History of the Irish Haemophilia Society

Brian O’Mahony
Beginning’s 1968 - 1975

• Society founded by parents, doctors

• Letter sent to National Newspaper calling for people to contact new organisation

• 1970 - First treatment centre in Meath Hospital
Meeting May 22, 1968: “It was agreed that the aims of an association would be similar to the following”:

1. Registration of all *haemophiliacs*
2. To enlist all *sufferers*, their families and other interested persons as members
3. Medical and dental care for all *haemophiliacs*
4. Education of *sufferers* and their families in the handling of their problems
5. Dissemination of information concerning *haemophilia*
6. To give assistance in the solution of individual problems of education, job-training, psychological adjustment, rehabilitation and finances
Treatment outside Dublin

Mercy Hospital, Cork

Regional Hospital, Galway
1970’s

• First Newsletter

• Free treatment - 1970 Health Act

• Swimming pool access

• Priority - education and extra home tuition as required

• 120 PWH on register

• First fundraiser

• Centre moved to St. James in 1977
I.H.S. services in the 1970’s

• Outreach to find person with haemophilia and have them register at Centre in Meath or Harcourt Street – Bill O’Sullivan and Jack Downey
  - Set the tone for the type of organisation we became
• Swimming lessons
• Christmas cards
• Paid for rental of television in hospital
• Visited members in hospital
• Treatment rudimentary- plasma/cryoprecipitate and some factor concentrates.
• Hospitalisation frequent
AGM 1982
The Society in 1982

- No permanent office - mail went to home address of whoever was Honorary Secretary
- No staff - all activities carried out by volunteers
- Annual “Flag day” fundraiser
- Budget was approximately £4,000 per year
MINUTES OF MEETING OF THE IRISH HAEMOPHILIA SOCIETY ON THURSDAY
28th July 1983 AT THE IRISH CANCER SOCIETY ROOMS, NORTHUMBERLAND
ROAD.

IHS 21/37

Present: Phil Byrne, Chairwoman, Jack Downey, Treasurer, Sharon
Dixon, Con Curtin, Brian O'Mahoney, Shay Farrelly, Sec.

Apologies: John Scallan, Noel O'Leary. M O'Byrne

Minutes of the previous meeting were read and adopted.

Brian O'Mahoney asked had we received a reply from Prof.
Tempereley to our letter of 31/5/1983 concerning AIDS. He
stressed his concern regarding the possible transmission
of AIDS and HEPATITIS through American blood products. He
pointed out that Germany & Switzerland had already banned
US products. He also stated that we should exert pressure
to have home produced products used.
1982 – 1987: HIV hits the community

- Newsletters, AGM the major activity

- AIDS hit the Community
  - Society sponsored research into Immune system
  - Educational materials
  - Speakers at conferences
  - Worked to try to influence availability of safer treatment
  - Provision of Condoms
1988

- 9 cases of AIDS in PWH; 4 deaths
- Society supports members in Legal case
- Published: Aids, Haemophilia and the Government – sent to Minister in May
- Called for a co-ordinated response from Government or a Trust Fund
- November- no response- decision to lobby politically and in media for recompense
- December- death toll now at 6
1989 Recompense campaign

- Society supports and funds legal test case
- Meetings with TDs/Opposition health spokespersons, Minister
- Continuing media coverage - factual and personal stories
- Private members Motion in Dail calling for fund of £400,000 annually for 3 years - results in Government defeat
- Government calls election after Dail defeat on Haemophilia motion
- Haemophilia HIV Trust (HHT) established
- Society gets first funding from Government - used to employ staff
1989 Dail defeat for Government

Private Members' Business. - HIV Infected Haemophiliacs: Motion.

Tuesday, 25 April 1989

An Ceann Comhairle: I now call Deputy Howlin. The Deputy has some 40 minutes to present his case.

Mr. Howlin:

On his return to Dublin, the news of the Government’s defeat on the Labour motion over an annual £400,000 State-funded trust for AIDS-infected haemophiliac sufferers found the Taoiseach in sable-rattling form, so much so that he threatened a political earthquake here in the shape of a general election.
First funding from Government

13. Measures taken to date to assist infected Haemophiliacs in Ireland.

(i) By Dept. of Health to Society
- Grant of £5,000 in 1988 from National Lottery to Irish Haemophilia Society for support services.
- Further grant of £50,000 offered (February 1989) but no indication from Society to date of acceptance.

(ii) From Eastern Health Board (with approval of Department) to Society
- Previous grant of £12,000 increased this year to £30,000.

(iii) Other Support from the Department
- Funding in 1988 (£15,000) from the National Lottery for counselling services has been provided to St. James Hospital where the National Haemophilia Unit is located.
1991: 4 Local Election Candidates

Four Friends of the Society brought the tragedy of its HIV-infected members to Dublin’s doorsteps when they stood in the June 1991 local election. Their campaign was in protest at the Government’s failure to offer adequate compensation despite persistent lobbying by the society for an out-of-court settlement of £15.5 million.

The four candidates were: Michael Kirwan, the father of a member in Lucan/Palmerstown; Marie O’Connor, a carer and committed friend of the society, in Clondalkin; Joe Dowling, a HIV-positive member, in Artane; and Gay McEvoy, the widow of a society member, who stood in Cabra.

Their campaign message was simple: ‘Irish people with haemophilia suffering from HIV and AIDS are being ignored by the Government – support the demand for a just settlement.’

According to Kirwan, about a third of the people he canvassed did not know what haemophilia was. He says: ‘It got to the stage that we had to bring the human aspect of the situation to peoples’ doorsteps. The response we got was quite good. We spent a lot of time explaining the situation to people and that in itself was very worthwhile.’ About three weeks before polling day – in which none of the candidates were elected – the Government made an offer of £8 million which the society accepted.

‘They spiked our guns,’ says Kirwan who says with a laugh that he has since lost his political ambition. Kirwan polled respectably with 210 votes. ‘I didn’t go along to the count, I heard it at work on the radio and I got an awful lot of flak.’
Rory O’Hanlon & Brian O’Mahony on Today Tonight
Haemophiliacs accept new £8m offer

By Marie O’Halloran

FRINT payments to HIV-positive haemophiliacs were made by October following their acceptance of the Government’s offer of £2m per patient. Acceptance in principle was reached in June at a meeting in Dublin between Government negotiators and representatives of the Irish Haemophilia Society, Dr O’Halloran said. The revised offer, an increase of £1m on the original £7m, was accepted by 95 per cent of haemophiliacs.

Oscar’s figure was a direct result of the Government’s offer of £8m to the families of children who have died as a result of tainted blood products.

The Government’s offer, which is to be made to 135 haemophiliacs and 200 children’s families, was based on a report by the Independent Inquiry into Blood Transfusion and the recent £250m offer to 1,200 haemophiliacs made by the British government.

The Irish Independent, 1 June 1991

Curb on blood imports

A CURB on blood imports was announced in January for patients with HIV/AIDS and other blood-related diseases. The Government’s offer, which was based on a report by the Independent Inquiry into Blood Transfusion, was aimed at reducing the number of imported blood products.

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The Irish Independent, 1 June 1991

Government defeated twice

The Irish Haemophilia Society, after losing two appeals, is now facing a third appeal to the European Court of Human Rights. The society was unable to raise the £250m needed to finance the appeal.

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The Irish Times, 8 July 1991

Local election campaign by haemophiliacs

The Irish Haemophilia Society is putting up a strong campaign in the recent local elections to highlight the plight of the HIV/AIDS affected. The society is also calling for a review of the compensation scheme.

The Irish Times, 27 April 1989
1992 - 1996
Death Toll from HIV

<table>
<thead>
<tr>
<th>Year</th>
<th>Death Toll</th>
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<tbody>
<tr>
<td>1992</td>
<td>3</td>
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<tr>
<td>1993</td>
<td>13</td>
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<td>1994</td>
<td>10</td>
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<tr>
<td>1995</td>
<td>6</td>
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<tr>
<td>1996</td>
<td>3</td>
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Total 35
Total 1986-1996 56
Critical Illness Service

Rosemary Daly

Margaret King

Margaret Dunne

Teresa Mulvey

- Hepatitis C virus characterised in 1989- first discussed at Society AGM in 1990
- 1990-1994: worked on getting members tested and access to treatment
- 1994-1995: discussions with DOH on compensation
- 1996 - Hepatitis C compensation tribunal
  - Health Amendment Act
- Assistance provided to members going through tribunal including sourcing of legal team and expert witnesses
I.H.S. Office: 1991 - Eustace Street
1993

- Celebrated 25\textsuperscript{th} Anniversary of I H S
- Videotape on 25\textsuperscript{th} produced
- President Robinson attended AGM
1996 WFH World Congress

- WFH Congress in Dublin with record attendance and profit for IHS
- Profit used toward purchase of HQ in 2007
- New Blood Product policy: Aspiration – recombinant for all
1997 – 2001  Tribunals of Inquiry

• 1997: Finlay Tribunal into BTSB- fails to deal with Society issues
• Society withdraws and demands new inquiry focused on Haemophilia
• Terms of reference agreed after 27 months
• Lindsay Tribunal sat for 196 days from Sept 1999 to Nov 2001
• Report issued in 2002
• Recommendations for the future and work by Society on these crucial
2002 Compensation Issues

- New Compensation scheme in 2002:
  - Fair and Equitable
  - Further compensation for HIV
  - Recognition of spouses, parents, carers
  - Proper compensation for families of those who had died
Improving access to care; During Tribunal Negotiations

- 1997 - Prophylaxis for all Children
- 1998 - Moved to new HQ in Smithfield:
  - near Lindsay Tribunal building
- 1999 - Recombinant Products for All
- 2001 - new National Centre: NCHCD
Tribunal Recommendations used to set up New Decision Making Bodies

- 2002- Haemophilia Product selection and Monitoring Advisory Board (HPSMAB)
  - formal role for Society in selection of Factor concentrates
- National Haemophilia Council (NHC)
  - Statutory Body in 2004
  - Formal role for I H S in recommending policy and Priorities
National Haemophilia Council

• Hepatitis C lookback in 2005

• Managed vCJD Risk Assessment in 2004

• Commissioned external Audits of treatment centre’s since 2006

• Recommendations on prioritisation of resources between centres and nationally
2006-2010

• Insurance scheme for members with HIV/Hepatitis C:
  - Life/Mortgage/travel insurance
• EHC Conference Dublin
• New haemophilia centre opened in Cork
• Increasing number of children and teenagers programmes and activities
2007: Finally...our own HQ
2010-2013

• 15 year mortgage paid off in 6 years
• Apartments purchased for members use near St. James
• Law to change contract holder for Haemophilia medications
• Clinical trials start for Extended half life (EHL) factors
2012-2016: Hepatitis C

• Successful advocacy for access to Hepatitis C treatments
• Strong support provided to members on treatment
• Commitment received from Minister for prioritised access
• 2016: Hepatitis C effectively eradicated in haemophilia in Ireland.
New ‘life saving’ drugs for Hep C sufferers

Mark O’Ragan

New ‘life saving’ drugs which cost €840,000 per patient, and have a 95% success rate, should be made available to Hepatitis C sufferers with only months to live.

The Irish Haemophilia Society is calling for an “immediate positive decision” on the drugs given a once-off treatment.

It is estimated 300 patients require these special treatments because they cannot tolerate the existing treatment care systems. In some cases this is causing severe liver change which can be life-threatening. A total of 12,352 people in Ireland need Hepatitis C treatment.

Brian O’Mahony, the society’s chief executive, said new licensed drugs on the market

Call for early access to Hepatitis C treatments

New ‘life saving’ drugs for Hep C sufferers

Mark O’Ragan

HUNDREDS of Hepatitis C sufferers face their failure or death within 12 months unless they get access to new treatments.

The CEO of the Irish Haemophilia Society said the block was “far too high” for 300 people who cannot tolerate their existing treatment as a result of adverse drug reactions and liver damage, which can be life-threatening. A total of 12,352 people in Ireland need Hepatitis C treatment.

Brian O’Mahony, the society’s chief executive, said new licensed drugs on the market

Patients with Hepatitis C should have immediate access to potential life-saving therapies’ - Irish Haemophilia Society

Mark O’Ragan

The Irish Haemophilia Society has called for 300 seriously ill people with the Hepatitis C virus to be given early access to new treatments that could save their lives.

He said Hepatitis C treatment, 350 have been in need of urgent treatment.

Brian O’Mahony, I H S AGM & Annual Conference 2018
Call for early access to Hepatitis C treatments

Dear Dr O’Mahony,

I am writing to you regarding the introduction in Ireland of new innovative Direct Acting Antiviral (DAA) treatments for the treatment of Hepatitis C. As you are probably aware, these drugs significantly alter the prognosis for people affected with Hepatitis C. In 2014, in order to access the most appropriate management of access to these newly approved drugs, a Hepatitis C Advisory Group was established by my Department. The findings of the Group were presented in an expert report entitled ‘A Public Health Plan for the Pharmacological Treatment of Hepatitis C’. The Report sets out the basis on which a multi-agency approach to the provision of treatment for Hepatitis C could be taken. This multi-agency approach has recently been approved by the Government. The key elements of the plan include the following:

- Access to these new innovative drugs will be based on internationally-accepted criteria for treatment indications.
- The HSE will establish a new National Treatment Programme for Hepatitis C which will be responsible for implementing the clinical prioritisation criteria and for making further reviews and decisions on the clinical criteria as the programme is rolled out in the coming years.

I am pleased to inform you that the Government is committed to funding this Plan. As of June, by the end of 2017, all patients who commenced Hepatitis C therapy prior to the implementation of these new treatments in the State will have access to these new treatments, if prescribed by their treating clinicians. It is important to note that in a number of cases, not all of these patients will be offered access to these drugs by the end of 2017, and in 2018. Instead of reviewing the treatment guidelines (which are non-statutory in nature) by the end of 2017, the updated revised guidelines will be completed and used by all HSE treating clinicians. These new guidelines will be implemented from January 2018, ensuring that all patients who require treatment will be reviewed and treated. The revised treatment guidelines will be completed and updated in 2018, with the aim of ensuring that all patients with Hepatitis C have access to appropriate treatment. The plan is currently underway, and you will be kept informed of any changes or updates.

The Irish Haemophilia Society has called for 350 seriously ill people with the Hepatitis C virus to be given early access to new treatments that could save their lives. It said this group can no longer tolerate the current interferon treatment, due to side effects which increase their risk of death.

The society said that of the 1,265 patients who need Hepatitis C treatment, 350 have been identified by specialist hepatologists to be in need of urgent treatment.

Hepatitis C in Irish haemophilia population ‘eradicated’

Press Release

Harris hails effective eradication of Hepatitis C in haemophilia patients a great achievement for Ireland


Minister for Health Simon Harris is delighted that haemophilia patients being treated under the HSE National Hepatitis C Treatment Programme have had excellent success rates. Haemophilia patients infected with Hepatitis C from blood products have been offered treatment under the Programme, the majority of whom have now completed treatment.
Haemophilia Product Selection and Monitoring Advisory Board 2002-2018

- Completed 17 National tenders;
- Recombinant FVIII
- Recombinant FIX
- Plasma derived FVIII for von Willebrands
- FX Concentrate

- Primary selection Criteria: Safety, Efficacy, Quality, Supply, Cost

- FVIII use of 13 Million IU for 2002 increased to 44 Million IU for 2015
- FIX per capita use at 2.36 IU highest in world
- “Savings” over old system of €132 Million from 2002-2014
Haemophilia Product Selection and Monitoring Advisory Board 2002- 2018

- Lower costs re-invested in Haemophilia care
- FVIII and FIX use in 2017 highest in world:
  - Council of Europe recommended minimum FVIII use 4 IU/capita
  - Global average use, high income countries: 6.16 IU/capita
  - Ireland FVIII use 11 IU/capita.

  Council of Europe recommended minimum: 0.5 IU/capita
  Ireland FIX use 2.52 IU/capita

- New comprehensive care centre in Cork, 2010
- New in-patient H and H unit Dublin, 2013
- New National Coagulation centre, St. James’s, 2017
National Coagulation Centre 2017
Collaborative work on HPSMAB

• We use the safest most efficacious treatments for all
• Significantly lower cost than EU- 70% lower
• Highest Factor use globally
• Significant investment in Haemophilia infrastructure- even during recession and bailout
• More innovative participation in clinical trials
• First country in world to treat all people with Extended half Life FVIII and FIX
Figure C4a. Mean per capita factor VIII use in 2016 – regional and GNI comparisons of IU/total population: Europe

Figure C4b. Mean per capita factor IX use in 2016 – regional and GNI comparisons of IU/total population: Europe

Economic category based on The World Bank Group 2016 rankings for "Gross national income (GNI) per capita, Atlas method (current US$)". (GNI in US dollars: D lower income, $5 - $1,005; C lower middle income, $1,006 - $3,995; B upper middle income, $3,996 - $12,235 and A high income, $12,235 or more) (Regions based on WHO regions.)

PLEASE NOTE: The X-axis showing the number of IU/capita is different in each graph. The orange line indicates 1 IU per capita of factor VIIa. The WHO has established that one international unit (IU) of FVIIa clotting factor concentrate per capita should be the target minimum for countries wishing to achieve survival for the hemophilia population. Higher levels would be required to preserve joint function or achieve a quality of life equivalent to an individual without hemophilia. Please note the orange line does not apply to factor IX. Only countries that completed the 2016 questionnaire are included in these charts.
FIX trough levels 2017: Switch to EHL FIX
**CRITERIA**

<table>
<thead>
<tr>
<th>SAFETY</th>
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<tr>
<td>Human Albumin in Culture Medium</td>
<td>5 - 15</td>
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<tr>
<td>Additional Human or Animal Protein (e.g. monoclonal antibodies)</td>
<td>3 - 7</td>
</tr>
<tr>
<td>Viral Inactivation</td>
<td>10 - 20</td>
</tr>
<tr>
<td>Inhibitors</td>
<td>20 - 40</td>
</tr>
<tr>
<td>Prion Removal</td>
<td>3 - 7</td>
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<tr>
<td>Other Adverse Events</td>
<td>5 - 15</td>
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<tr>
<td>Other Safety Concerns</td>
<td>10 - 20</td>
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<tr>
<td><strong>Total for Safety</strong></td>
<td><strong>56 - 124</strong></td>
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<th>EFFICACY</th>
<th><strong>EFFICACY</strong></th>
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<tr>
<td>Pk (Half Life / Time to trough of 3%/ AUC)</td>
<td>20 - 60</td>
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<tr>
<td>Data in relation to ability to infuse prophylactically twice per week</td>
<td>5 - 15</td>
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<tr>
<td>Recovery</td>
<td>10 - 20</td>
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<tr>
<td>Clinical Response (adult/paediatric)</td>
<td>10 – 20</td>
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<td><strong>Total for Efficacy</strong></td>
<td><strong>45 - 115</strong></td>
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**QUALITY**

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<th><strong>QUALITY</strong></th>
<th><strong>Stability</strong></th>
<th>3 - 10</th>
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<tbody>
<tr>
<td>Volume of Administration</td>
<td>3 - 10</td>
<td></td>
</tr>
<tr>
<td>Instructions for Use &amp; Handling</td>
<td>3 - 5</td>
<td></td>
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<tr>
<td>Ease of Administration</td>
<td>3 - 5</td>
<td></td>
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<tr>
<td>Application of Unique Bar-Code</td>
<td>3 - 5</td>
<td></td>
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<tr>
<td><strong>Total for Quality</strong></td>
<td><strong>15 - 35</strong></td>
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<tr>
<th>SECURITY OF SUPPLY &amp; AVAILABILITY</th>
<th><strong>SECURITY OF SUPPLY &amp; AVAILABILITY</strong></th>
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<tbody>
<tr>
<td>Number of Manufacturing Plants</td>
<td>5 - 10</td>
</tr>
<tr>
<td>Security of Supply</td>
<td>10 - 20</td>
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<tr>
<td>Supply/ Availability</td>
<td>15 - 30</td>
</tr>
<tr>
<td><strong>Total Scores Awarded: Phase 1</strong></td>
<td><strong>131 - 304</strong></td>
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<tr>
<th>COST</th>
<th><strong>COST</strong></th>
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<tr>
<td>Rebate 4%</td>
<td>10 - 20</td>
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<tr>
<td><strong>Total Scores Awarded: Phase 2</strong></td>
<td><strong>166 - 399</strong></td>
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Innovative and early use of Technology

• Electronic patient record system
• App to report home treatment now in use for 11 years
• HSE funded Lighthouse project being used to develop patient portal
• Return more control to PWH over their condition
Ireland at forefront with Clinical Trials

- Children participated in clinical trials on EHL FVIII and FIX
- Clinical trial for Emicizumab SC therapy
- Clinical trial on EHL for Immune Tolerance

Clinical trials due to commence this year:
- Fitusiran SC therapy
- Gene Therapy for FIX
Research and Development projects

• Outcomes research on treatment:
  - PROBE, Hemo-Qol, qualitative
• IPATH Research project to answer fundamental biological questions on haemophilia
• Development programme with Vietnam Haemophilia Society:
  - improved access to treatment and care
  - micro employment
  - home adaptation
Research - Unanswered questions

1. Why is factor concentrate cleared rapidly from the blood in some patients and slowly in other patients?

2. Why do some patients with severe haemophilia demonstrate lots of bleeding complications whilst other patients bleed rarely?

3. Why do some young boys with severe haemophilia develop joint degeneration after only a few joint bleeds whereas other patients have well preserved joints despite lots of joint bleeding?

4. Why do some patients develop inhibitors and others do not?
Global Contribution

Twinning programmes with:

• Hungary (1994-1997)
• Belarus (1997-1999)
• Greece (2000-2003)
• Bosnia and Herzegovina (2004-2008)
• Vietnam (2010- Present)
• Contribution to WFH GAP programme
Strategic Planning for Society

Strategic plan 2011-2014

Strategic Plan 2015-2018
Education / Activities for Kids and Teens
Website & Social Media
Co-Designed service

Clinicians and Irish Haemophilia Society work together on co-design of service

• Statutory National Haemophilia Council oversees service
• Haemophilia Product Selection New technology introduced with patient participation
• Research projects jointly conducted
• Joint training and education initiatives
“The farther backward you can look, the farther forward you are likely to see.” Winston Churchill
50th Anniversary activities

• Movie on history of Society
• Digital archive
• Chronology and photo history
• Graffiti Art project
• World Haemophilia Day events
• Gala dinner
• 10 events/conferences
50th Anniversary: Conferences

- AGM/Annual conference
- Members Conference
- Ageing
- Carriers
- von Willebrand’s
- Haemophilia B
- Mild Haemophilia
- Father and Son event
- Mother and Daughter event
- Inhibitor summit
I H S Staff team
I H S Board
I.H.S. Volunteers
ANIMAL PHYSIOLOGY

A Peanut Factor for Haemostasis in Haemophilia

It is known that there are unpredictable apparent remissions of clinical symptoms enjoyed by haemophiliaics; but these remissions have not been correlated with any influences such as time of year, food eaten, weather conditions, other diseases, or physical condition of the patient. The lack of such a correlation is more apparent than real, but the mechanism of a peanut factor cannot be proved, however tempting it is to speculate on it. It is not certain whether the factor is present in the blood or in the tissues.
Where are we now...

- Strong sense of community maintained through last 50 years
- Personal empathy, commitment by all allied to strong and forward looking strategic goals

That which does not destroy you will make you stronger

Nietzsche
The Future

• Better treatment, more options: better EHL, SC, Gene Therapy
• Better options for inhibitors, VWD, rare bleeding disorders
• Reduced treatment burden and improved quality of life

• 60th Anniversary: young men will tell disbelieving children how they used to infuse intravenously every week
  : newly diagnosed children may receive 1 treatment with Gene Therapy
• Comprehensive care centres will survive and flourish
The Future- will we need the Society

YES

• Gene defect remains- individuals and families will always need support

• Never assume resources will be available for best treatment- continued advocacy, work, collection of outcome data

• Promotion of haemophilia as a career to medical students

• Maintain the community of belonging, of empathy, of support, of innovation
“The past is not dead. It’s not even past” William Faulkner