

# haemophilia.ie

Magazine of the Irish Haemophilia Society

Edition: April 2014

*Representing people in Ireland with  
Haemophilia and related bleeding disorders.*



## The Society at a Glance

AGM & Annual  
Conference  
Attendance



**253**

Followers  
on  
Facebook



**500**

Planned Giving  
Contributors



**49**

IHS  
Volunteers



**52**

Website Hits  
(Dec - Feb)



**4,588**

## WHAT'S INSIDE:

- \* A report on the 2014 AGM.
- \* The Fun Factor.
- \* Dates for your Diary.
- \* The importance of dental care.
- \* Facts about an IHS founding member.



# Parents' Conference

**Date:** 13th – 15th June 2014

**Venue:** Castleknock Hotel, Dublin

## Preliminary Programme



### **Friday 13<sup>th</sup> June**

6.30pm – 7.30pm

Registration

### **Saturday 14<sup>th</sup> June**

10.00am – 11.00am

Open Forum

11.00am – 11.30am

Tea & Coffee Break

11.30am – 1.00pm

Communication with Health  
Care Workers

1.00pm – 2.00pm

Lunch

2.00pm – 3.30pm

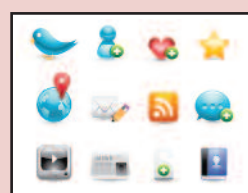
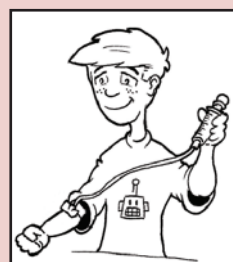
Self Infusion Workshop

3.30pm – 5.00pm

Mothers' & Fathers' Groups

7.15pm

Dinner & entertainment



### **Sunday 15<sup>th</sup> June**

10.00am – 11.30am

IT for Parents

11.30am – 12.00pm

Introduction to PEP

12.00pm – 12.45pm

Siblings

1.00pm

Lunch

## In 2013, the event was described as:

PROFESSIONAL

INVALUABLE

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BRILLIANT

PRACTICAL

BENEFICIAL

INFORMATIVE

POSITIVE

FANTASTIC

EXCELLENT

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E

*How will you find it?*

*Come along & find out!*

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**Debbie Greene**  
Administrator

### A Note from the Editor

**H**ello everyone and welcome to the first edition of our quarterly newsletter for 2014. I hope you enjoy reading it. From reports to fundraising, to dental care, it is jam packed.

The next IHS event is the Parents Conference and on page 2 you will find the preliminary programme. Registration packs will be going out in the post in May, so keep an eye out if you want register! There are lots of events taking place this year so be sure to check out Dates for your Diary on page 12 and don't forget to check the website [www.haemophilia.ie](http://www.haemophilia.ie) for further updates!

In our CEO's report on page 4 you will find some excellent information in relation to clinical trials, and market exclusivity for new longer acting factor, which is well worth a read.

Ladies it's that time of year again to start thinking about registering for the Women's Mini Marathon. And what a great fun day out this is. For more information, please go to page 7.

Who would have thought that a 500ml bottle of orange juice contains 51 grams of sugar, so you can imagine how bad that can be for your teeth? Dr. Alison Dougall tells us more about the worst sugary drinks in Ireland on pages 8 and 9.

For our younger members check out the Cubs Club and another edition of "The Slobs" by Conor Birkett on page 10 and the Kidlink Club on page 11.

Read a review from our recent AGM on page 13, which was written by board member Brian O'Riordan. The weekend was a great success, thanks to everyone who helped make it a great weekend, particularly all our volunteers. We are always looking for volunteers so, if you are interested in volunteering at events or if you come across an article that might be useful to us and fancy putting pen to paper, be sure to let us know!

In this edition of haemophilia.ie, we remember one of the founding members of the Irish Haemophilia Society Mr. Bill O'Sullivan. The article, written by Nuala McAuley, is on page 17. I hope you all enjoy reading this as much as I have.

Finally, if there is anything we can assist you with or if you fancy dropping into the office for a cup of tea and a chat or would like to speak to someone in confidence, do not hesitate to contact the staff on 01 657 9900.

**Debbie Greene**  
Administrator

# CEO'S Report

At the AGM and Annual Conference in Kilkenny in early March, Professor Katherine High delivered a lecture on Gene Therapy, where she discussed the exciting new clinical trial which is now underway, led by the Children's Hospital of Philadelphia. Participants in the clinical trial will receive a single intravenous injection which contains a vector delivery system which in turn contains the gene to produce factor IX.



**Brian O'Mahony**  
Chief Executive

Discussions have been ongoing over the past 18 months between Professor High, Dr. Barry White of the National Centre for Hereditary Coagulation Disorders (NCHCD) and the Society in relation to potential participation of Irish people with factor IX deficiency in this clinical trial. A submission has gone to the Irish Medicines Board in relation to this. A number of meetings were also held over the past year for people with factor IX deficiency to inform them about this clinical trial and to gauge the level of interest. The level of interest was high.

As a preliminary step, prior to participation in any actual clinical trial, potential participants must undergo a blood screening test to see if they have existing antibodies to the vector delivery system, if this is the case they are not eligible to take part in the trial. In late March following the AGM & Annual Conference, the screening tests were carried out on people with factor IX deficiency. It is exciting to think that we may be on the verge of people participating in a clinical trial here for factor IX deficiency.

Later in March it was announced that the first longer acting recombinant factor IX concentrate has been licensed in Canada. The product, Alprolix, which is manufactured by Biogen in the United States, will now undergo an economic assessment prior to availability for people with haemophilia in Canada. It is expected that the longer acting factor VIII and factor IX from Biogen will be licensed later this year in the United States, Australia and other regions of the world. This will be the first of a number of longer acting factor concentrates to come on the market.

The potential availability of these products in European community countries, including Ireland, will be significantly delayed until 2015 or 2016. This is due to a difference in the clinical trial regulations and guidelines between those propagated by the European Union and those propagated by other regulatory authorities. In other countries when clinical trials are completed in adults and initiated in previously treated children, the product can be licensed for use in adults prior to completion of the trials in children. New clinical trial guidelines that have been in effect in the European Union since 2012 require that clinical trials in previously treated children are completed before the products can be licensed for use in adults. These guidelines were put in place primarily to prevent off label use of the products in children once they were licensed in adults before they are licensed for use in children. The practical impact of this is a significant delay in access to these new therapies for people with haemophilia.



A more significant concern for availability of these new longer acting factors for people with haemophilia in the European Union are the EU Regulations on Orphan Medicinal Products. These regulations, which have now been in place for 15 years, are designed to encourage companies to develop products for rare conditions. They are a commendable set of regulations which have resulted in approximately 85 therapies being approved for rare diseases. They effectively give companies incentive and motivation to produce medications for rare diseases. Once a company produces a new therapy for a rare disease under the orphan drug regulations they can be granted market exclusivity or a monopoly in respect of any similar product which comes to the market for a period of ten years. This is designed to prevent a situation where a company puts significant investment into developing a new product for treating a rare disease and then finds that a competitive product comes on the market very quickly. It is understandable that in this scenario companies would not invest in the research and development required to develop therapies for rare diseases.



These regulations are ideal for very rare conditions including rare bleeding disorders such as factor V, factor X, factor XI or factor XIII deficiency. They are however entirely unsuited to haemophilia A and haemophilia B which are well characterised and easily diagnosed conditions for which there are currently many therapies already on the market. For example, there is currently no concentrate on the market for factor V deficiency. Any company who develops a concentrate for that particular factor deficiency should be entitled to market exclusivity. However, there are currently 40 plasma derived or recombinant factor concentrates available for treatment of haemophilia A worldwide and 30 plasma derived or recombinant products available for treatment of haemophilia B. Haemophilia meets the criteria for a rare disease, but in fact it is quite a common rare disease and does not need the protection of orphan drug designation.

Market exclusivity is granted against products which are similar. However, in our view there are at least three non-similar methods being used by companies to develop longer acting factor VIII and factor IX concentrates. Different companies will be coming to the market over the coming years with factor VIII and factor IX concentrates which have different methods of protein modification or enhancement of the factor VIII / factor IX protein. Essentially, these approaches involve linking the factor VIII / factor IX to something else which will allow it to stay in the circulation for longer. The approaches being taken include; fusion to other human proteins (Fc portion of a human immune globulin or albumin) or fusion to a molecule called polyethylene glycol (PEG). These, in our view, are clearly distinct and non similar methods for increasing the activity of the factor VIII / factor IX, but under the existing European Orphan Drug Regulations they could be interpreted as being similar. We clearly want to see a situation where all of the different products being developed for factor VIII and factor IX deficiency have a chance to come to the market in the European community, including Ireland. We want to see a situation where there is competition between these products and where the clinicians and patients can have a strong role in decision making in the future on which of these products are the safest and most efficacious for particular individuals with haemophilia.

We do not know in real clinical practice, which of these products will be best at this point of time. It may well be that one of the products or one of the classes of products will turn out to be clearly superior to the others. It may well be that some products will be more suited to some individuals than others. We do not want to see the choice removed. When the Haemophilia Product Selection and Monitoring Advisory Board (HPSMAB) looks at procurement of factor concentrates in the future when these products are available on the European market, we want to be in a situation where we can evaluate each of these products on their merits and choose the product which is best going to serve the needs of people with haemophilia in Ireland.

If market exclusivity is granted this would give a monopoly to one product. It would severely limit the choice of product in the future and it would also lead to decreased competition, higher prices and potential non-availability of new products which will be required by the Haemophilia community.



The European Haemophilia Consortium (EHC) has been taking a leading role in trying to ensure that this market exclusivity does not occur. The EHC has met formally with the European Medicines Agency, have made representations to the European Commission and have sent a letter to the European Commission and to the relevant regulatory bodies. The letter is jointly signed by the President of the WFH, the President of the European Association for Haemophilia and Allied Disorders (an organisation representing doctors who treat people with haemophilia) and by myself as President of the EHC. I have also submitted an editorial to the Haemophilia Journal and we will continue to make strong efforts to ensure the appalling vista of monopoly for one, of a potentially exciting new class of products, does not occur.

**Brian O'Mahony**  
Chief Executive

# That They May Face the Rising Sun!

April 25<sup>th</sup> & 26<sup>th</sup> will mark the 25<sup>th</sup> anniversary of a debate in Dáil Éireann on the plight of people with haemophilia who were infected with HIV. A year earlier, we had outlined the appalling plight of our members who had contracted HIV through blood products. Despite setting out a clear and unambiguous case for limited financial assistance, we had made no clear progress. In 1988, when we sent that submission to the Department of Health, 4 members had died of AIDS. I recall the events of that year, those weeks and those days vividly. Every effort was made to persuade the then Government to seek agreement, to compromise, to provide this much needed assistance. All efforts at compromise failed. The Government brought this to a vote which they lost by 72 votes to 69. The Government then called an election, following which they lost seats. The new Government, following a further delay, implemented a trust fund of £1 million administered by the Haemophilia HIV Trust (HHT).

On re-reading the contributions to the Dáil debate 25 years later, I again feel frustrated and angry at the needless delay and prevarication, at the self serving hypocrisy masquerading as Government concern, at the seemingly virtuous desire not to assist one group of people who had contracted HIV to the exclusion of others and the reality of ignoring the plight of all. The Government position that they were not responsible and could not make any provision, however small, to those who were infected via blood products supplied by the state was nonsense, and a clear abdication of moral responsibility. This was clearly demonstrated six years later in the case of Hepatitis C when the Government established a compensation tribunal for those who had contracted Hepatitis C via blood or blood products supplied by the state.

The purpose of this article is not, however, to re-visit the detail of that Dáil debate. I want to remember our members on whose behalf we undertook that painful campaign and on whose behalf we continue to work. In April 1989, of the 106 people with haemophilia who contracted HIV, 7 had died and a further 10 had developed fullblown AIDS. This appalling reality continued unchecked until 1996 when new therapy for HIV for the first time slowed down progression of this infection. This progress came too late for the 4 who had died of HIV prior to the Dáil debate. It came too late for the 10 who had developed AIDS at that time, all of these brave individuals died of AIDS. It came too late for the other 56 people with haemophilia with HIV who have since died. To date, a total of 70 of our members with HIV have tragically died.

In 1989, as the increased safety of the blood supply was being trumpeted during that debate, infection with Hepatitis C continued. This insidious virus, known prior to 1989 as non A – non B Hepatitis, has infected people with haemophilia as far back as the 1970's. The immediacy and urgent nature of the HIV catastrophe overshadowed the underlying prevalence of and infection with Hepatitis C in our members. A total of 245 people with haemophilia were infected with Hepatitis C, including all of those with HIV with 1 exception. An additional 37 people with Hepatitis C have since died. In total, 107 of our members have died. In retrospect, it seems clear to me now that several of those with HIV infection succumbed to Hepatitis C as their symptoms were more consistent with liver disease. The burden of HIV and Hepatitis C in our community, on our members, on families, on individuals and on their dependants has been immense. Treatment for HIV and Hepatitis C are now much more successful. Since 1996, the surviving members with HIV can look to the future with confidence. This is a consolation but does not negate the tragedy and pain of the past and indeed of the present for many people. Recently, I have been in contact with some families where significant anniversaries are imminent for their lost husbands, sons or fathers or where the, now grown up, children of fathers long dead want to discuss with me my memories of their fathers and those times.

None of our members who have died from HIV or Hepatitis C or a combination of both will be forgotten by the Society. The many battles we had to fight to seek better treatment, to seek compensation for their families and to seek recognition of the appalling events which consumed them were the basis for the strong and active Society we have today. Several of the young men who died, leaving behind grieving and bewildered families and young children now have grandchildren whom they will never meet. Some of these grandchildren themselves have haemophilia, but their reality now is an experience of excellent treatment, support and near normal quality of life. From the suffering of the earlier generation has come the motivation, the fight for and the reality of a better future for all with haemophilia. Some of those who died were children who will never know the freedom from pain and suffering which now characterises haemophilia. Some were older men with haemophilia who had to endure the end of their life in a crucible of suffering, fear and regret for the life un-lived.

From the present, more fortunate time to have haemophilia, we remember them. We remember them at every conference where people with haemophilia gather to celebrate the strong sense of community and mutual concern for each other they helped foster. We remember them when every advance in treatment is announced. We speak of them often, remembering their humour and their ability to endure. We remember them when we speak with their surviving family members or glimpse their face in the face of their child or grandchild. I hope they are all in a better place. Wherever they may be, in the words of John Mc Gahern, I hope that they may face the rising sun.

**Brian O'Mahony,**  
Chief Executive

# The Fun Factor!



**W**e all know that living with a bleeding disorder can be difficult at times, for example when a baby is newly diagnosed with a bleeding disorder, the family may never have heard of Haemophilia or von Willebrands Disease or they may be only vaguely aware of it in the family.

That is why the support and services of the Society are so important to families and individuals. But we need your help to continue with this level of support. So we are asking you to unleash your Fun Factor! What is the Fun Factor, you ask? It is your inner fundraiser, who can help the IHS by creating, taking part in or supporting an IHS fundraiser!

Fundraising not only raises funds to allow this support to continue, but also increases awareness of Haemophilia and other related bleeding disorders.

All fundraising is greatly appreciated by the Society, whether you take part in an organised race or decide to organise a fundraiser yourself. Some people like to take part in an organised event such as the Flora's Women's Mini Marathon or other such races organised around the country.

This year's **Flora's Women's Mini Marathon** will take place on the **Monday 2nd June, starting at 2pm**. If you are interested in taking part you can walk, jog or run the race, trust me if I can do it anyone can. Firstly you need to register with the race organisers by completing the registration form printed in the Evening Herald Newspaper every Wednesday or log onto [www.florawomensminimarathon.ie](http://www.florawomensminimarathon.ie), this ensures you have a race number and will receive your medal at the finish line. Be sure to register early as places fill up quickly.

Secondly contact me in the office to let me know you are taking part and would like to raise funds for the Society.



*The 2013 Mini Marathon IHS Team!*

As usual this year we will be in the Georgian Suite in Buswells Hotel on Molesworth Street on the day to give out T-shirts, so come along for a get together before the race and some refreshments after the race. We will be happy to look after your belongings while you take part in the race. Honestly, this is a great day for everyone involved, the atmosphere is fantastic, and you can't help but enjoy yourself.

If you want to organise an event yourself be assured that any fundraiser will be supported by the Society from start to finish, we can print posters, tickets, advertise on the I.H.S. website and Facebook page, provide T-Shirts and apply for Garda permits if required. A fundraiser can be anything from a bake or book sale in your child's school to a table quiz or theme night with a raffle or a collection at your local church.

If you would like to do a fundraiser but don't know where to start, start by contacting me on 01 657 9900 or email [nina@haemophilia.ie](mailto:nina@haemophilia.ie) and I will be happy to give you some ideas and answer any questions you have.

I just want to say a big thank you to everyone who took part in or organised a fundraiser in aid of the Society in 2013, you are all amazing and we cannot thank you enough for your support.

**Nina Storey**  
**Irish Haemophilia Society**

# Dental Care - The Worst Sugary Drinks in Ireland

**Dr. Alison Dougall**

**W**e all know that sweets are bad for our teeth but the



saddest stories I hear are from people sitting in my dental chair who have made huge efforts to clean their teeth and tell me they don't drink coca cola and are often puzzled after choosing so called healthy options in their diet - unknowingly causing huge cavities or thinning of the enamel on their teeth by choosing the wrong drinks. Until recently, we thought the 'bad' drinks were those such as Coke and Pepsi, while orange juice was an easy way to get one of our 'five a day'. But, a single serving of so-called healthy fruit juice has been found to contain the same amount of sugar as three-and-a-half doughnuts or 13 hobnob biscuits.

So have the goalposts shifted again? We hear so often nowadays experts are warning that sugary drinks in any form are largely to blame for our ballooning waistlines and the decay in our teeth, but why is orange juice, for example, so bad? The key issue is a lack of fibre. When we eat fruit in its natural state for example an apple or an orange or a pear in a snack box then the fibre forms a protective layer that acts as a barrier which slows absorption of sugar. But in fizzy drinks, fruit juices and smoothies, the fructose without the associated fibre increases the blood sugar rapidly, decays the teeth and the acidity of the fruit or fizz also thins the enamel on the teeth.

Dental Decay is preventable and we know the culprits are sugar and plaque so lets see which drinks are rotting our teeth if we are not careful:

## **ORANGE JUICE**

500ml of freshly squeezed Orange Juice contains 229 calories and 51g sugar. It is acidic and contains more calories than a can of coke. Sugar equivalent : 13 hobnob biscuits



## **SUGGESTED ALTERNATIVE:**

500ml bottle of carrot juice 60 calories and only 5g sugar.

## **BOTTLE OF RIBENA**

500ml blackcurrant ribena contains 215 calories and 52.6g sugar and contains more calories than a can of coke. Sugar Equivalent : 13 oreo biscuits



## **SUGGESTED ALTERNATIVE:**

Small carton of no - added sugar ribena drunk through a straw with only 1.3g sugar.

## **STARBURST Strawberry Flavour**

This kids favourite contains 288 CALORIES AND 42G SUGAR and is as sugary as a can of coke despite deceptive marketing as a school friendly healthy drink it contains the same amont of sugar as 11 hobnob biscuits.



## **SUGGESTED ALTERNATIVE:**

Cold milk drunk through a straw.

## **250ml INNOCENT SMOOTHIE:**

### **Pomegranate Blueberry Superfood**

This not so innocent smoothie contains 34g sugar and more sugar per ml than coca cola. The fibre has been so heavily pulped during the processing that the full sugar load is absorbed by the body.



## **SUGGESTED ALTERNATIVE:**

An apple and a pomegranate.



### 500ml LUCOZADE SPORT elite orange

195 calories and 40g sugar

We know that sports drinks are supposed to contain sugar to replace what is lost through sweat after vigorous exercise and this one contains 40 percent more for big match day giving you a bigger sugar hit than a can of coke and more calories than 2 magnum ice creams



#### SUGGESTED ALTERNATIVE:

Research and current evidence suggests that unless you are doing high intensity sport for more than an hour choose water.

### BURGER KING LARGE CHOCOLATE MILKSHAKE

contains 612 calories and 102 g sugar

This is officially the highest sugar content drink in Ireland and the only one to break the 100g sugar barrier to boot (20 teaspoons)

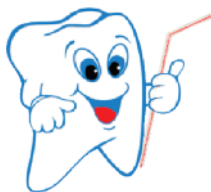
Sugar equivalent:

One whole strawberry cheesecake (serves 4)



#### SUGGESTED ALTERNATIVE:.

Anything else on the planet!!!!



#### TOP TIP:

It doesn't matter if it's juice or coke, concentrated sugar is bad for your teeth full stop and should always be drunk through a straw and limited to meal times where it does less damage because there is more saliva around to protect the teeth. A great idea is to chew sugar free gum after a sugary or fizzy drink as this will stimulate saliva, which has a protective role for the teeth and helps to repair and remineralise some of the damage done by the acids. Certainly after drinking anything acidic then it is always best to wait at least half an hour before brushing your teeth, as the teeth need time to repair and remineralise before giving them a good scrub with a toothbrush.

### Dental Health and Haemophilia?

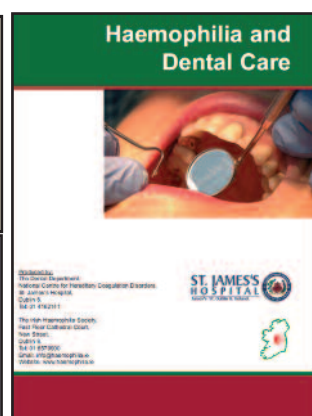
If you have haemophilia it is even more important to visit your dentist and hygienist once a year so that you can get your teeth checked out and prevent problems from escalating. Nowadays small holes in the teeth can be monitored, reversed or filled by your dentist or hygienist without requirement for factor replacement or specialist treatment.

### Can I visit my local dentist?

If you or your child has haemophilia you can attend a normal family dentist for check ups, sealants and most fillings and cosmetic treatment including braces, cleaning of the teeth, and tooth whitening. Always tell your dentist that you have haemophilia and ask your treatment centre for a letter to take to your dentist informing them which treatments are safe to receive.

### What do I do if I need a tooth out?

Nowadays it is very safe to have a tooth extracted safely and without the worry of bleeding with the use of a variety of modern local and systemic haemostatic measures which may include factor replacement, tablets and mouthwash and other materials which the dentists uses locally. However, always contact your local treatment centre for advice about how to proceed even if you have a mild or borderline bleeding disorder.



The Irish Haemophilia Society have information leaflets for adults and children on dental care and haemophilia.

# Cubs Club

Have you been to the dentist before?

Do you brush your teeth  
twice every day?

It is so important to look after your teeth  
especially if you have haemophilia or another  
bleeding disorder so that you don't need to get  
fillings or get a tooth out when you are older!

Plus you will want to have a lovely healthy smile too!

*Can you think of three ways to keep your teeth healthy?*



1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

Here are some tips: Try not to eat too many sweets, don't drink  
too many sugary drinks and always brush your teeth twice a day.

Can you find the  
8 words written  
below in the  
wordsearch?

Brush  
Clean  
Dentist  
Gums  
Teeth  
Smile  
White  
Toothpaste

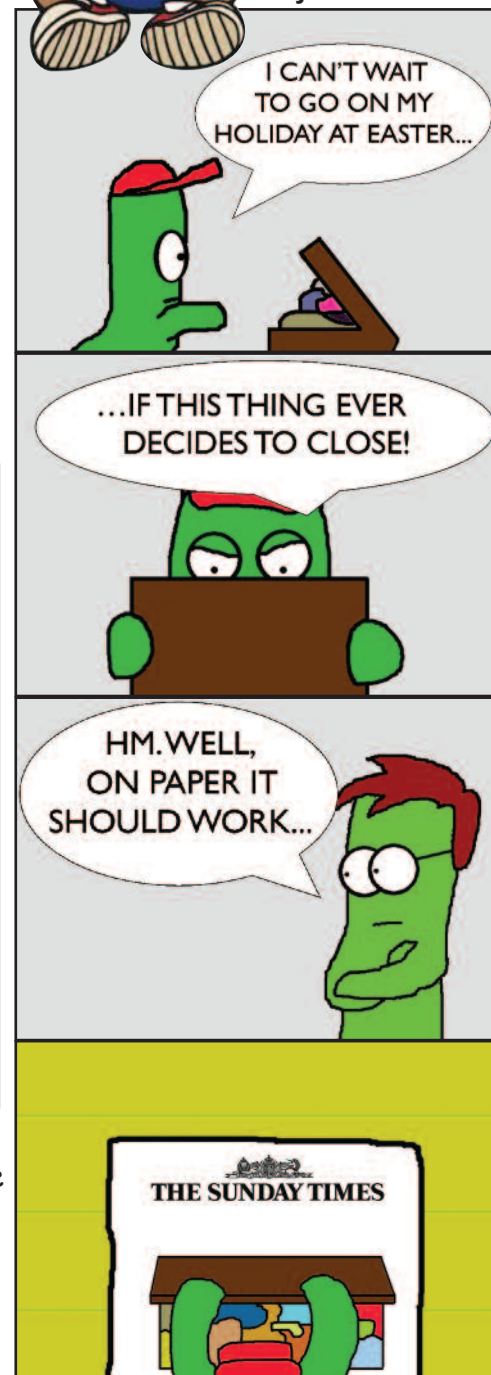
R	S	P	W	N	A	E	L	C	T
K	G	D	P	M	A	S	U	S	E
T	S	I	T	N	E	D	B	W	E
K	R	Y	Q	N	X	Z	I	F	T
V	W	J	S	M	I	L	E	V	H
U	N	S	H	F	D	U	Q	U	Y
T	O	O	T	H	P	A	S	T	E
G	U	M	S	B	R	U	S	H	Y
I	I	C	E	T	I	H	W	Q	M
W	G	I	J	T	K	R	Q	Q	N

Log on to [www.haemophilia.ie](http://www.haemophilia.ie) to see  
the answers, but remember to  
ask your parents permission  
first!



## The Slobs

by Conor Birkett



We all know about bullying from school, our parents and even TV, but sometimes people don't talk about bullying when they really need to! Bullying can happen in lots of different ways. It is important to know that if you are bullied, you are not alone and it is wrong, not just a part of growing up.

It might be scary or embarrassing to talk to an adult you trust, but adults are there to help. Bullying can be stopped and it is important to remember there are people who can help you.

<p style="text-align: center;"><b><u>What is bullying?</u></b></p> <p style="text-align: center;"><b>Which one do you think is the worst type of bullying?</b></p> <p style="text-align: center;"><b>Number the boxes 1 – 4 starting with number 1 as the worst.</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Ignoring or excluding someone on purpose</li> <li><input type="checkbox"/> Making fun of someone</li> <li><input type="checkbox"/> Causing physical harm</li> <li><input type="checkbox"/> Threatening people</li> </ul>	<p style="text-align: center;"><b><u>Why people bully??</u></b></p> <p style="text-align: center;"><b>Why do you think people bully?</b></p> <p style="text-align: center;"><b>Number the boxes 1 – 4 starting with number 1 which is the biggest reason for bullying.</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> They need to feel powerful or in control</li> <li><input type="checkbox"/> They might feel angry</li> <li><input type="checkbox"/> Someone is bullying them</li> <li><input type="checkbox"/> Jealousy</li> </ul>
<p style="text-align: center;"><b><u>What can you do?</u></b></p> <p style="text-align: center;"><b>What can YOU do to stop bullying?</b></p> <p style="text-align: center;"><b>Number the boxes 1 – 4 starting with number 1 being the BEST thing to do.</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Tell your friends and talk to them</li> <li><input type="checkbox"/> Be assertive</li> <li><input type="checkbox"/> Talk to an adult and explain what is happening</li> <li><input type="checkbox"/> Ignore a bully</li> </ul>	<p style="text-align: center;"><b><u>Why people don't tell?</u></b></p> <p style="text-align: center;"><b>Why do you think people don't want to talk to anybody about bullying?</b></p> <p style="text-align: center;"><b>What do you think is the biggest reason number these boxes 1 – 4!</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> You might feel embarrassed</li> <li><input type="checkbox"/> You might feel ashamed</li> <li><input type="checkbox"/> You might be afraid of what will happen</li> <li><input type="checkbox"/> You might think nobody can help</li> </ul>



**Which of the answers above do you think is most important?**

**Answer:** All of them, there is no type of bullying, reason for bullying or way of bullying that is better or worse than the other!

If you are being bullied and would like to talk or need some advice contact the I.H.S. on 01 657 9900.

# Calendar of Events

## JUNE

**Dates:** 2nd June

**Event:** Mini Marathon

**Venue:** Buswells Hotel,  
Molesworth Street, Dublin



## JUNE

**Dates:** 13th - 15th June

**Event:** Parents' Conference \*

**Venue:** Castleknock Hotel, Dublin

*\* See page 2 for more information on this conference.*



## JULY

**Dates:** 18th - 20th July

**Event:** Hep C / HCV Conference

**Venue:** Pembroke Hotel, Co. Kilkenny



## AUGUST

**Dates:** 15th - 17th August

**Event:** PEP Conference

**Venue:** Clarion Hotel Liffey Valley, Dublin



## SEPTEMBER

**Dates:** 27th & 28th September

**Event:** Carriers' Conference

**Venue:** Clarion Hotel Liffey Valley, Dublin



## OCTOBER

**Dates:** 10th - 12th October

**Event:** Members' Conference

**Venue:** Carlton Shearwater Hotel,  
Ballinasloe



# 2014 AGM Report

**A**s we all become busier and our diaries fuller, we carefully mark our calendars with birthdays, holidays, Christmas, Easter and family occasions. And of course, added to these major events is the AGM of the Irish Haemophilia Society. The year has barely begun when we turn our minds to the annual pilgrimage to a midlands hotel in order to take stock of the year, assess how our Society is faring, listen to medical updates and scientific progress and, most of all, catch up with old and new friends, relax, laugh and maybe dance a little. Well into its fourth decade (but wearing it well), the IHS gets stronger with the years. It provides so many services, so much information and such a range of weekends and meetings to its members. But the AGM is the most valuable of all, as on top of the lectures and presentations, it gives the members a forum to ensure that their Society is being run as they would wish. As we have seen recently, proper management of a charity isn't always a guaranteed thing and the values any organisation represents can only be taken seriously on the back of the steady structure of good governance.

When we arrived on Friday evening, we met our friends, caught up with their families and settled in for a weekend of updates and a lot of fun. As it did for most of the weekend, laughter rang around the registration area, the bar and the lobby. Hands were shaken, hugs were had and children raced about, re-acquainting themselves with their mates. The important business would begin on Saturday morning but for now it was relaxation over food and a drink. There were Dunnes to be seen everywhere, Jim and Margaret sitting royally, beaming at their family gathered around them. Jim seemed particularly happy, nothing to do with Margaret's lost voice!



**Far Left:** IHS Volunteer Mary Flanagan and IHS Nurse / Counsellor Anne Duffy sign in members for the AGM. Over 250 people attended the 2014 AGM & Conference.

**Left:** The AGM Business meeting began the Conference.

The business meeting of the AGM took place the next morning. Before it got underway, Fiona Brennan and Brian O'Mahony reminded all parents of some important guidelines for the safety and wellbeing of the children at the weekend. Our Chairperson, Traci Marshall Dowling, opened the meeting, welcoming everyone and then the officers of the board and the CEO gave their reports. All were very well delivered and equally well received. Mary Hanney, our Honorary Secretary gave her report for 2013, summarising the weekends and other conferences hosted by the IHS, mentioning the home and hospital visits made by the staff and paying tribute to the many volunteers who serve the Society so well. Ger O'Reilly, our Honorary Treasurer, gave his account of our finances. This was presented in a very detailed and transparent fashion and Ger was further able to answer any questions fully. Traci Marshall Dowling then gave the Chairperson's report, talking us through the other work done by the Society throughout the year. It was a difficult year for some of our members, particularly those on Hepatitis C treatment and Traci praised them, their partners and families and also the IHS staff for their support. Brian, later in his report, made mention of the wonderful peer support within the haemophilia community, particularly involving the men who underwent the treatment. Sadly, the news came at this point that our popular guests from Vietnam, Dr. Mai and Ms. Hang were not going to be able to make it due to sandstorms in Abu Dhabi. This was a disappointment as our members have very much taken the twinning programme with Vietnam to their hearts. The business meeting was a great success. It is vital that the members are confident in how the Society is being run and it certainly seemed that way from the delegates and their questions and comments.

The presentations began after lunch. First up was an 'Open Forum' with the Haemophilia Treatment Centres. It was chaired by Traci Marshall Dowling and featured Dr. Barry White and Dr. Michelle Lavin from St. James's Hospital. Dr. Lavin was very informative about her research into Pharmacokinetics. Also present were Haemophilia Nurse Specialist, Mary Kavanagh from Crumlin and our old friends Dr. Barry Harrington and Dr. Alison Dougall from the Dental Clinic at St. James's. Alison talked about personalising the message about dental care. For example, teenagers are more interested in white teeth and fresh breath than long term care so that might be a useful tool to engage with them. Once again, there was no one in attendance from Cork's Comprehensive Care Centre which was a disappointment.



*The coffee breaks are a great opportunity for members to socialise.  
At the AGM, it also allowed the Society carry out surveys to review and help improve haemophilia services in Ireland.*

There was a short coffee break (the homemade biscuits were unbelievably good) during which there were surveys to be completed and then we had two sessions on medical progress, namely gene therapy and the clinical trials into longer acting factor. Now, as interesting as these topics were, at this point many of the men at the conference, bless them, got very tired and felt the need for a short rest. So they dragged their weary bodies for a little lie down in their rooms, (where there just happened to be a TV showing Brian O'Driscoll's last home game for Ireland.) Sarah Gilgunn chaired the first lecture on gene therapy, which was given by the esteemed Professor Katherine High from the University of Pennsylvania. Even though the topic was very scientific, Sarah ensured that it could be understood as easily as possible. Considering we have wished for this kind of therapy for decades and decades, it seems to finally be on the horizon. We might have only one more decade to wait! The second session of the afternoon was on the ongoing clinical trials into longer acting factor treatments. One of the speakers was member John Phoenix, father of a child with haemophilia on the trial, who impressed upon us the practical benefits of the longer acting factor. His son now had fewer infusions which led to less stress and a more normal weekly schedule. I'm sure this is something many parents can related to. John's contribution was very valuable because for all the scientific data available to us, there's nothing like the experience of someone living with haemophilia, child or parent. Declan Noone looked at it from a slightly different point of view as his preference was for higher trough levels as opposed to fewer infusions. The huge progress made by these therapies is all the better served by contributions from within the haemophilia community.

That evening was the Gala Dinner of the AGM, the highlight of the weekend for many. There was a great buzz around the banquet room and this year, the Society had arranged an Arts and Crafts area in the room for kids to entertain themselves. Our guests were present, the food was excellent and the atmosphere was wonderfully relaxed.

*After a jam packed day full of talks for the adults and activities for the childrens' groups, everyone enjoyed the Gala Dinner.*



After the meal, the annual award ceremony took place. Education grants, named after Jack & Maureen Downey, Margaret King and Fr. Paddy McGrath were awarded to Eoin Moriarty, Shauna Keniry and Sean Hanney. The Bill O'Sullivan Fundraiser of the year award went to David Curtin for organising the incredible Malin to Mizen cycle, which raised over €32,000 for the IHS. The Brian O'Mahony award for services to haemophilia was presented to the much loved Margaret Dunne whose years of service, support, commitment and love to the Society and its members will never be forgotten by any of us. The band tuned up and dancing started and went on until the early hours. There was a lovely sense of comfort for the evening – a group of over 200 people happy in each other's company.



(L to R) IHS Chairperson Traci Marshall Dowling presented the Maureen and Jack Downey Educational Grant to Catherine Moriarty, who accepted the award on behalf of her son Eoin Moriarty.

IHS Treasurer Ger O'Reilly presented Shauna Keniry with the Margaret King Educational Grant.

Michael Hanney accepted the Fr. Paddy Mc Grath Educational Grant from myself on behalf of his son Sean Hanney.

IHS Chief Executive Brian O'Mahony presented Margaret Dunne with the Brian O'Mahony Award for Outstanding Contribution to Haemophilia.

Sunday got off to a rather unorthodox start as Greig Blamey, a physiotherapy consultant from Canada, gave a presentation on 'Sex and Haemophilia', which had a curiously large attendance for such an early hour. Greig takes his job seriously but presents in a very light hearted and informal manner. His blend of scientific knowledge and relaxed humour was a perfect combination. It was a fun and informative session and highlighted an issue that many may not have considered. This was followed by a session on our twinning programme with Vietnam. Sadly, our Vietnamese guests weren't here but Debbie Greene and Fiona Brennan gave a good account of what's going on in Vietnam, how much progress has been made and where we hope to go from here. As usual, there was an energetic contribution from the floor. This issue seems to matter a great deal to our members and some interesting ideas, such as child sponsorship and charity sales, were suggested. There was a parallel session on Haemophilia B chaired by Brian O'Mahony.

The presentations had come to an end for this year's AGM. We finished with a lovely lunch and then said our farewells and made our journeys home to the four corners of the country. The weekend was a great success, largely due to the huge work done by the IHS staff. Without them, these weekends wouldn't even get off the ground. The fact that they run so smoothly is a testament to the staff's hard work and innovation, so thanks to them. Thanks also to all of the volunteers whose energy, kindness and no little patience ensure that the kids have full and safe programmes of their own and their parents can enjoy their weekend worry free.

We gather together every year because we are a community. And at a time when Irish society is growing more separated, being part of a community is a good thing. Every concern is shared, every triumph is celebrated and every member welcomed. The difficulties we individually face are fought with an army of support behind us. Till next year, when we gather again and raise a glass to the Irish Haemophilia Society and all who sail in her.

**Brian O'Riordan**  
Vice Chairperson



# New Kids on the Block at the 2014 AGM



**T**he 2014 AGM saw a record number of children attending the children's programmes with lots of new faces this year. With 70 kids and 24 volunteers, it was set to be a busy weekend!

The Crèche Group with 12 of our smallies, spent the weekend doing arts n crafts, having story and movie time and going for walks in the grounds of Lyrath Estate Hotel, Kilkenny. Our Cubs Group, didn't have a moment to spare with treasure hunts taking them around the hotel and its grounds, learning (and teaching me at times, may I add!) about self-infusion and trips to the cinema. The Kidlink group, kept the volunteers and each other busy with the obligatory swimming session. We broke the mould and combined kidlink and youth teams for a marathon treasure hunt, let's just say there was no rest for the wicked! The Kidlink Group also had educational sessions on self – infusion and First Aid – there may be some future doctors or nurses lurking in the Kidlink group. Finally, the youth group, took part in an IT session, showing the group how to stay safe online and The Apprentice, you might not see them on TV just yet, but the youth group came up with some fantastic ways of promoting World Haemophilia Day.

As you can imagine, there were some tired and sad faces saying goodbye on Sunday at lunch, but not to worry the Parents Conference is just around the corner!



At the 2014 AGM, David Curtin was awarded the Bill O'Sullivan Fundraiser of the Year Award. As is the case with our Educational Grants, the Fundraiser of the Year award is named after someone who contributed a lot to the Society and haemophilia care in Ireland. In this issue of haemophilia.ie we remember one of the founding members and a lifelong friend of the Society, Bill O'Sullivan.



Bill O'Sullivan  
Founding Member &  
Forever Friend of the IHS.

**B**orn in Sneem, Co. Kerry Bill O'Sullivan had severe haemophilia. In 1968 Bill joined four other people with haemophilia and parents in setting up The Irish Haemophilia Society. Treatment for haemophilia with factor concentrates had only just been introduced in Ireland and Bill and the other founding members recognised a need for a support organisation to help people with bleeding disorders and their families understand the changes to haemophilia care.

I was keen to find out how Bill became involved in the Society and why he felt an organisation was needed, but before that I needed to find out what kind of a man he was. I spoke to several members who knew Bill, as well as his family and one word that everyone used to describe him was a "gentleman". Such a simple word, with a deep meaning, but it is rare to hear people described as this. So when I spoke to Bill's wife Hilary she elaborated on this;

*"People often said that about Bill, because he was a gentleman. My father said that at our wedding actually, he said Bill was a gentleman and a gentle man".*

As treatment for haemophilia only became available in the late 1960s, the life span of a person with haemophilia was short. In fact, as has been noted by the IHS, other National Member Organisations (NMO's) and the World Federation of Hemophilia (WFH), it is only now that we are seeing the first ageing population of people with haemophilia. As a person with severe haemophilia it would have been very tough for Bill growing up. Indeed, without any treatment, severe haemophilia meant missing a lot of school, which had an impact on education and job prospects. Bill went onto college himself and became an Environmental Health Inspector and then Supervisor. Promoting education and a positive view of haemophilia was something Bill was determined the Society endorse, Hilary explained:

*"It was an achievement for Bill, without treatment, to have gone as far in his education as he did. He felt it was important that people coming to meetings would see people with haemophilia who were functioning well, had finished their education and were in good jobs."*

The introduction of factor concentrates was a positive step in haemophilia care for a condition that would have been viewed negatively. Changing the outlook of people with bleeding disorders and their families was something Bill was extremely passionate about. Bill wanted to put a positive point of view across and focus on what people with bleeding disorders could do, rather than their limitations;

*"Although he couldn't play sports, Bill was a supporter of the GAA and Irish music and culture. He developed other interests becoming a keen gardener with roses being a particular favourite. He also developed his skills in DIY and public speaking. After we were married Bill took swimming lessons and found his mobility improved,"*

Hilary recalls.

*"It was hard for boys with bleeding disorders at that time to be told they couldn't play a sport, because they are meant to be active and running around. Bill thought it was important to emphasise what the boys could do and to develop their skills in other areas."*

Sport is a hot topic with all haemophilia organisations. It is important for people to stay fit and healthy regardless of their bleeding disorder status, but for people with haemophilia keeping fit helps to develop strong muscles. Things have moved on since Bill's time and there are still sports which are discouraged, but at the end of the day it will always be the individual's choice as to how they live their life. From all accounts Bill was very disciplined when it came to his haemophilia care.

*"Bill faced a lot of challenges in life, because people with haemophilia generally didn't survive long without treatment. He realised that he needed to be careful about things and knew what he could and couldn't do."*

Bill was very committed to his job, often to his detriment;  
*"I saw Bill going into work when he wouldn't be feeling well because of a bleed, but he would rather go in and struggle through the day than take time off."*

This was and indeed is something that happens quite often and in some cases can be traced back to the issue of disclosure. People with haemophilia often feel they will be judged or viewed differently if they take time off sick because of their condition.



*Bill taking part in a "Knit In" in aid of the IHS.*

In Ireland, approximately 50% of new haemophilia diagnoses are spontaneous mutations. Coming to terms with a lifelong condition in your family is a test. Although there was a family history of haemophilia for Bill, Hilary says it was something he would have dealt with privately;

*"He wouldn't have spoken a lot growing up about his haemophilia, which would have been typical at that time."*

The privacy around haemophilia was not uncommon and again can be traced back to disclosure. It was felt that if people knew about your haemophilia diagnosis it would affect your education and job prospects. When established, the IHS committee would visit members in hospitals and talk to them about their concerns and explain haemophilia care to them. At that time there were no haemophilia treatment centres so information was hard to come by. Medical staff did not have the same level of involvement as they would have now, so people with bleeding disorders generally did not know where to find information or support. As the years passed the Society became recognised as a support organisation and began regular communication with members by establishing a mailing list.

Today there are three haemophilia treatment centres in Ireland. The Irish Haemophilia Society regularly meet with the teams from the treatment centres to discuss haemophilia care and issues that members may have. This involvement began with the founding members who worked on improving hospital conditions for patients with bleeding disorders, as Hilary told me;  
*"Some beds were in the leukaemia wards. It was very difficult to be in hospital, but for people with haemophilia who were trying to get better and be positive about their situation, they were in a very difficult and emotionally painful environment. Also children could not visit these wards."*



*Bill (right) with fellow founding member and friend, Jack Downey.*

As well as advocacy and outreach another contribution Bill made to the Society was involving his nephew Brian O'Mahony, who described Bill as a "persuasive man", something I'm sure many past and current board members would describe Brian as today!

Bill was already very involved in the Society when he met Hilary in 1971. He was also a committee member of the Dublin - Kerry Association and became Chairman that year.

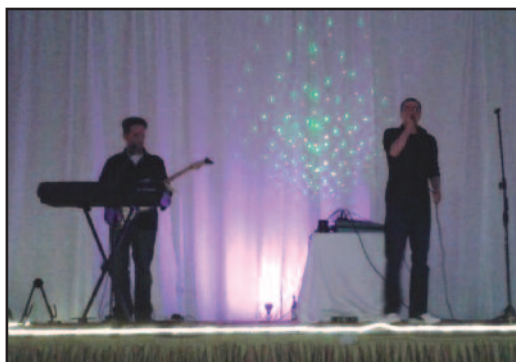
*"I met Bill in February 1971, we got engaged that August and married in April 1972. Things moved quite fast, which was a surprise, because as you know Kerry men can be cautious!"*

Hilary lists Bill's sense of humour as one of the things that attracted her to Bill, but also his ability to stay calm and relaxed;

*"He faced many things in his life, so he didn't get stressed over the little things. He was a dedicated, loving husband and father. The combination of his sense of humour and strong Kerry roots played a key part in our family life."*

Hilary regularly attends events so is known to many members, her son Liam is the lead singer in the B Sharps, who provide the entertainment following the Gala Dinner at the AGMs and her daughters Mary Clare and Grace have participated in the Mini Marathon in aid of the IHS. November 2013, marked the 20<sup>th</sup> anniversary of Bill's death and I was keen to know why staying involved with the Society is so important to the family;

*"It was important to Bill, so it is important to us. That the standard and quality of blood products being used is closely monitored is something we would consider to be of the utmost importance. The great thing is to see how far it has come, the work that has been done and the strides that have been made. Personally, I've always been struck by the dedication of the staff and committee, quite over and beyond the call of duty. There is a great sense of community in the Society, which is something Bill wanted to achieve. He would have been so happy and proud. We have a grandson, Denis, with haemophilia, who unfortunately Bill never got to meet, but I know he would be so chuffed to see that he is part of an organisation that is so positive and that with current treatment, managed at home by his parents, he never misses any school."*



Left: Bill's wife Hilary presenting David Curtin with the Bill O'Sullivan Fundraiser of the Year Award at the 2014 AGM.

Centre: Bill's son Liam is the lead singer in the B Sharps who provide entertainment after the Gala Dinner at the AGM.

Right: Bill's daughters Grace (third from left) and Mary Clare (second from right) regularly take part in the Mini Marathon for the IHS.

That Bill's family remain involved in the Society shows that the caring nature people remember so fondly in Bill is something that runs in the family. Although he is still quite young I have no doubt that Denis will be one person Brian O'Mahony will hope to "persuade" to join the board in the future and help bring the Society forward and carry on the work that his grandfather began.

In the chaos of everyday life and with the level of haemophilia care available today, it is hard to imagine what life with a bleeding disorder was like before treatment was available. The Society offers services and supports to all people with bleeding disorders and their families. Although not everyone avails of the supports available to them, I'm sure they take comfort in knowing they are there if they do.

After the AGM, several members thanked myself and the other staff for the work we do. However none of the work we do as staff would be possible without the dedication of Bill and the other founding members as volunteers. So I would like to take this opportunity to thank him for everything he did, so much of which cannot be captured in an article, but will always be remembered in the hearts of those he helped and in the legacy he left behind.

A gentleman with an enormous amount of empathy, a persuasive man with a great sense of humour and a family man with a helping hand for those in need. I never had the pleasure of meeting Bill, but from what I have learned about him that was certainly my loss.

**Nuala Mc Auley**  
Irish Haemophilia Society



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