History of the Irish Haemophilia Society

Figure 8. Tsarevich Alexis.

Brian O'Mahony

Beginning’s 1968 - 1975

THE IRISH TIMES, FRIDAY, NOVEMBER 10, 1967

—Yours, etc.,

DALE F. GIESE.

2323 Kathryn S.E., 285,
Albuquerque,
New Mexico.

HAEMOPHILIACS

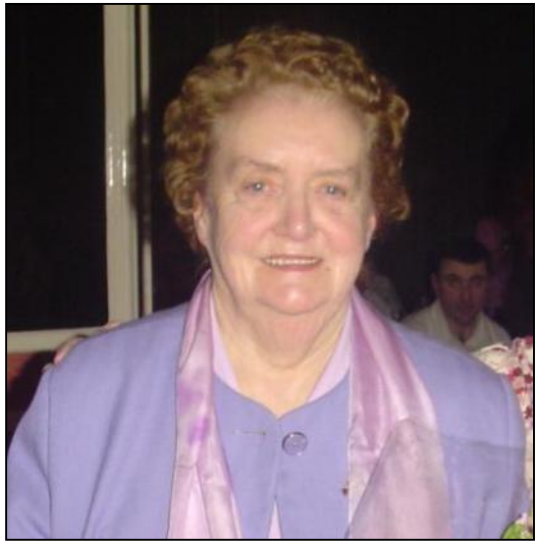
Sir, — Michael Viney's recent articles on the long-neglected haemophilia problem in this country were welcome indeed; even more welcome is the valuable article just published in the *Irish Medical Journal* by Dr. J. P. O'Riordan, director of the Blood Transfusion Service Board, following as it does, the gratifying announcement last month by the Minister for Health that more money is to be made available for research into this rare, crippling disease.

Dr. O'Riordan's interest in this condition and his enthusiastic plans to help those affected, must come like a bright light into the lives of many despairing families. Only the families of one or more haemophilic children can begin to know

- 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



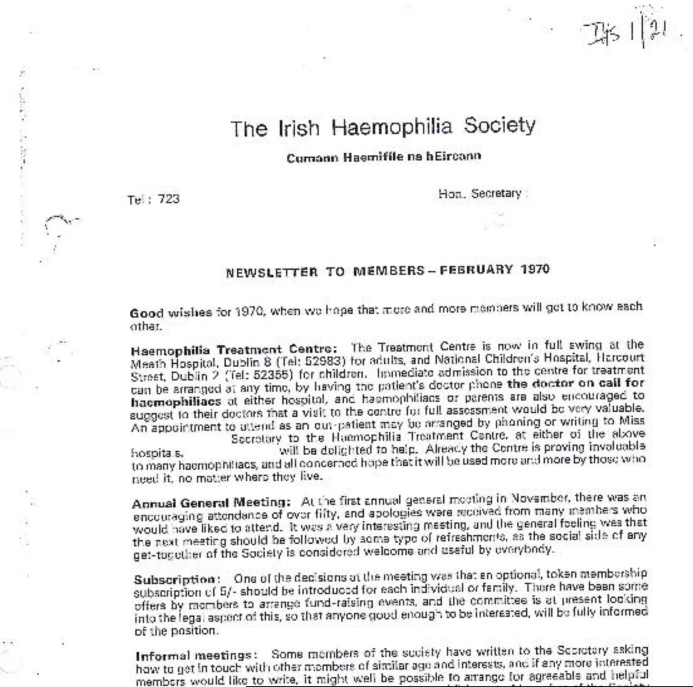
Treatment outside Dublin

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



I45 1|21

The Irish Haemophilia Society

Cumann Haemifile na hEireann

Tel: 723

Hon. Secretary

NEWSLETTER TO MEMBERS – FEBRUARY 1970

Good wishes for 1970, when we hope that more and more members will get to know each other.

Haemophilia Treatment Centre: The Treatment Centre is now in full swing at the Meath Hospital, Dublin 8 (Tel: 52983) for adults, and National Children's Hospital, Harcourt Street, Dublin 2 (Tel: 52355) for children. Immediate admission to the centre for treatment can be arranged at any time, by having the patient's doctor phone **the doctor on call for haemophiliacs** at either hospital, and haemophiliacs or parents are also encouraged to suggest to their doctors that a visit to the centre for full assessment would be very valuable. An appointment to attend as an out-patient may be arranged by phoning or writing to Miss Secretary to the Haemophilia Treatment Centre, at either of the above hospitals. will be delighted to help. Already the Centre is proving invaluable to many haemophiliacs, and all concerned hope that it will be used more and more by those who need it, no matter where they live.

Annual General Meeting: At the first annual general meeting in November, there was an encouraging attendance of over fifty, and apologies were received from many members who would have liked to attend. It was a very interesting meeting, and the general feeling was that the next meeting should be followed by some type of refreshments, as the social side of any get-together of the Society is considered welcome and useful by everybody.

Subscription: One of the decisions at the meeting was that an optional, token membership subscription of 5/- should be introduced for each individual or family. There have been some offers by members to arrange fund-raising events, and the committee is at present looking into the legal aspect of this, so that anyone good enough to be interested, will be fully informed of the position.

Informal meetings: Some members of the society have written to the Secretary asking how to get in touch with other members of similar age and interests, and if any more interested members would like to write, it might well be possible to arrange for agreeable and helpful
contacts in some are
around the country.

Free Medical Tre
of Health in an effo
most helpful if we c
have had problems
Please write to the s
of course, appear in

Education: It is
as our project for 1
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standing, lack of tr
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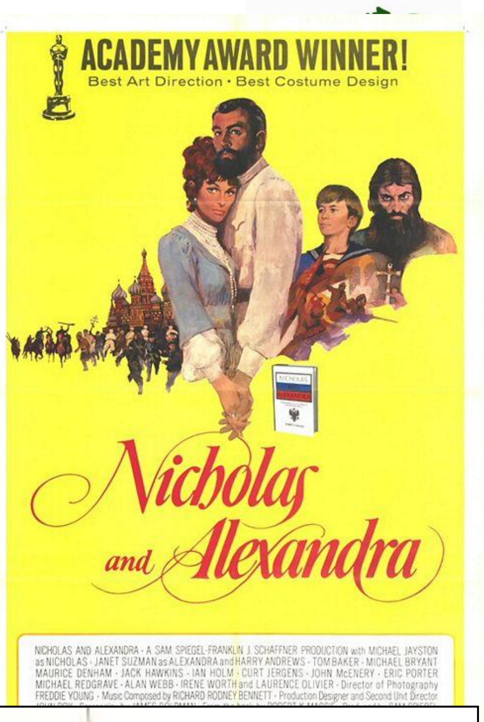
problem.

Please do write t
with your problems



I.H.S. services in the 1970's

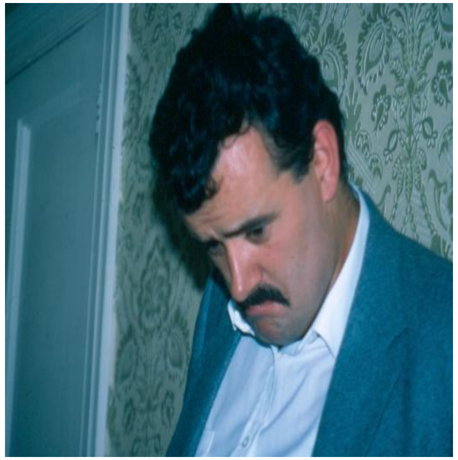
- Outreach to find person with haemophilia and have them register at Centre in Meath or Harcourt Street – Bill O'Sullivan and Jack Downey

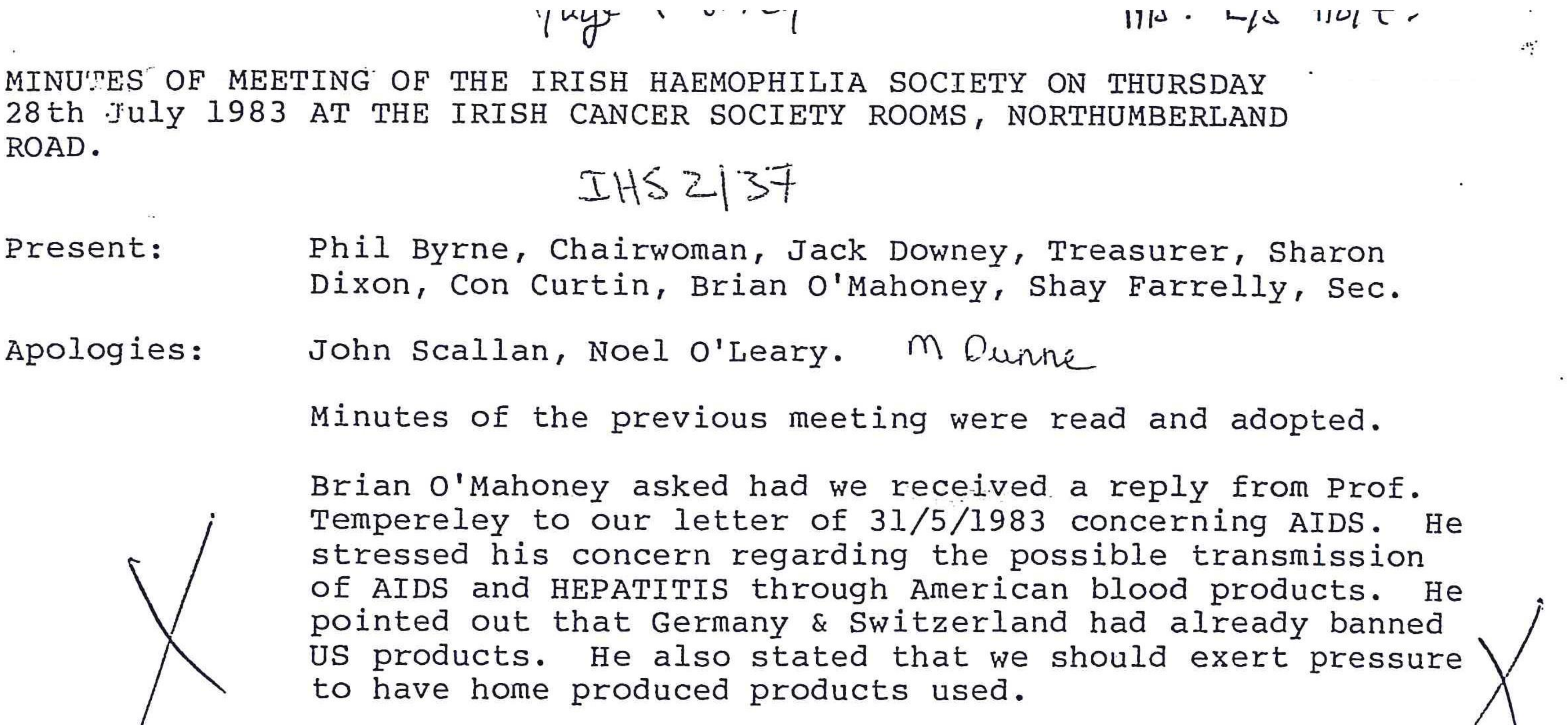
  - Set the tone for the type of organisation we became
- Swimming lessons
- Christmas cards
- Paid for rental of television in hospital
- Visited members in hospital
- Treatment rudimentary- plasma/cryoprecipitate and some factor concentrates.
- Hospitalisation frequent

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 2/37

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

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

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 activit

- **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

Irishman ha killer AIDS blood diseas

By PHILIP MOLLOY

A YOUNG Irish haemophiliac has contracted the kil disease, AIDS. The National Haemophilia Treatm Centre in Dublin confirmed yesterday that a 20-year- was being treated for AIDS symptoms.

The man, who is not a homosexual, was in hospital recently for three weeks and is now being treated in his home. It is thought that he may have contracted AIDS through transfusions of Factor 8, a blood concentrate used for a clotting deficiency in haemophiliacs.

The Department of Health, which revealed that four cases of AIDS had been reported since it was recognised as a disease entity in the U.S. in 1981, appealed to practising homosexuals and drug addicts last night not to give blood.

Homosexual activity is recognised as one of the main ways in which the disease is transmitted. Another is through blood and blood products.

Brian O'Mahony, secretary of the Haemophilia Society, said they were concerned, but they felt that if their members stopped taking treatment, they would be in much greater danger. They had ~~learned~~ this case two weeks ago and had been monitoring the situation and keeping their members informed.

A spokesman for the Blood Transfusion Service said that all Factor 8 was now being "heat treated" before use. It was believed, he said, that heating to 70 degrees over a period of 72 hours destroyed the AIDS virus.

Half the Factor 8 used in Ireland is imported from abroad. The spokesman for the Blood Transfusion Service said they hadn't taken the decision to pre-heat as a result of this case. It had been taken some time ago but only came into effect on January 1.

Prof. Ian Temperley, of the Haemophiliac Treatment Centre, said they were satisfied that they were now importing a safer product. It was possible that this young man had contracted disease through impor blood, he said.

All the circumstant evidence indicated that man had AIDS. "If you do treat it, the sufferer gets in a variety of ways. All I c say is that we are treatin this man," he said.

Dr. Temperley refused speculate on the danger of t man transmitting the diseas to others.

The Department of Healt statement said that two peopl who had contracted AIDS ha been reported prior to 198 Both were imported cases. O of the people involved returne to the United States and th other died.

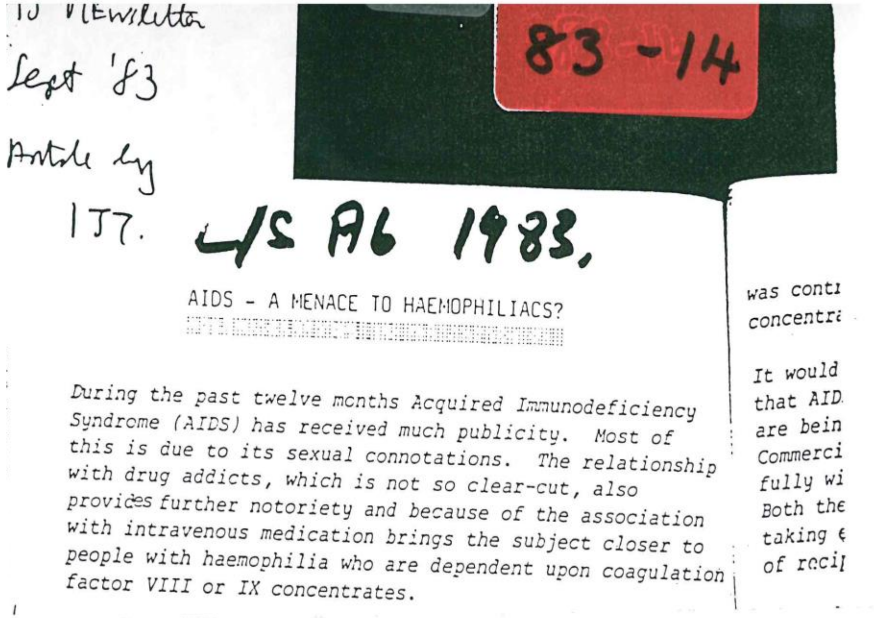
Since the establishment of detailed monitoring system here in July, 1984, two other cases conforming to the accepted definition of the ~~both cases it was~~ the source came from outside the country.

The statement said tha the experience internationall showed that one per cent o AIDS cases occurred in haemophiliacs using blood products

There are about 250 haemo philiacs in this country. Mr Mahony said that Factor 8 which is one of 13 clottin Factors, had changed many o their lives.

"It was introduced relativel recently. I'm 27 and I first g it when I was 15. It has helpe to remove the old fears, to giv our members a much free lifestyle. Haemophiliacs no have a normal life expectancy."

Factor 8 is injected into th vein. The injection rate vari greatly according to the indi idual. Mr. O'Mahony said the used it when they felt "bleed" coming on.



To NEwsletter

Sept '83

Article by

IJ7.

I/S A6 1983.

83-14

AIDS - A MENACE TO HAEMOPHILIACS?

During the past twelve months Acquired Immunodeficiency Syndrome (AIDS) has received much publicity. Most of this is due to its sexual connotations. The relationship with drug addicts, which is not so clear-cut, also provides further notoriety and because of the association with intravenous medication brings the subject closer to people with haemophilia who are dependent upon coagulation factor VIII or IX concentrates.

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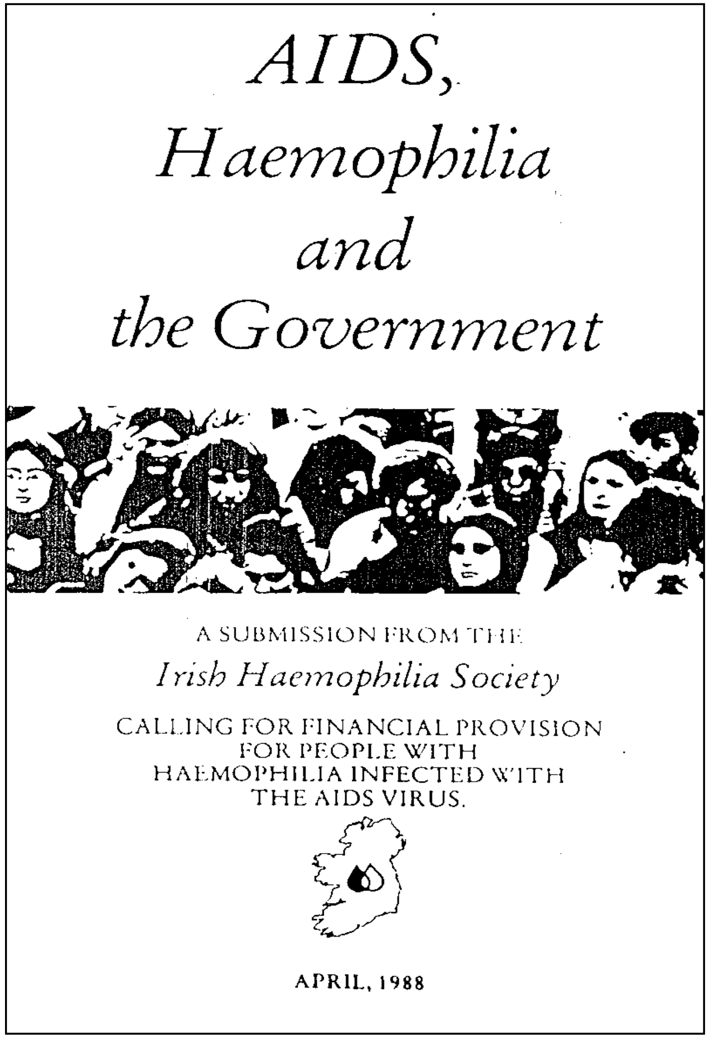
1988

- 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



AIDS,
Haemophilia
and
the Government

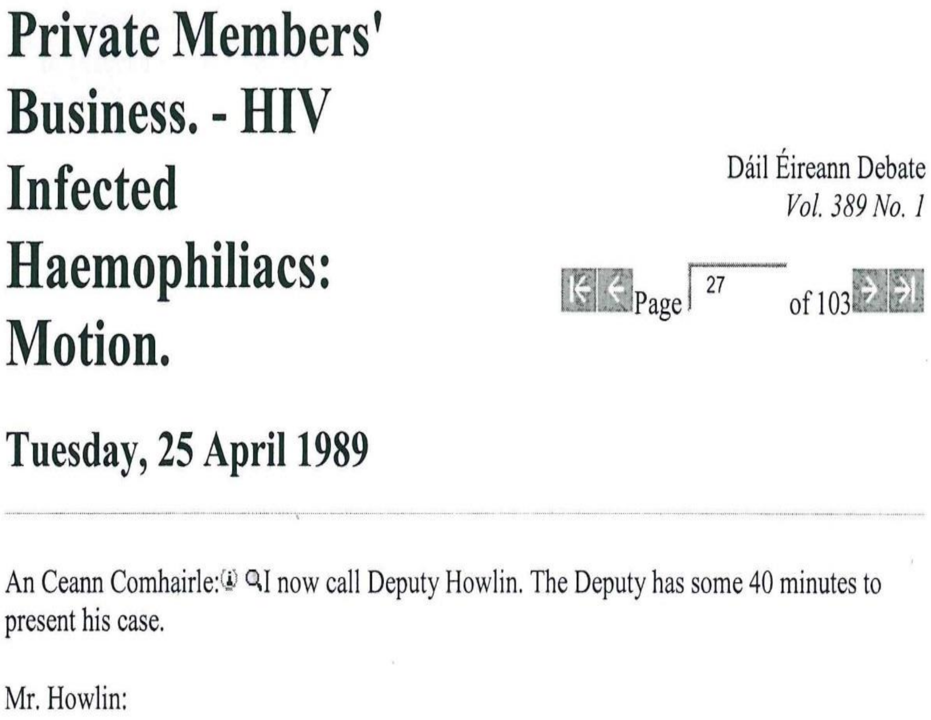
A SUBMISSION FROM THE
Irish Haemophilia Society
CALLING FOR FINANCIAL PROVISION
FOR PEOPLE WITH
HAEMOPHILIA INFECTED WITH
THE AIDS VIRUS.

APRIL, 1988

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



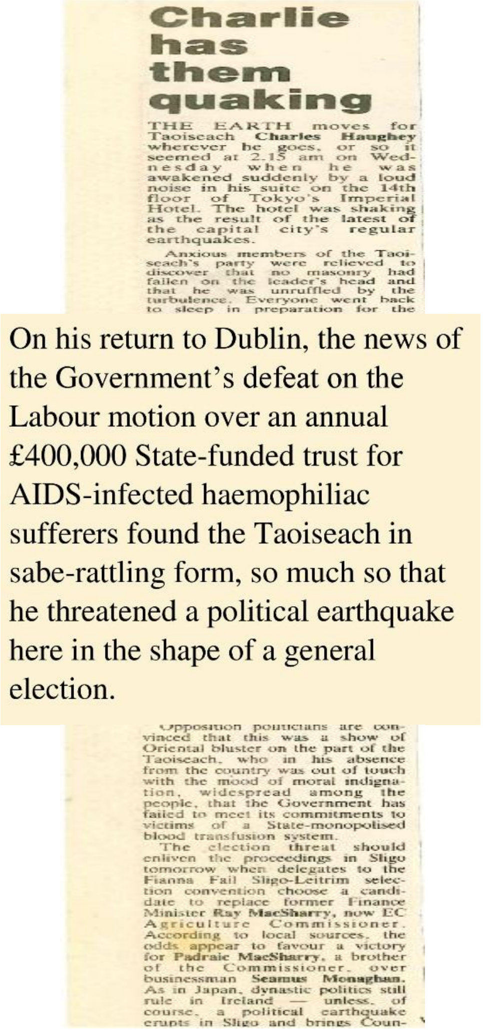
Private Members' Business. - HIV Infected Haemophiliacs: Motion.

Dáil Éireann Debate
Vol. 389 No. 1

Tuesday, 25 April 1989

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

Mr. Howlin:



Charlie has them quaking

THE EARTH moves for Taoiseach **Charles Haughey** wherever he goes, or so it seemed at 2.15 am on Wednesday when he was awakened suddenly by a loud noise in his suite on the 14th floor of Tokyo's Imperial Hotel. The hotel was shaking as the result of the latest of the capital city's regular earthquakes.

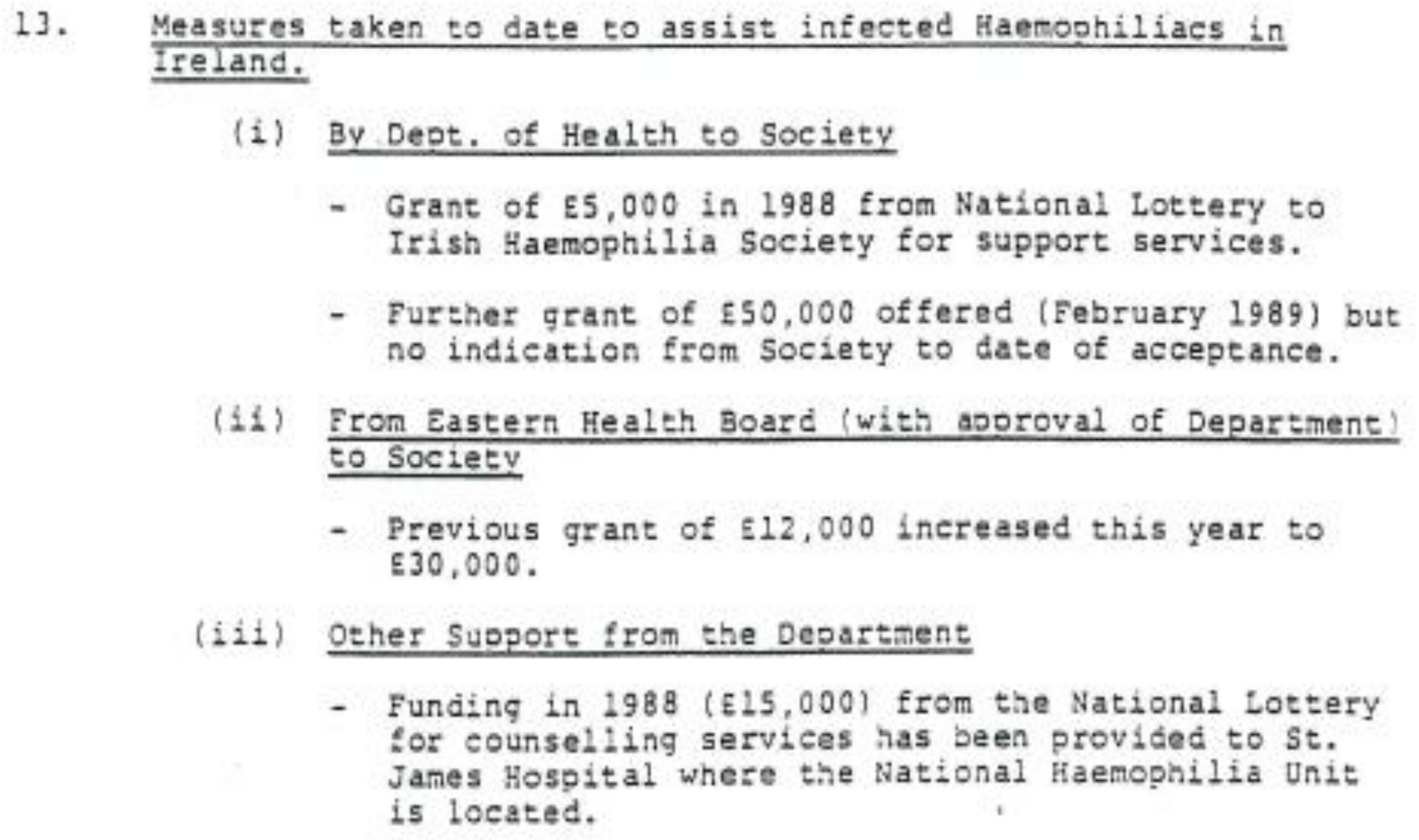
Anxious members of the Taoiseach's party were relieved to discover that no masonry had fallen on the leader's head and that he was unruffled by the turbulence. Everyone went back to sleep in preparation for the

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 sabe-rattling form, so much so that he threatened a political earthquake here in the shape of a general election.

Opposition politicians are convinced that this was a show of Oriental bluster on the part of the Taoiseach, who in his absence from the country was out of touch with the mood of moral indignation, widespread among the people, that the Government has failed to meet its commitments to victims of a State-monopolised blood transfusion system.

The election threat should enliven the proceedings in Sligo tomorrow when delegates to the Fianna Fail Sligo-Leitrim selection convention choose a candidate to replace former Finance Minister **Ray MacSharry**, now EC Agriculture Commissioner. According to local sources, the odds appear to favour a victory for **Padraic MacSharry**, a brother of the Commissioner, over businessman **Seamus Monaghan**. As in Japan, dynastic politics still rule in Ireland — unless, of course, a political earthquake erupts in Sligo and brings Coun-

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.

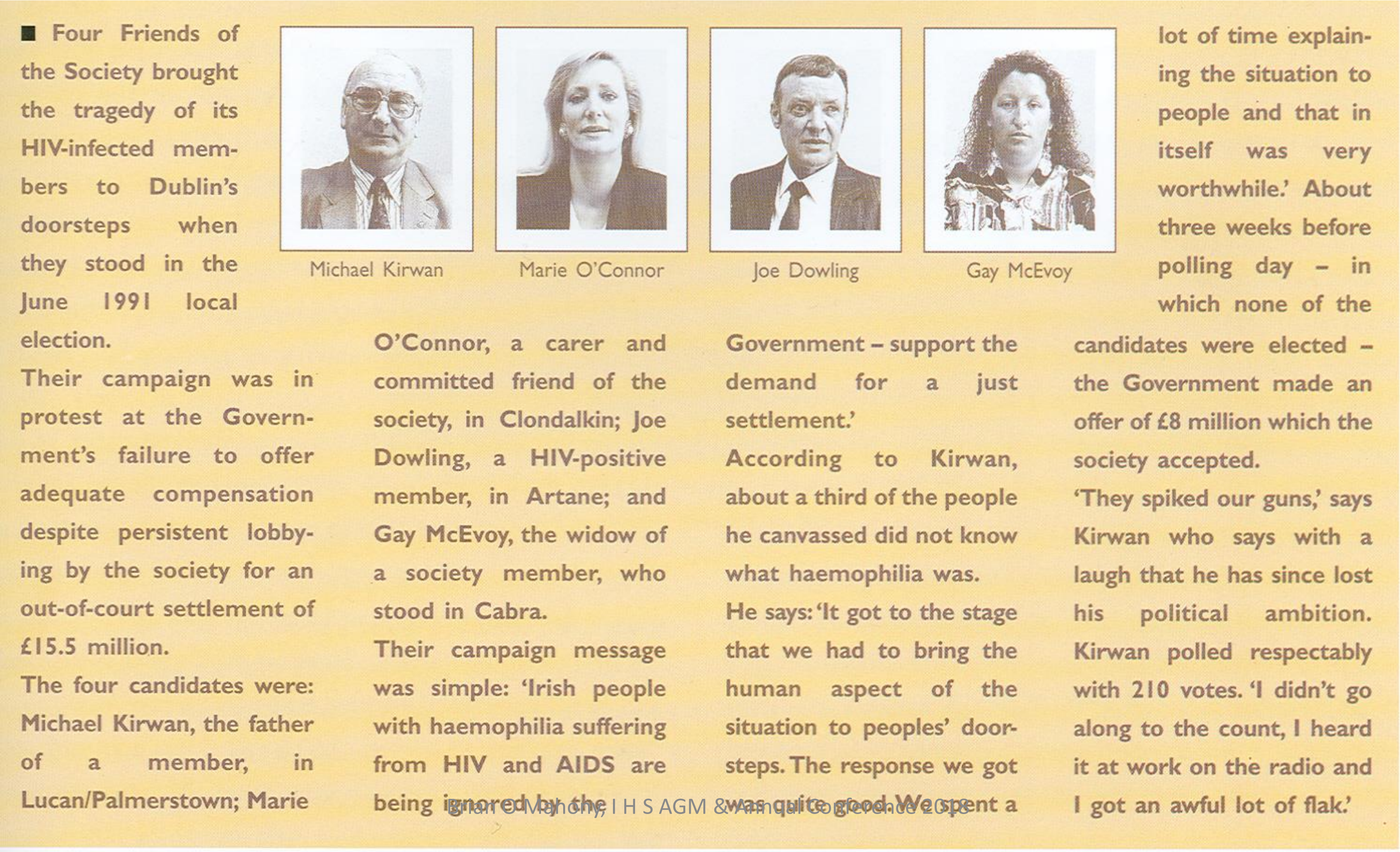
(ii) From Eastern Health Board (with approval of Department) to Society

- 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



Michael Kirwan Marie O'Connor Joe Dowling Gay McEvoy

■ 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

FIRST payments to HIV-positive haemophiliacs could be made by October following their acceptance of the Government's £8 million compensation. At a meeting in Dublin on Saturday attended by 85 people, the revised offer, an increase of £1 million, was unanimously accepted.

One hundred and three haemophiliacs in Ireland, of whom 20 have died, contracted HIV through contaminated blood products. Three have died since the Minister for Health, Dr O'Hanlon, first requested submissions for compensation from the Irish Haemophilia Society in January.

Ms Rosemary Daly, administrator of the IHS, said the Government's offer had been accepted in desperation. "Time has not been on the haemophiliacs' side. They have even less time now and because of the government's attitude, there wasn't going to be any other offers," she said.

Acceptance was conditional on withdrawal of legal claims for compensation taken by 73 haemophiliacs. The main defendants were the Blood Transfusion Service Board, St James's Hospital, Cork Regional Hospital, the National Drugs Advisory Board, two named doctors and the Department of Health. The offer was also accepted on the basis that the defendants would not seek costs from the haemophiliacs. It is understood that the legal costs of the 73 haemophiliacs will be paid from the £8 million.

Payments are expected to vary between £76,000 for single people with no dependants to £100,000 for married people with children. Reduced compensation will be made to relatives of deceased haemophiliacs with dependants. Ms Daly said that the haemophiliacs and their families had wanted the same payment for each person affected but had been advised that this would not be ratified.

The High Court is expected to approve the rates of payment and it is hoped that the first part will be paid by October, with a further and final payment next January.

The first offer from the Government was rejected last month and the Irish Haemophilia Society then sought £12½ million. When the IHS made the first submission on behalf of HIV-infected haemophiliacs, the claim was for £15.5 million.

Ms Daly said the families were relieved that the decision had been made. "People could cope with having HIV and with dying but not with leaving their families without financial security," she said. The IHS would now be able to devote much more time to programmes for their members, who needed a lot of support and back-up. Most of the society's activities in the last three to four years had been devoted to the plight of HIV-infected haemophiliacs and their bid for compensation.

There are 300 haemophiliacs in Ireland and of the 103 who contracted the HIV virus, 20 have died, 21 have full-blown AIDS and two are terminally ill.

Irish Independent, 1 June 1991

Curb on blood imports

A CURB on blood imports is among new initiatives in a £5 million EC anti-AIDS programme, it emerged today.

The new three-year initiative will include attempts to ensure high quality condoms and more emphasis on health education.

The announcement comes as the number of confirmed AIDS cases across the EC has risen to 43,000 for the past year.

That represents a rise of 50 per cent - but some of the increase is due to the inclusion of the former East Germany with a population of 17 million and a considerable AIDS problem.

"The Community is to encourage each member state to mount new blood donor campaigns. This would cut down on blood imports which are a major cause of AIDS," an EC official said.

Figures released last week in Belgium show a blood import ban is effective. The number of haemophiliacs affected by the AIDS virus is just 5 per cent in Belgium compared to 50 per cent in France where blood imports are permitted.

The EC's new programme will also concentrate on ending discrimination against people who test

Evening Herald, 18 June 1991

Abdication

...stagging about assistance for haemophiliacs who are under the threat of AIDS has thrown into the political marketplace an issue that ought to have been resolved long ago with sensitivity, compassion and speed.

As it is, the debate in the Senate and Dáil has been allowed to drag on for months, though the central issue — whether the haemophiliacs' plight should be regarded as a special case and if so, how much should be set aside to meet it — was clear from the beginning.

But, having said quite properly that he could not be accountable for one sufferer more than another, the Minister for Health, Dr O'Hanlon, appeared last night to have abdicated responsibility for the decision: he is prepared to leave it up to the AIDS Fund, a voluntary group, to set up a trust fund to disburse such money as the State may provide from the National Lottery funds.

* * *

Dr O'Hanlon's immediate promise is to make £250,000 available to the AIDS Fund this year and to provide £50,000 for the counselling of haemophiliacs. He cannot, however, give any guarantees for the years ahead. The Opposition parties, which have been pressing for an annual State contribution of up to £400,000 for at least three years, are dissatisfied with this arrangement and seem to find the Minister's reasoning of methods of disbursement difficult to follow.

To get into arguments about degrees of innocence — as between those who contract the AIDS virus as a result of its transmission in blood products and, for instance, those born with it because their mot... been addicted to drugs...

Irish Times, 26 April 1989

Government defeated twice

Irish Times, 27 April 1989

Local election campaign by haemophiliacs

THE IRISH Haemophiliac Society is putting up four candidates in the local elections to protest at the Government's failure to offer adequate compensation for AIDS infected blood transfusions.

Friends of the Society have urged candidates to enter the political stage because of the "deafening silence" from Government on requests for a £13m compensation fund, offering £150,000 to each hae[illegible]iac affected.

... Society made a submission in January but have [illegible]ived no reply from [illegible]th Minister Dr O'Hanlon and a request for a [illegible]ting with the Taoiseach [illegible] gone unanswered.

Since then, two more [illegible]emophiliacs have died, [illegible]inging to 18 the number [illegible]f deaths of those who [illegible]ontracted the HIV virus from contaminated Factor 8 blood products.

Among the Dublin candidates are haemophiliac Joe Dowling from Artane and Mrs Gay McEvoy from Cabra whose husband Brendan died from an infected transfusion; Marie O'Connor from Clondalkin who is a carer of haemophiliac Jerome Stephens and Mic[illegible] Kirwan from Palmerstown whose son suffers from the clotting condition.

● Mr O'Hanlon: request

A group of 70 initiated a High Court action against the Department of Health and other State agencies. Difficulties arose over alleged delays in making the results of previous blood tests available from the Virus Reference Laboratory.

Last July, Dr Irene Hillery, director of the laboratory was directed by the High Court to make the records available subject to the payment of costs.

● Fine Gael will field 470 candidates in the council elections. Overall, there will be about 2,000 candidates for some 800 seats in 27 county and five city councils.

Irish Times, 8 July 1991

1992 - 1996
Death Toll from HIV

1992	3
1993	13
1994	10
1995	6
1996	3
Total	35
Total 1986-1996	56

Critical Illness Service


Rosemary Daly


Margaret King

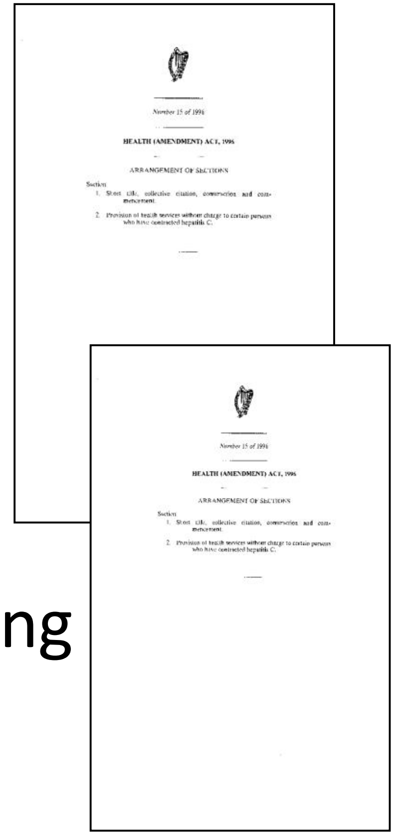

Margaret Dunne


Teresa Mulvey

1990-1995 : A new Virus emerges: Hepatitis C

- 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



Number 15 of 1996

HEALTH (AMENDMENT) ACT, 1996

ARRANGEMENT OF SECTIONS

Section

1. Short title, collective citation, construction and commencement.
2. Provision of health services without charge to certain persons who have contracted hepatitis C.

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HEALTH (AMENDMENT) ACT, 1996

ARRANGEMENT OF SECTIONS

Section

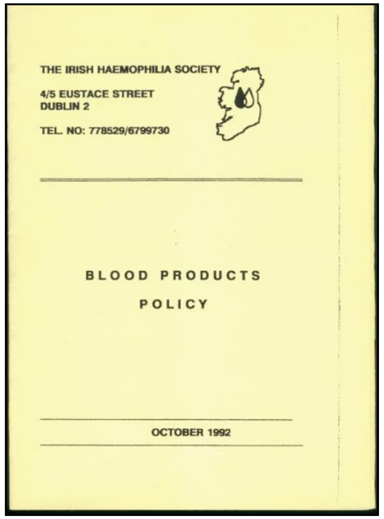
1. Short title, collective citation, construction and commencement.
2. Provision of health services without charge to certain persons who have contracted hepatitis C.

I.H.S. Office: 1991 - Eustace Street

1993

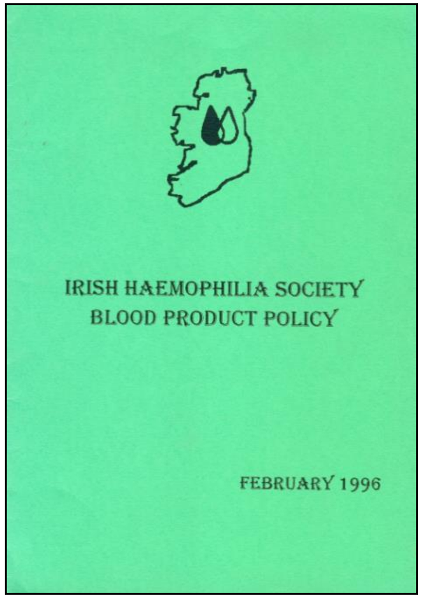
- Celebrated 25th Anniversary of I H S
- Videotape on 25th produced
- President Robinson attended AGM

1996 WFH World Congress


THE IRISH HAEMOPHILIA SOCIETY
4/5 EUSTACE STREET
DUBLIN 2
TEL. NO: 778529/6799730

BLOOD PRODUCTS
POLICY

OCTOBER 1992

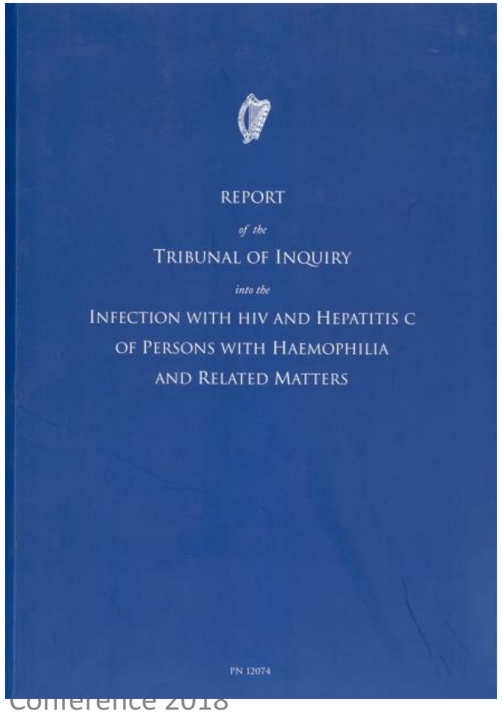

IRISH HAEMOPHILIA SOCIETY
BLOOD PRODUCT POLICY

FEBRUARY 1996

- 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

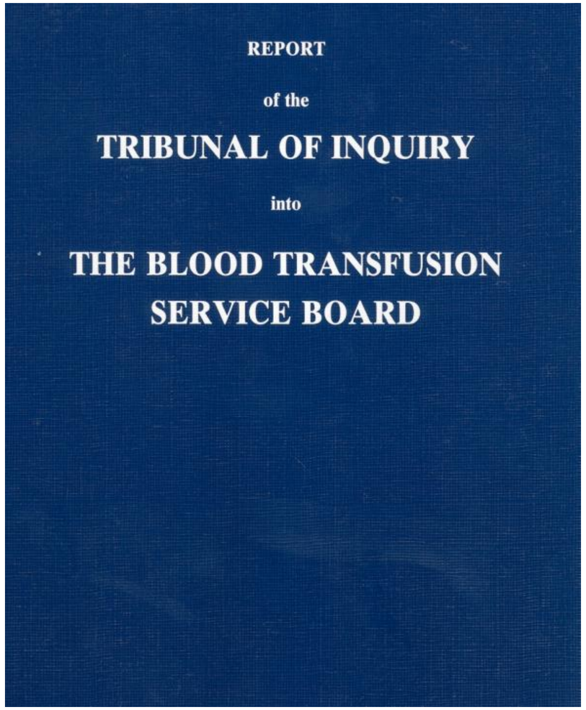
1997 – 2001 Tribunals of Inquiry

- 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**



REPORT
of the
TRIBUNAL OF INQUIRY
into the
INFECTION WITH HIV AND HEPATITIS C
OF PERSONS WITH HAEMOPHILIA
AND RELATED MATTERS

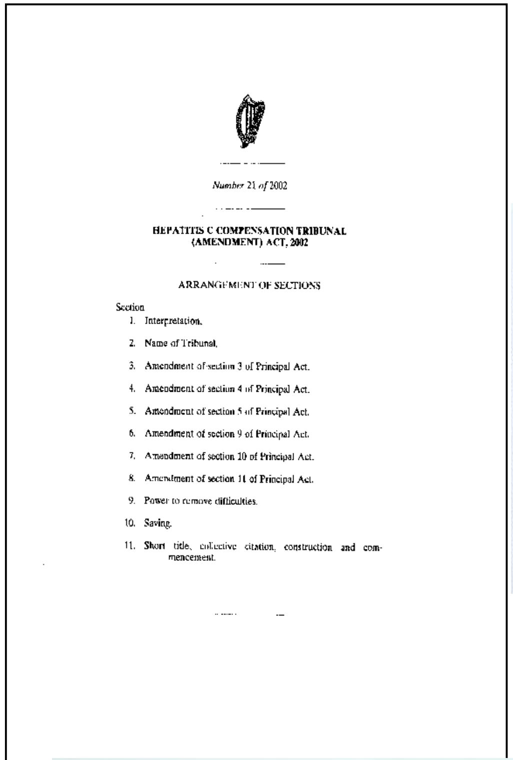
PN 12074



REPORT
of the
TRIBUNAL OF INQUIRY
into
THE BLOOD TRANSFUSION
SERVICE BOARD

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



Number 21 *of* 2002

HEPATITIS C COMPENSATION TRIBUNAL (AMENDMENT) ACT, 2002

ARRANGEMENT OF SECTIONS

Section
1. Interpretation.
2. Name of Tribunal.
3. Amendment of section 3 of Principal Act.
4. Amendment of section 4 of Principal Act.
5. Amendment of section 5 of Principal Act.
6. Amendment of section 9 of Principal Act.
7. Amendment of section 10 of Principal Act.
8. Amendment of section 11 of Principal Act.
9. Power to remove difficulties.
10. Saving.
11. Short title, collective citation, construction and commencement.

BTSB clotting agent caused infection

Dr Emer Lawlor, deputy medical director of the Irish Blood Transfusion Service, said "in all probability" the BTSB-made product infected a patient in Galway University Hospital in 1985 or earlier. Photograph: Pat Langan

***NIAMH KAVANAGH** reports on the private agonies of Ireland's haemophiliacs as the Lindsay Tribunal winds down. Many have lived and died heroically confronting their fear of Aids but too traumatised to even contemplate sharing their burden.*

IT IS the silence that haunts Peter Scallan, the silent anguish of the surviving haemophiliacs that are afraid to speak out. Haunted by the stigma of AIDS and the fear of isolation in lonely, rural communities, they have kept their stories quiet. Some have not even told their families that they are infected with HIV.

That is why he is speaking out about the death of his brother, John.

John Scallan was born in Wexford on February 11, 1960. He had severe haemophilia.

In 1987 he was told he had HIV. In 1994, aged just 34, he died from an AIDS related illness. He died because he contracted HIV and Hepatitis C from contaminated blood products.

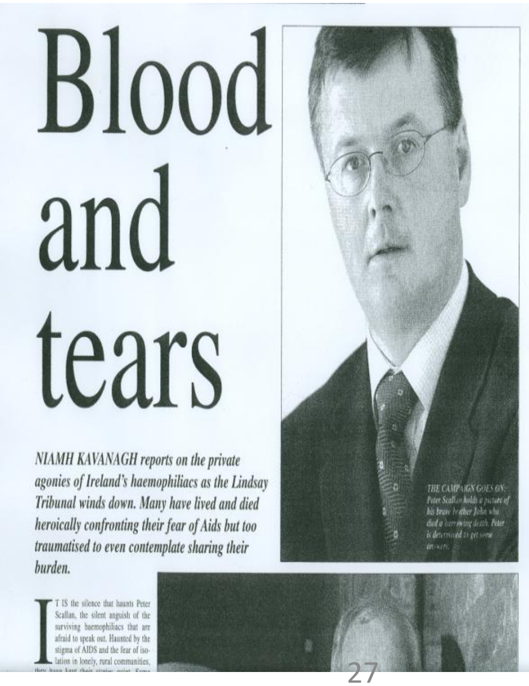
He didn't talk about his illness. A year before he died, he gave his solicitor a statement about his HIV litigation claim against the State.

Now his family wants anwers. Peter wants answers from the Lindsay Tribunal as to how his brother became infected with these diseases. He is furious at the tribunal's decision not to investigate the US manufacturers of blood products imported here and to seek disclosure of vital documents.

"I want to see the truth out. My mother broke down in tears the day the tribunal

THE CAMPAIGN GOES ON: Peter Scallan holds a picture of his brave brother John who died a harrowing death. Peter is determined to get some answers.

A CRUEL BLOW: Ray Kelly lost his vibrant son John



Blood and tears

NIAMH KAVANAGH reports on the private agonies of Ireland's haemophiliacs as the Lindsay Tribunal winds down. Many have lived and died heroically confronting their fear of Aids but too traumatised to even contemplate sharing their burden.

THE CAMPAIGN GOES ON: Peter Scallan holds a picture of his brave brother John who died a harrowing death. Peter is determined to get some answers.

IT IS the silence that haunts Peter Scallan, the silent anguish of the surviving haemophiliacs that are afraid to speak out. Haunted by the stigma of AIDS and the fear of isolation in lonely, rural communities,

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

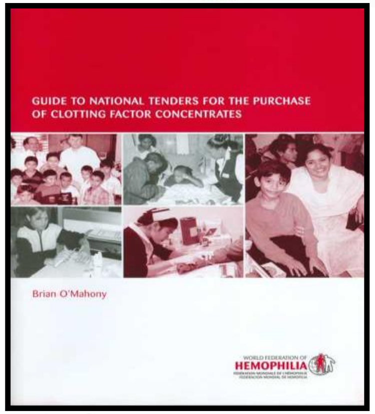
- 2002- Haemophilia Product selection and Monitoring Advisory Board (HPSMAB)

 - 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

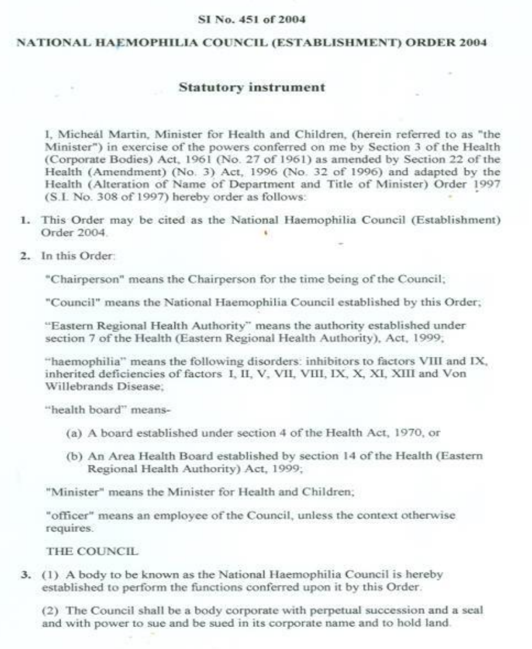


GUIDE TO NATIONAL TENDERS FOR THE PURCHASE OF CLOTTING FACTOR CONCENTRATES

Brian O'Mahony

WORLD FEDERATION OF HEMOPHILIA

NHC National Haemophilia Council



SI No. 451 of 2004

NATIONAL HAEMOPHILIA COUNCIL (ESTABLISHMENT) ORDER 2004

Statutory instrument

I, Micheál Martin, Minister for Health and Children, (herein referred to as "the Minister") in exercise of the powers conferred on me by Section 3 of the Health (Corporate Bodies) Act, 1961 (No. 27 of 1961) as amended by Section 22 of the Health (Amendment) (No. 3) Act, 1996 (No. 32 of 1996) and adapted by the Health (Alteration of Name of Department and Title of Minister) Order 1997 (S.I. No. 308 of 1997) hereby order as follows:

1. This Order may be cited as the National Haemophilia Council (Establishment) Order 2004.

2. In this Order:

"Chairperson" means the Chairperson for the time being of the Council;

"Council" means the National Haemophilia Council established by this Order;

"Eastern Regional Health Authority" means the authority established under section 7 of the Health (Eastern Regional Health Authority), Act, 1999;

"haemophilia" means the following disorders: inhibitors to factors VIII and IX, inherited deficiencies of factors I, II, V, VII, VIII, IX, X, XI, XIII and Von Willebrands Disease;

"health board" means-

(a) A board established under section 4 of the Health Act, 1970, or

(b) An Area Health Board established by section 14 of the Health (Eastern Regional Health Authority) Act, 1999;

"Minister" means the Minister for Health and Children;

"officer" means an employee of the Council, unless the context otherwise requires.

THE COUNCIL

3. (1) A body to be known as the National Haemophilia Council is hereby established to perform the functions conferred upon it by this Order.

(2) The Council shall be a body corporate with perpetual succession and a seal and with power to sue and be sued in its corporate name and to hold land.

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

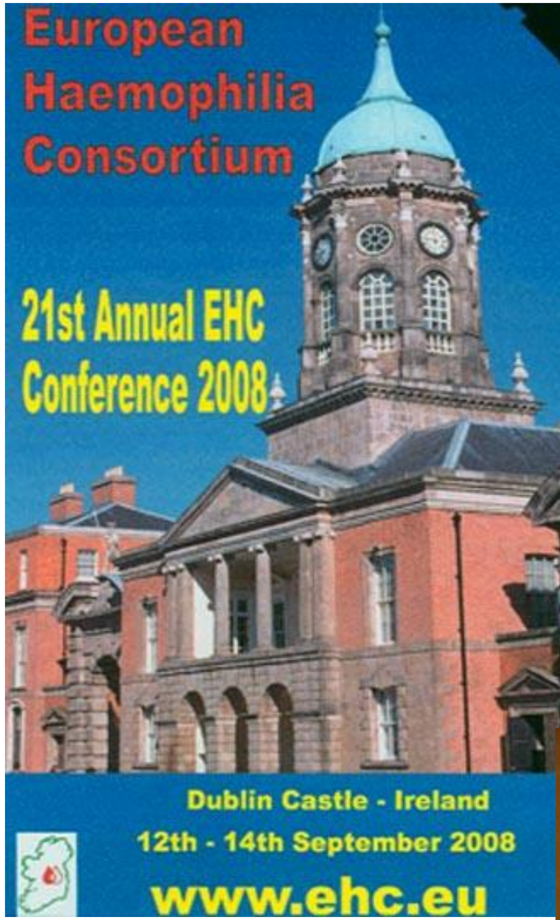
National Haemophilia Council

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


European Haemophilia Consortium

21st Annual EHC Conference 2008

Dublin Castle - Ireland

12th - 14th September 2008

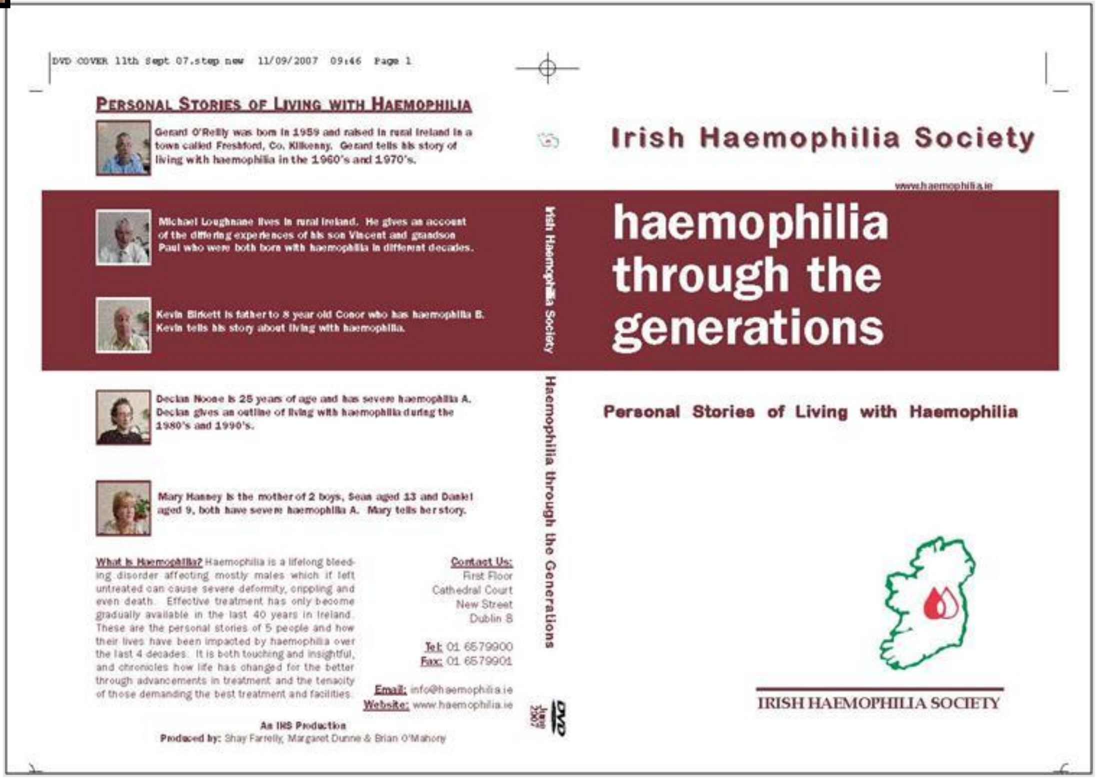
www.ehc.eu

KIDLINK PROGRAMME

40th Anniversary AGM 2008

The Park Plaza Hotel,
Tyrrelstown, Dublin 15

29th February, 1st & 2nd March



DVD COVER 11th Sept 07.step new 11/09/2007 09:46 Page 1

PERSONAL STORIES OF LIVING WITH HAEMOPHILIA

Gerard O'Reilly was born in 1959 and raised in rural Ireland in a town called Freshford, Co. Kilkenny. Gerard tells his story of living with haemophilia in the 1960's and 1970's.

Michael Loughnane lives in rural Ireland. He gives an account of the differing experiences of his son Vincent and grandson Paul who were both born with haemophilia in different decades.

Kevin Birkett is father to 8 year old Conor who has haemophilia B. Kevin tells his story about living with haemophilia.

Declan Noone is 25 years of age and has severe haemophilia A. Declan gives an outline of living with haemophilia during the 1980's and 1990's.

Mary Hanney is the mother of 2 boys, Sean aged 13 and Daniel aged 9, both have severe haemophilia A. Mary tells her story.

What is Haemophilia? Haemophilia is a lifelong bleeding disorder affecting mostly males which if left untreated can cause severe deformity, crippling and even death. Effective treatment has only become gradually available in the last 40 years in Ireland. These are the personal stories of 5 people and how their lives have been impacted by haemophilia over the last 4 decades. It is both touching and insightful, and chronicles how life has changed for the better through advancements in treatment and the tenacity of those demanding the best treatment and facilities.

Contact Us:
First Floor
Cathedral Court
New Street
Dublin 8

Tel: 01 6579900
Fax: 01 6579901

Email: info@haemophilia.ie
Website: www.haemophilia.ie

An IHS Production
Produced by: Shay Farrelly, Margaret Dunne & Brian O'Mahony

Irish Haemophilia Society through the Generations

DVD June 2007

Irish Haemophilia Society

www.haemophilia.ie

haemophilia through the generations

Personal Stories of Living with Haemophilia

IRISH HAEMOPHILIA SOCIETY

2007: Finally…our own HQ

XX1 - V1

Irish Examiner
Friday 15.06.2007

NEWS 9

Haemophilia headquarters after 40 years

by Evelyn Ring

AFTER almost 40 years the Irish Haemophilia Society that championed the rights of haemophiliacs caught up in the blood contamination scandal has permanent headquarters.

President Mary McAleese, who opened the new offices in Dublin's Liberties yesterday, said it was a "landmark day" for both members and supporters of the society.

The day was more than tinged with sadness, however, because of lives lost and damaged by infected blood products used to treat people with haemophilia between the mid-1970s and 1991.

Infected blood products were
responsible for infe since
haemophiliacs with had
220 with hepatitis HIV
have been 91 deaths. lt of

The society plans blood
permanent memoria
people who have diers we
new offices. using

President McAleeat are
those who had died wod or
be honoured by th
worked in the new relief
ters. com-

"It is through the now
ried out here that a n than
ter future will be cr past.
our citizens with ha to be
and related bleeding d s in
she said.

The society plays a tional
tant role in shaping ha NHC)
ia treatment policy a who
might have received HIV or hepatitis C before 1992 to come forward to be tested for the viruses.

Mr O'Mahony said one person who had contracted hepatitis C prior to 1991, but had not been diagnosed or identified, came forward.

There are about 450 people with haemophilia in Ireland and more than a 180 regularly attend the society's annual meetings.

The society also has a very active children's and teenagers' programme for up to 100 of its younger members.

- ● www.haemophilia-society.ie
- ● www.nationalhaemphilia-council.ie

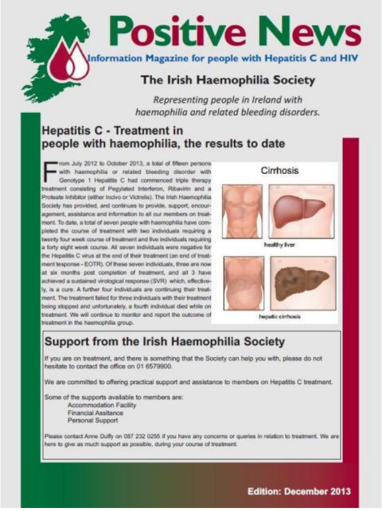
President Mary McAleese with Luz Maria Heaney and Conor Birkett at the opening of the Irish Haemophilia Society office yesterday.

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.



Positive News

Information Magazine for people with Hepatitis C and HIV

The Irish Haemophilia Society

Representing people in Ireland with haemophilia and related bleeding disorders.

Hepatitis C - Treatment in people with haemophilia, the results to date

From July 2012 to October 2013, a total of fifteen persons with haemophilia or related bleeding disorder with Genotype 1 Hepatitis C had commenced triple therapy treatment consisting of Pegylated Interferon, Ribavirin and a Proteate Inhibitor (either Incivo or Victrelis). The Irish Haemophilia Society has provided, and continues to provide, support, encouragement, assistance and information to all our members on treatment. To date, a total of seven people with haemophilia have completed the course of treatment with two individuals requiring a twenty four week course of treatment and five individuals requiring a forty eight week course. All seven individuals were negative for the Hepatitis C virus at the end of their treatment (an end of treatment response - EOTR). Of these seven individuals, three are now at six months post completion of treatment, and all 3 have achieved a sustained virological response (SVR) which, effectively, is a cure. A further four individuals are continuing their treatment. The treatment failed for three individuals with their treatment being stopped and unfortunately, a fourth individual died while on treatment. We will continue to monitor and report the outcome of treatment in the haemophilia group.

Support from the Irish Haemophilia Society

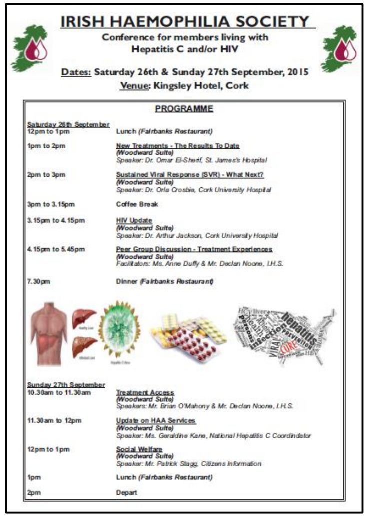
If you are on treatment, and there is something that the Society can help you with, please do not hesitate to contact the office on 01 6579900.

We are committed to offering practical support and assistance to members on Hepatitis C treatment.

Some of the supports available to members are:
  Accommodation Facility
  Financial Assitance
  Personal Support

Please contact Anne Duffy on 087 232 0255 if you have any concerns or queries in relation to treatment. We are here to give as much support as possible, during your course of treatment.

Edition: December 2013



IRISH HAEMOPHILIA SOCIETY

Conference for members living with Hepatitis C and/or HIV

Dates: Saturday 26th & Sunday 27th September, 2015
Venue: Kingsley Hotel, Cork

PROGRAMME

Saturday 26th September	
12pm to 1pm	Lunch *(Fairbanks Restaurant)*
1pm to 2pm	New Treatments - The Results To Date *(Woodward Suite)* *Speaker: Dr. Omar El-Sherif, St. James's Hospital*
2pm to 3pm	Sustained Viral Response (SVR) - What Next? *(Woodward Suite)* *Speaker: Dr. Orla Crosbie, Cork University Hospital*
3pm to 3.15pm	Coffee Break
3.15pm to 4.15pm	HIV Update *(Woodward Suite)* *Speaker: Dr. Arthur Jackson, Cork University Hospital*
4.15pm to 5.45pm	Peer Group Discussion - Treatment Experiences *(Woodward Suite)* *Facilitators: Ms. Anne Duffy & Mr. Declan Noone, I.H.S.*
7.30pm	Dinner *(Fairbanks Restaurant)*
Sunday 27th September	
10.30am to 11.30am	Treatment Access *(Woodward Suite)* *Speakers: Mr. Brian O'Mahony & Mr. Declan Noone, I.H.S.*
11.30am to 12pm	Update on HAA Services *(Woodward Suite)* *Speaker: Ms. Geraldine Kane, National Hepatitis C Coordindator*
12pm to 1pm	Social Welfare *(Woodward Suite)* *Speaker: Mr. Patrick Stagg, Citizens Information*
1pm	Lunch *(Fairbanks Restaurant)*
2pm	Depart

Haemophiliacs seek access to new treatment

Group says 350 Hepatitis C patients urgently need new therapies to stay alive

The Irish Haemophilia Society has called for early access to new treatments for 350 seriously ill patients with Hepatitis C. Photograph: Andrew Matthews/PA Wire

Paul Cullen

Topics: News Health Brian O Mahony Deirdre Mulholland Paul Cullen Suzanne Norris Department of Health

Mon, Sep 15, 2014, 13:19

The Irish Haemophilia Society has called for early access to new treatments for 350 seriously ill patients with Hepatitis C.

It says this group cannot medically tolerate the current Interferon-based treatments

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Call for early access to Hepatitis C treatments

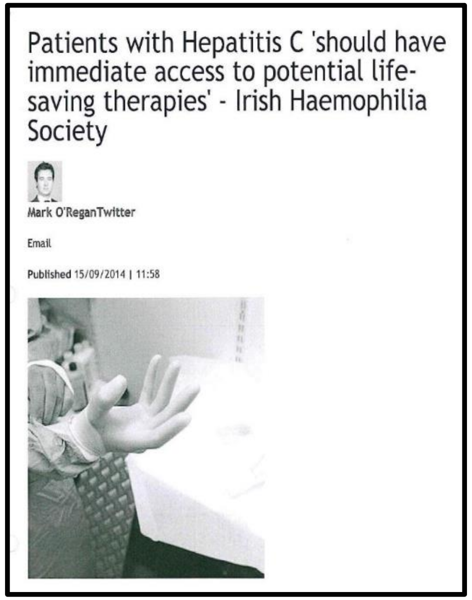
Monday 15 September 2014 21.41

More than 260 people with haemophilia were infected with the virus from contaminated blood products

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.

ate the current Interferon treatment, due to risk of death.

ho need Hepatitis C treatment, 350 have been be in need of urgent treatment.



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

Mark O'ReganTwitter

Email

Published 15/09/2014 | 11:58

Tuesday 16 September 2014

New 'life saving' drugs for Hep C sufferers

Mark O'Regan
EMAIL

PUBLISHED
16/09/2014 | 02:30

Brian O'Mahony, Irish Haemophilia Society Chief Executive.

New "life saving" drugs which cost €45,000 per patient, and have a 95pc 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 as a once-off treatment.

It is estimated 350 patients require these special treatments because they cannot tolerate the existing treatment care system. In some cases this is causing severe liver damage, which can be life-threatening. A total of 12,365 people in Ireland need Hepatitis C treatment

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

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Irish Independent
Tuesday 16 September 2014

New 'life saving' drugs for Hep C sufferers

Mark O'Regan

NEW "life saving" drugs which cost €45,000 per patient, and have a 95pc success rate, should be made available to Hepatitis C sufferers with only months to live.

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Brian O'Mahony, the society's chief executive, said new licensed drugs on the market should be provided to the most severe sufferers "as a matter of urgency".

"The sickest 3pc are in great risk of death within 12 months without the treatment," he told the *Irish Independent*.

Hep C patients 'will die without new therapies'

HUNDREDS of hepatitis C sufferers face liver failure or death within 12 months – unless they get access to new therapies.

The CEO of the Irish Haemophilia Society said the clock was ticking 'very loudly' for 350 people who cannot tolerate their Interferon-based drugs.

Brian O'Mahony has now called on Health Minister Leo Varadkar and the HSE to provide early access to the new treatments, which cost around €45,000 and are administered as a one-off.

There are 12,365 patients here who need hepatitis C treatment, 350 of whom need immediate care.

'What we're worried about at the moment is the 350 people who urgently need treatment,' said Mr O'Mahony. 'Otherwise they face a very significant chance of death or liver failure or the requirement of liver transplant in the next year. They can't wait.'

Interferon-based therapies can cause severe liver damage and can increase the risk of death if a patient uses them for a long period of time.

Mr O'Mahony said the State can save €10.5million if the decision to provide treatment is taken before the end of October when one of the two new drugs is licensed.

Call for early access to Hepatitis C treatments

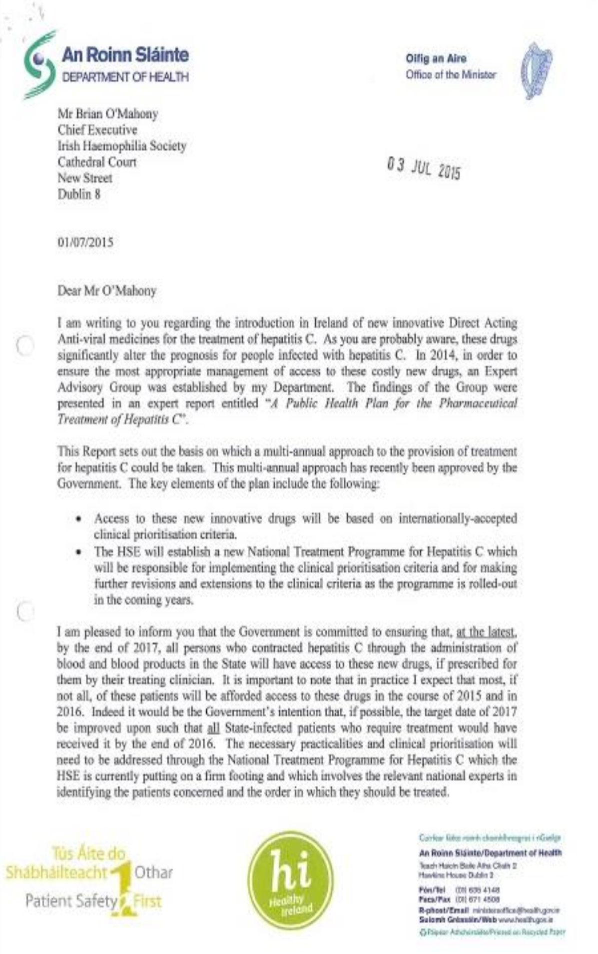
Monday 15 September 2014 21.41

More than 260 people with haemophilia were infected with the virus from contaminated blood products

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 not medically tolerate the current Interferon treatment, due to severe liver damage that increases their risk of death.

The society said of the 12,365 patients who need Hepatitis C treatment, 350 have been identified by specialist hepatologists to be in need of urgent treatment.


An Roinn Sláinte
DEPARTMENT OF HEALTH

Oifig an Aire
Office of the Minister

Mr Brian O'Mahony
Chief Executive
Irish Haemophilia Society
Cathedral Court
New Street
Dublin 8

03 JUL 2015

01/07/2015

Dear Mr O'Mahony

I am writing to you regarding the introduction in Ireland of new innovative Direct Acting Anti-viral medicines for the treatment of hepatitis C. As you are probably aware, these drugs significantly alter the prognosis for people infected with hepatitis C. In 2014, in order to ensure the most appropriate management of access to these costly new drugs, an Expert 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 Pharmaceutical Treatment of Hepatitis C*".

This Report sets out the basis on which a multi-annual approach to the provision of treatment for hepatitis C could be taken. This multi-annual 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 clinical prioritisation criteria.
- 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 revisions and extensions to 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 ensuring that, at the latest, by the end of 2017, all persons who contracted hepatitis C through the administration of blood and blood products in the State will have access to these new drugs, if prescribed for them by their treating clinician. It is important to note that in practice I expect that most, if not all, of these patients will be afforded access to these drugs in the course of 2015 and in 2016. Indeed it would be the Government's intention that, if possible, the target date of 2017 be improved upon such that all State-infected patients who require treatment would have received it by the end of 2016. The necessary practicalities and clinical prioritisation will need to be addressed through the National Treatment Programme for Hepatitis C which the HSE is currently putting on a firm footing and which involves the relevant national experts in identifying the patients concerned and the order in which they should be treated.

An Roinn Sláinte/Department of Health

Hepatitis C in Irish haemophilia population 'eradicated'

Updated / Dec. 22, 2016 **10:59**

Over a 20-year period, 240 people with haemophilia in Ireland were infected with Hepatitis C by blood products

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Press Release

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

22.12.2016

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

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/pc

  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

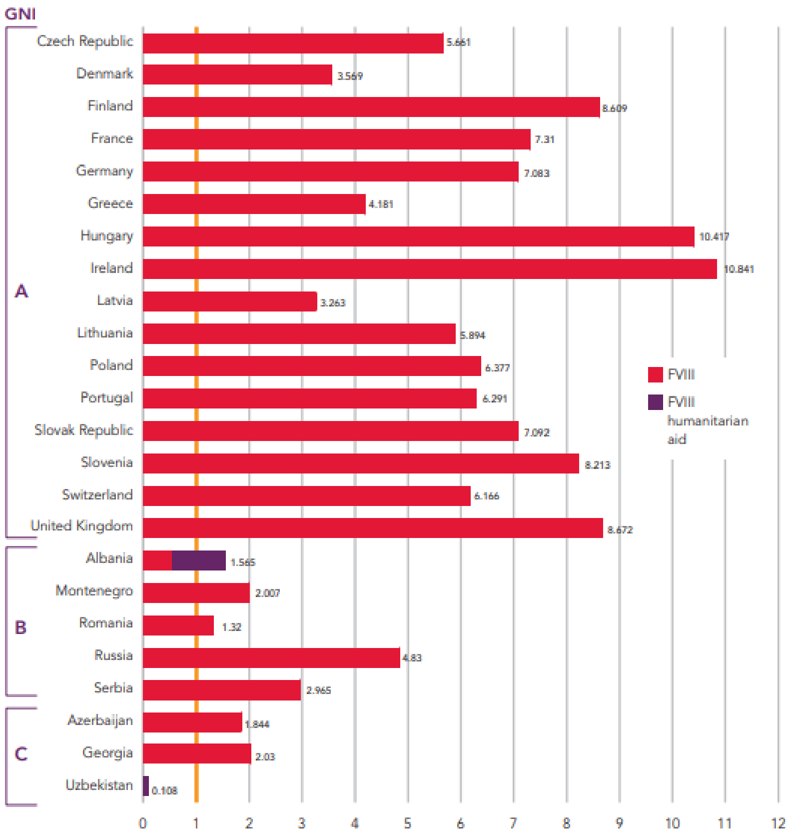
- New comprehensive care centre in Cork, 2010
- New in-patient H and H unit Dublin, 2013
- New National Coagulation centre, St. James's, 2017

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

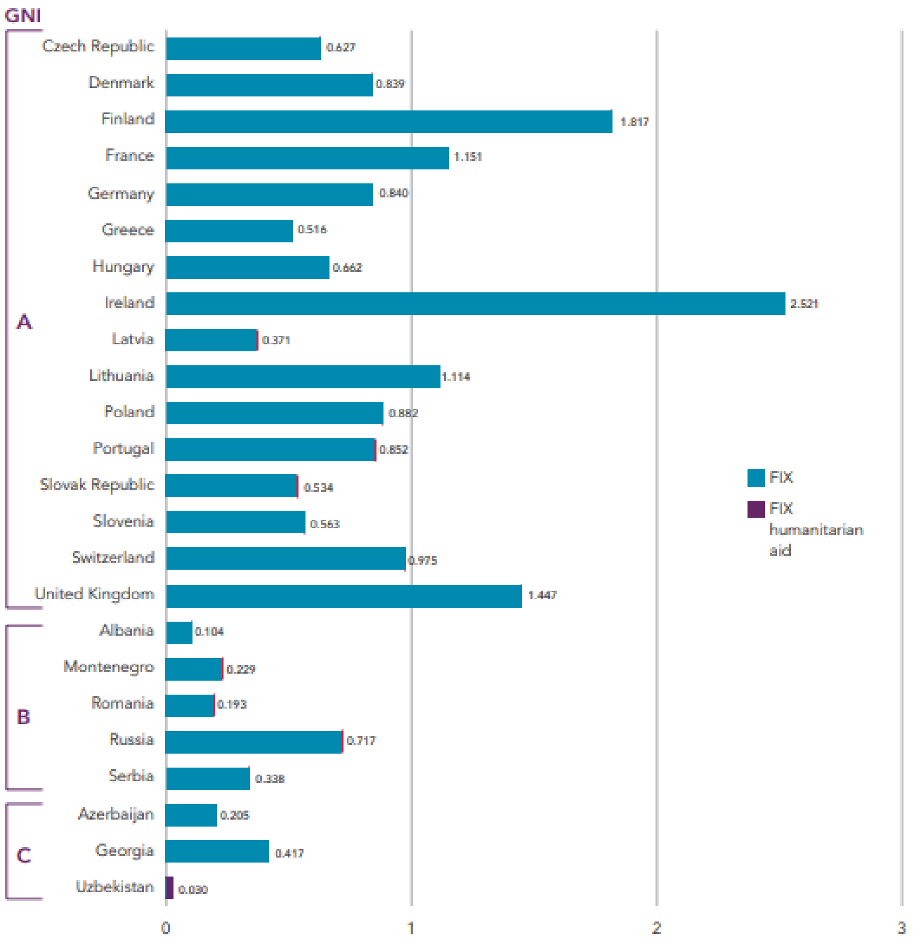
Figure C4a. Mean per capita factor VIII use in 2016 – regional and GNI comparisons of IU/total population: Europe



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, $0-$1,005; C lower middle income, $1,006 - $3,955; B upper middle income, $3,956 - $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 VIII. The WFH has established that one international unit (IU) of FVIII 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.

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



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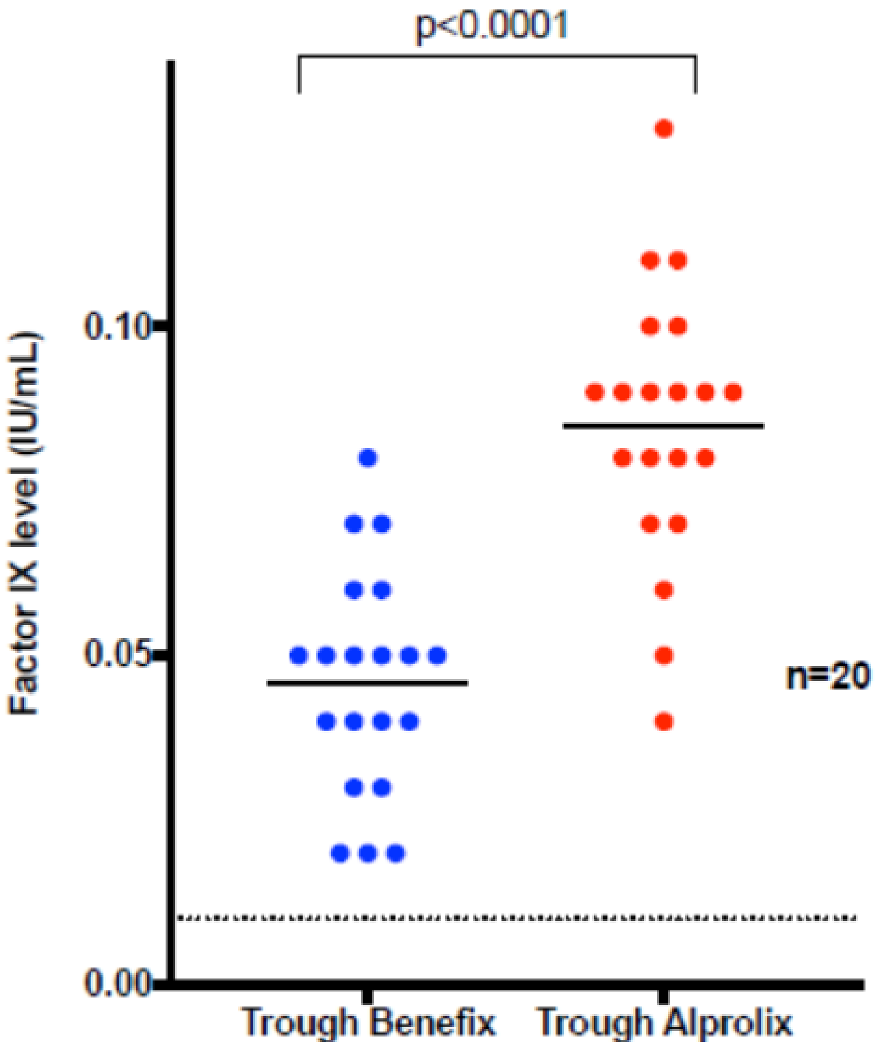
PLEASE NOTE: The X axis showing the number of IU/capita is different in each graph. Only countries that completed the 2016 questionnaire are included in these charts.

FIX trough levels 2017: Switch to EHL FIX



FVIII Tender Ireland 2017: First country to switch entirely to EHL FVIII and FIX

CRITERIA		
SAFETY	Human Albumin in Culture Medium	5 - 15
	Additional Human or Animal Protein (e.g. monoclonal antibodies)	3 - 7
	Viral Inactivation	10 - 20
	Inhibitors	20 - 40
	Prion Removal	3 - 7
	Other Adverse Events	5 - 15
	Other Safety Concerns	10 - 20
	Total for Safety	**56 - 124**
EFFICACY	Pk (Half Life / Time to trough of 3%/ AUC)	20 - 60
	Data in relation to ability to infuse prophylactically twice per week	5 - 15
	Recovery	10 - 20
	Clinical Response (adult/paediatric)	10 – 20
	Total for Efficacy	**45 - 115**
QUALITY	Stability	3 - 10
	Volume of Administration	3 - 10
	Instructions for Use & Handling	3 - 5
	Ease of Administration	3 - 5
	Application of Unique Bar-Code	3 - 5
	Total for Quality	15 - 35
SECURITY OF SUPPLY & AVAILABILITY	Number of Manufacturing Plants	5 - 10
	Security of Supply	10 -20
	Supply/ Availability	15 - 30
Total Scores Awarded: Phase 1		131 - 304

Phase 2

COST	25 – 75
Rebate 4%	10 - 20
Total Scores Awarded:	166 - 399

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

Confirmed 4/8

John Smith

All scanned products are your product of choice:
Advate

All scanned products are in date:
Today is 17/01/2014

☐ Retrospective Treatment

Set date

26 Feb 2013

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

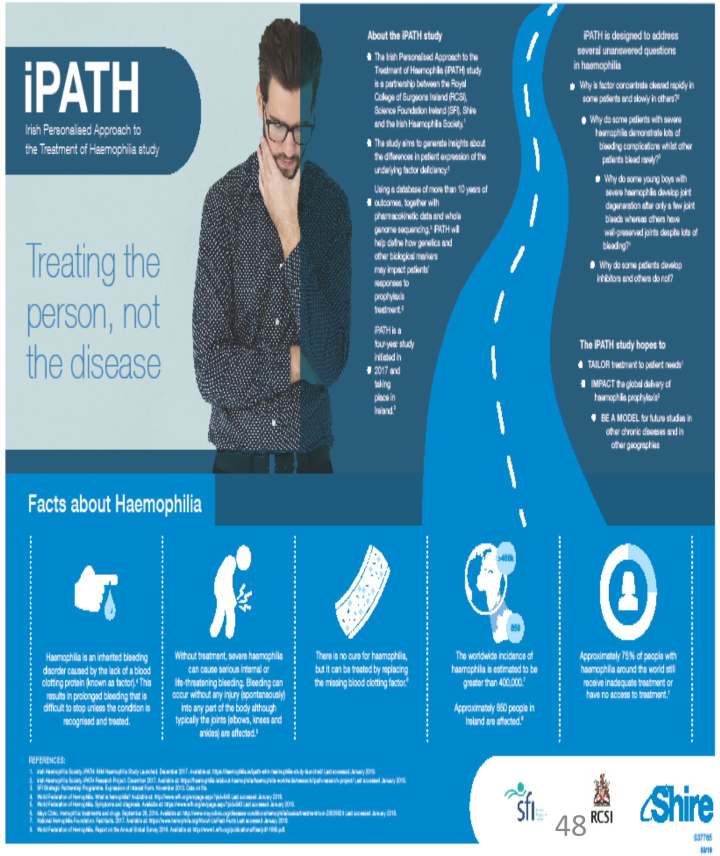
1. Why is factor concentrate cleared rapidly from the blood in some patients and slowly in other patients ?
2. Why do some patients with severe haemophilia demonstrate lots of bleeding complications whilst other patients bleed rarely ?
3. Why do some young boys with severe haemophilia develop joint degeneration 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 ?

€4m haemophilia treatment study to be launched

Updated / Monday, 4 Dec 2017 **11:39**

Study is open to children and adults wi
moderate to severe haemophilia

A €4 million four-year long study tha
to develop personalised treatments
people with haemophilia will be lau



About the iPATH study

- The Irish Personalised Approach to the Treatment of Haemophilia (iPATH) study is a partnership between the Royal College of Surgeons Ireland (RCSI), Science Foundation Ireland (SFI), Shire and the Irish Haemophilia Society.[1]
- The study aims to generate insights about the differences in patient expression of the underlying factor deficiency.[2]
- Using a database of more than 10 years of outcomes, together with pharmacokinetic data and whole genome sequencing,[3] iPATH will help define how genetics and other biological markers may impact patients' responses to prophylaxis treatment.[2]
- iPATH is a four-year study initiated in 2017 and taking place in Ireland.[3]

iPATH is designed to address several unanswered questions in haemophilia

- Why is factor concentrate cleared rapidly in some patients and slowly in others?[2]
- Why do some patients with severe haemophilia demonstrate lots of bleeding complications whilst other patients bleed rarely?[2]
- Why do some young boys with severe haemophilia develop joint degeneration after only a few joint bleeds whereas others have well-preserved joints despite lots of bleeding?[1]
- Why do some patients develop inhibitors and others do not?

The iPATH study hopes to

- TAILOR treatment to patient needs[1]
- IMPACT the global delivery of haemophilia prophylaxis[3]
- BE A MODEL for future studies in other chronic diseases and in other geographies

Facts about Haemophilia

Haemophilia is an inherited bleeding disorder caused by the lack of a blood clotting protein (known as factor).[4] This results in prolonged bleeding that is difficult to stop unless the condition is recognised and treated.

Without treatment, severe haemophilia can cause serious internal or life-threatening bleeding. Bleeding can occur without any injury (spontaneously) into any part of the body although typically the joints (elbows, knees and ankles) are affected.[5]

There is no cure for haemophilia, but it can be treated by replacing the missing blood clotting factor.[6]

The worldwide incidence of haemophilia is estimated to be greater than 400,000.[7]

Approximately 850 people in Ireland are affected.[8]

Approximately 75% of people with haemophilia around the world still receive inadequate treatment or have no access to treatment.[7]

REFERENCES:

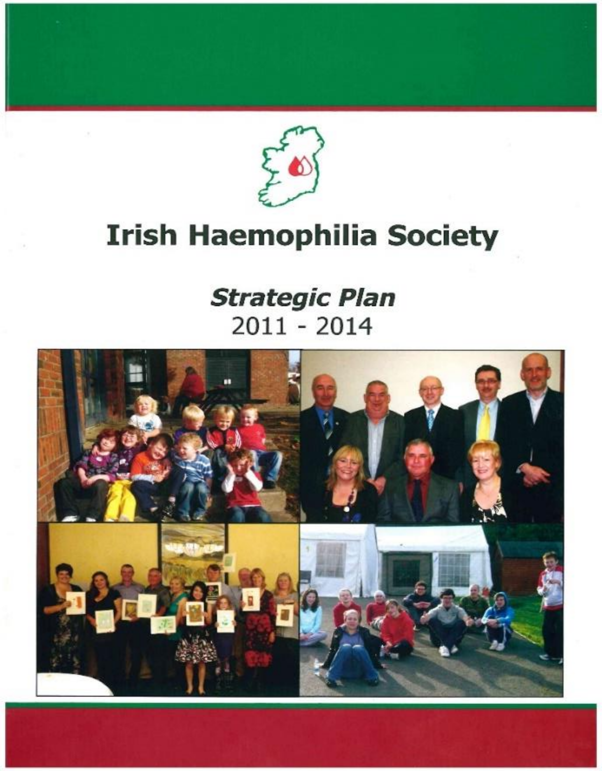
Global Contribution

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

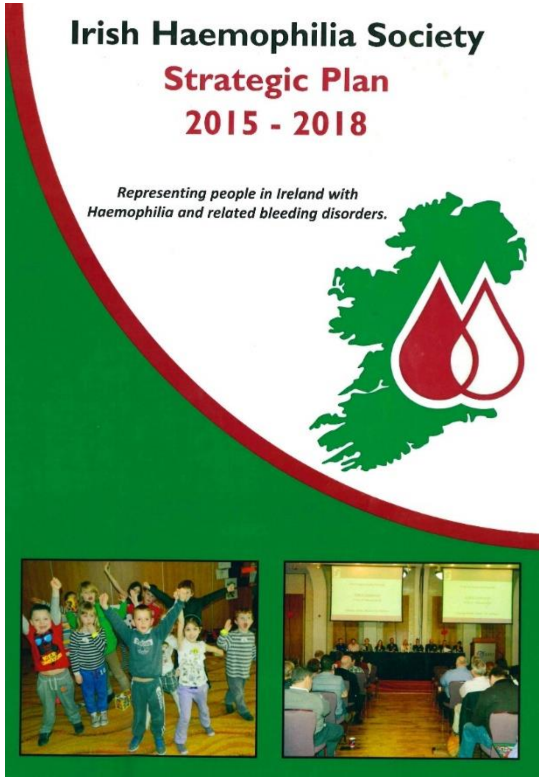
Strategic plan 2011-2014



Irish Haemophilia Society

Strategic Plan
2011 - 2014

Strategic Plan 2015-2018



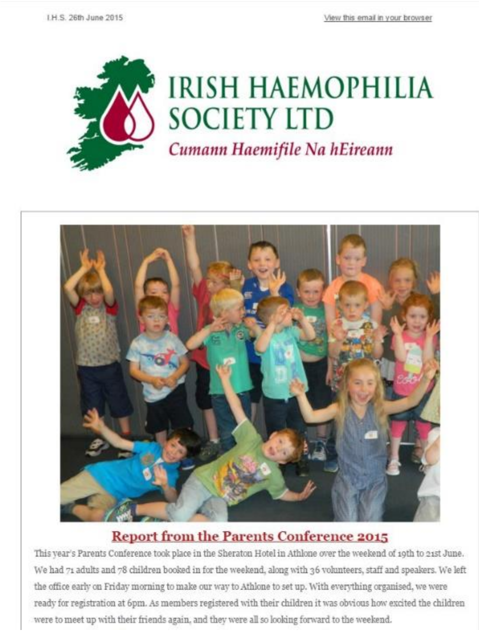
Irish Haemophilia Society
Strategic Plan
2015 - 2018

Representing people in Ireland with Haemophilia and related bleeding disorders.

Conferences

Education / Activities for Kids and Teens

Publications


I.H.S. 26th June 2015

View this email in your browser

IRISH HAEMOPHILIA SOCIETY LTD
Cumann Haemifile Na hEireann

Report from the Parents Conference 2015

This year's Parents Conference took place in the Sheraton Hotel in Athlone over the weekend of 19th to 21st June. We had 71 adults and 78 children booked in for the weekend, along with 36 volunteers, staff and speakers. We left the office early on Friday morning to make our way to Athlone to set up. With everything organised, we were ready for registration at 6pm. As members registered with their children it was obvious how excited the children were to meet up with their friends again, and they were all so looking forward to the weekend.

Website & Social Media

get your registration form back to us asap as bookings are taken on a first come first served

Welcome to haemophilia.ie

The Irish Haemophilia Society represents the interests of people with haemophilia, von Willebrand's disease and other inherited bleeding disorders. We provide information, education, publications, outreach and support, advocacy, hospital and home visits and conferences and events for people with

New HIV cases in injecting drug users more than doubled in 2015

A new campaign is being launched this morning which

Private Group

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

Severe Bleeding Disorder Alert Card

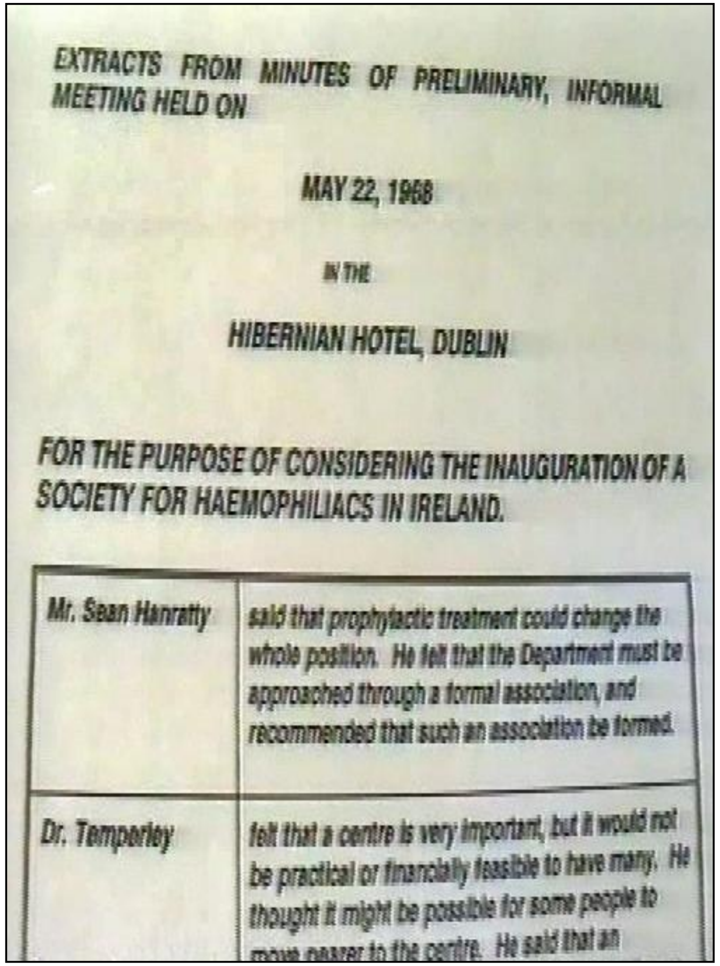
ST. JAMES'S HOSPITAL
James's St. Dublin 8. Ireland.

NHC National Haemophilia Council

“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



EXTRACTS FROM MINUTES OF PRELIMINARY, INFORMAL MEETING HELD ON

MAY 22, 1968

IN THE

HIBERNIAN HOTEL, DUBLIN

FOR THE PURPOSE OF CONSIDERING THE INAUGURATION OF A SOCIETY FOR HAEMOPHILIACS IN IRELAND.

Mr. Sean Hanratty	said that prophylactic treatment could change the whole position. He felt that the Department must be approached through a formal association, and recommended that such an association be formed.
Dr. Temperley	felt that a centre is very important, but it would not be practical or financially feasible to have many. He thought it might be possible for some people to move nearer to the centre. He said that an

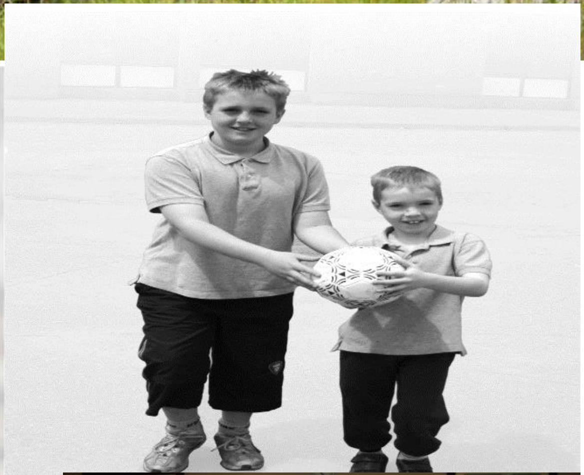
50th Anniversary: Conferences

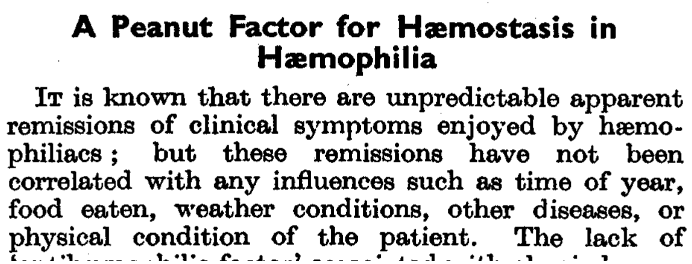
- AGM/Annual conference
- Members Conference
- Ageing
- Carriers
- von Willebrand’s
- Haemophilia B
- Mild Haemophilia
- Father and Son event
- Mother and Daughter event
- Inhibitor summit

I H S Staff team

I H S Board

I.H.S. Volunteers





ANIMAL PHYSIOLOGY

A Peanut Factor for Hæmostasis in Hæmophilia

It is known that there are unpredictable apparent remissions of clinical symptoms enjoyed by hæmophiliacs; 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

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