receive updates from the I.H.S. To check this contact Declan in the office on 01 6579900.

Social Media

Did you know that the I.H.S. are on Facebook and Twitter?

Why not like us on Facebook or follow us on twitter to receive regular updates on events and activities, services and other relevant information. For information on the various ways to keep in touch with the I.H.S., log onto www.haemophilia.ie

Noticeboard

Educational Grants

The closing date for applications for educational grants was Friday 25th September. Thanks to everyone who has applied. The educational grants committee will be meeting during the month of October to score all applications. Successful recipients will be notified in the post at the end of October.

Ezine

If you would like to sign up for our monthly electronic Ezine magazine, please contact Leah in the office on 01 6579900. (Email: leah@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.)

World Federation of Hemophilia Congress 2016

The XXXII International Congress of the World Federation of Hemophilia (WFH's) takes place in Orlando, Florida from 24th to 28th July 2016. This congress is expected to be the largest in the WFH's history with more than 6,000 delegates expected from 125 countries. The National Hemophilia Foundation of the USA are honoured to host the largest international meeting dedicated to haemophilia, von Willebrand's disease and rare bleeding disorders for the first time in over 25 years. If you are interested in attending or would like more information please click on the following link: www.wfh.org/congress

I.H.S. Travel Card

This is a reminder to you all to make sure that you carry an I.H.S. Travel Card with you when you are travelling as it gives some excellent tips for the traveller in different languages. If you do not have a card, please call Declan in the office on 01 6579900 and he will gladly post one out to you in the post.

VON WILLEBRANDS GENETICS

50%
Chance of having a child with von Willebrand Disease.

Von Willebrand disease (vWD) is an inherited bleeding disorder whereby the protein in the blood, called Von Willebrand factor (vWF), which helps blood to clot is low or doesn't work well. Inherited means that the disorder is passed from parent to child through genes. vWD affects both males and females equally.

The three major types of vWD are called Type 1, Type 2 and Type 3.

You can inherit Type 1 or Type 2 vWD if only one of your parents passes a defective von Willebrand Factor gene to you.

You inherit Type 3 vWD if both of your parents pass a defective vWF gene on to you. As a result, your symptoms may be different from your parent's symptoms.

A person can have a defective vWF gene without symptoms of vWD. However, he or she can still pass the defective vWF genes on to their children.

Some people get vWD later in life as a result of other medical conditions. This type of vWD is called acquired von Willebrand syndrome.

50%
Chance of having a child with von Willebrand Disease.

The Irish Haemophilia Society

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