



History of the Irish Haemophilia Society 1968 to 1982



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



THE IRISH TIMES, FRIDAY, NOVEMBER 10, 1967

To Editor, The Irish Times,
—Yours, etc.,
DALE F. GIBB,
2123 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 not so many haemophiliacs can begin to know





1968

- First meeting in April – Professor Ian Findlay, Dr. Liam O Connell, Dr. Ian Temperley, Dr. Jack O Riordan, Mr. Sean Hanratty
- Inaugural meeting of Society: 7th October 1968
- Lecture at conference on “*The helplessness of the Haemophiliac*”
- Meetings at Irish Cancer Society, until mid 1980’s
 - Origins of Society Christmas Cards
- Department of Health (DOH): 58 boys with haemophilia - “not practical to have a centre”



**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.**

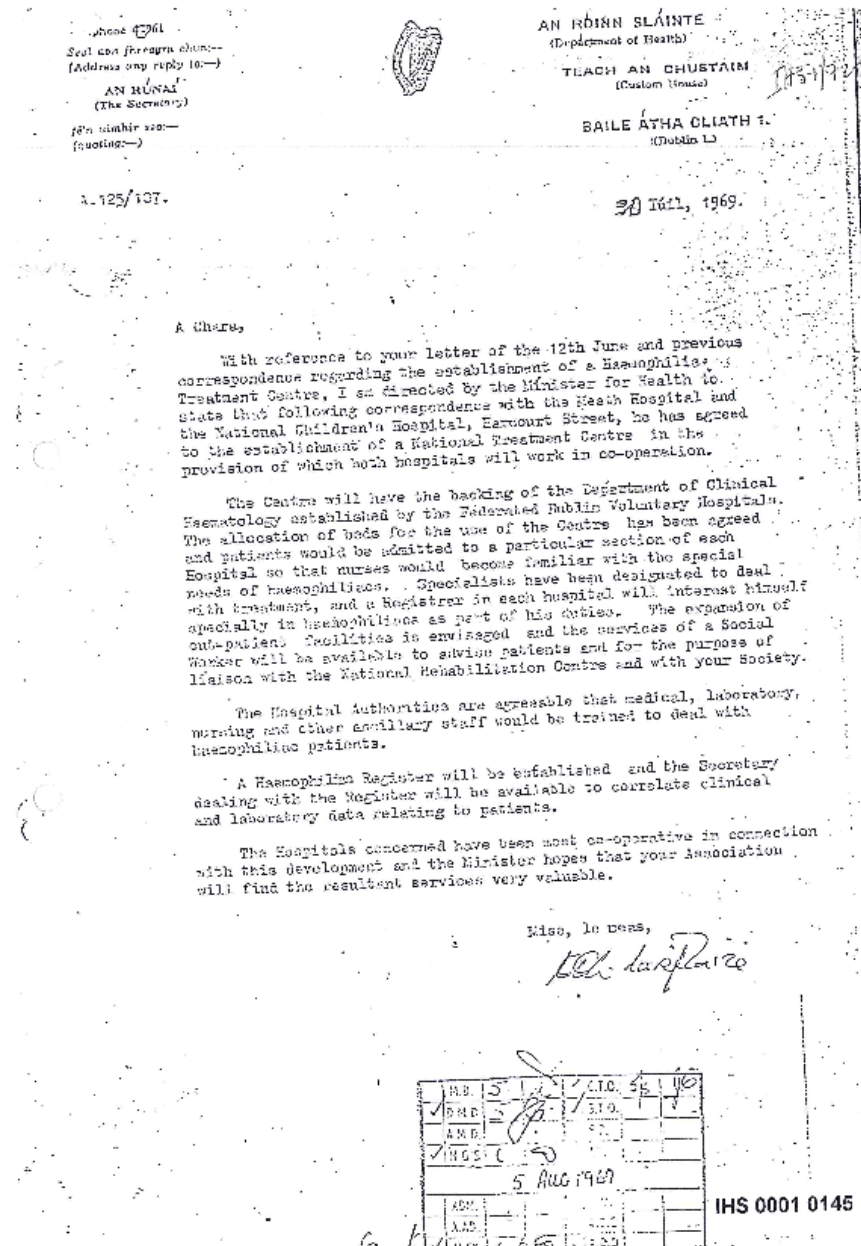
Mr. Sean Hanratty	said that prophylactic treatment could change the whole position. He felt that the Department must be approached through a formal association, and recommended that such an association be formed.
Dr. Temperley	felt that a centre is very important, but it would not be practical or financially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





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- **Chairperson**: Eithne Scallan (1969-1972)
- Society recommends setting up a National Centre
- Centre approved by DOH in July
 - Meath Hospital
 - Harcourt Street (children)
- Mailing list – 108 PWH
- First AGM
- Joined WFH
- Cryoprecipitate available



1970

- First Newsletter
- Free treatment - 1970 Health Act
- Swimming pool access
- Visit to Zoo
- Priority - education and extra home tuition as required
- 120 PWH on register

The Irish Haemophilia Society
Cumann Haemifile na hEirinn

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. 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 areas, possibly leading later to the establishment of branches of the Society around the country.

Free Medical Treatment: The committee is continuing to negotiate with the Department of Health in an effort to ensure free medical treatment for all haemophiliacs, and it would be most helpful if we could be supplied with further data in the form of details from members who have had problems in regard to cost of treatment, facilities for payment, health insurance, etc. Please write to the secretary if you have had any difficulties of this kind - your name will not, of course, appear in any reports which may be prepared.

Education: It is hoped to consider the problems surrounding education of haemophiliacs as our project for 1970, and again it would be extremely helpful if haemophiliacs or parents could send the secretary details of difficulties concerning education - such as lack of understanding, lack of transport facilities, child's inability to keep up in class, psychological difficulties, etc. We need all the material we can get in order to do something worthwhile about the problem.

Please do write to us if you have any questions, or any suggestions as to how we can help with your problems.

IHS 0001 0044



First Treatment Centre - Meath Hospital, 1970



Children's Centre - Harcourt Street Hospital





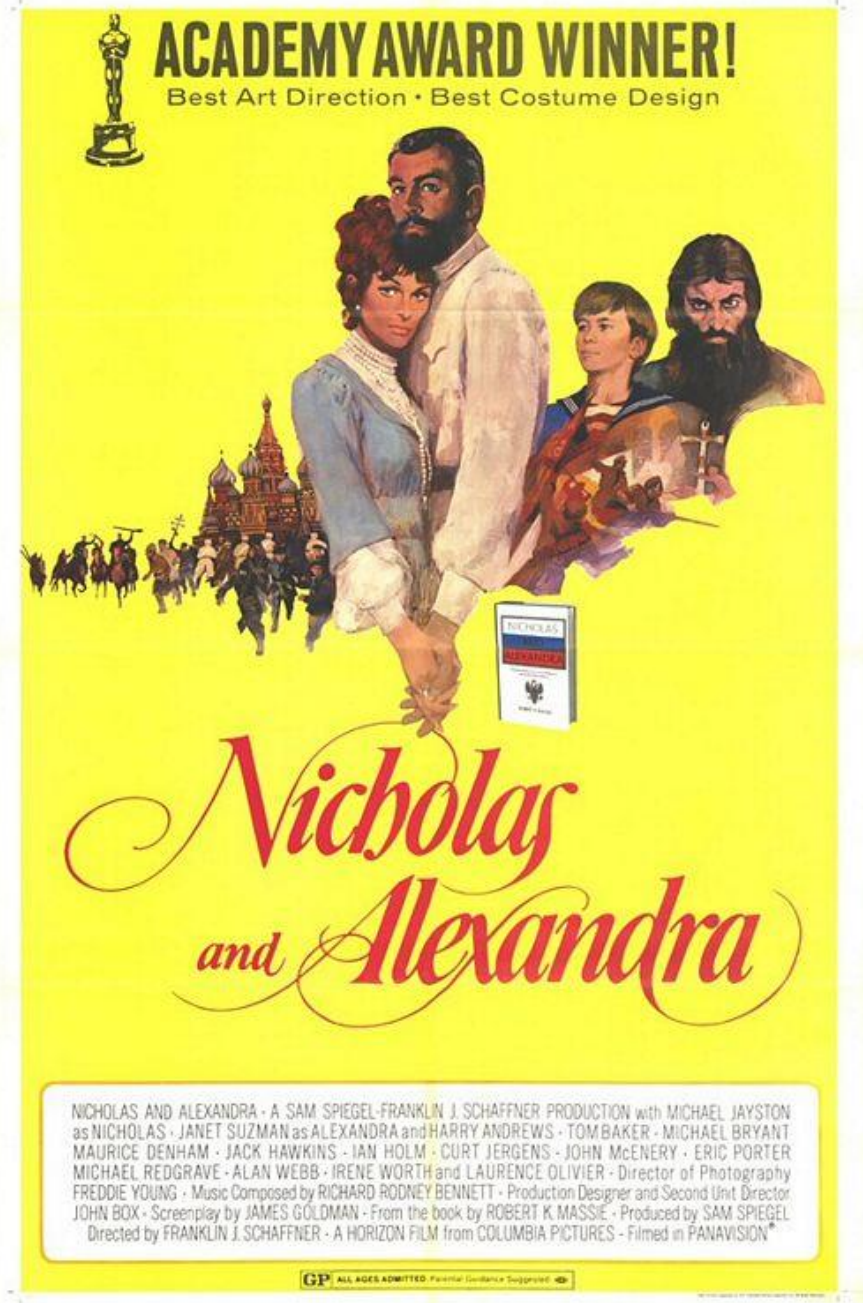
1971

- Centre officially opened by Minister for Health



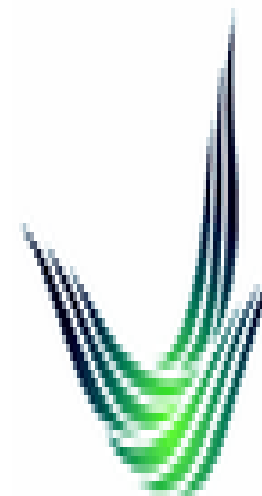
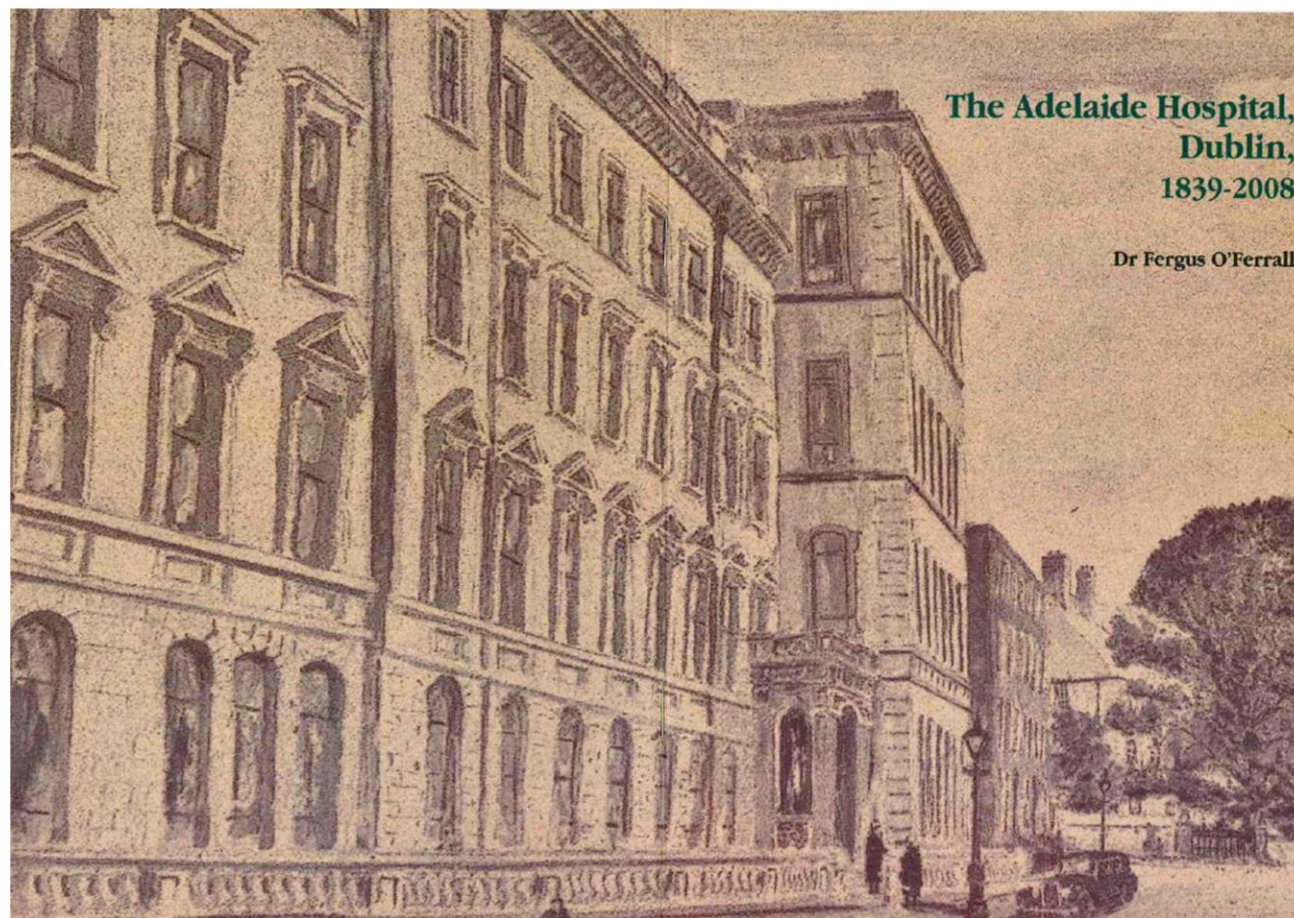
1972

- **Chairperson**: Sean Hanratty
(1972-1974)
- Irish Premiere of
Nicholas and Alexandra - £300 raised
- *Money used to buy board games and supplies for centre and meeting in Cork*





Adelaide Hospital – Orthopaedic Surgery



THE ADELAIDE & MEATH
HOSPITAL, DUBLIN
INCORPORATING
THE NATIONAL CHILDREN'S HOSPITAL



Treatment outside Dublin

Mercy Hospital, Cork



Regional Hospital, Galway





1973 and 1974

1973

- Medic alert bracelets provided
- Regional meeting in Limerick



1974

- **Chairperson:** 1974-1976
Bill O'Sullivan
- DOH register had 100 PWH
 - 87 were < 30 years old
- Ongoing discussion on training a nurse to give treatment, resistance by Department



1975

- Local committee established in Cork
- Grant from DOH for separator to make cryoprecipitate for Pelican House (IBTS)
- Home treatment started for limited number with factor concentrates
- Group counselling for teenagers with Mrs. Brenda Cawley
- Social evening with Ronnie Drew

IRISH HAEMOPHILIA SOCIETY

IHS 1/68

Income and Expenditure Account to 14th November 1975.

Opening Balance per previous account and as confirmed by Deposit Book		190.80
<u>ADD</u> Interest Credited 30/10/74		15.87
Subscriptions received (15 subscribers)		40.50
Contributions towards Bracelets		5.50
Proceeds of Function per .		86.55
Christmas Card Sales per	267.09	
LESS Cost	<u>145.80</u>	
Profit on Christmas Cards		121.29
Interest as at 14/11/75		<u>21.98</u>
		482.49

<u>LESS</u> Office Stationery	30.15	
Post and stationery (Hon. Sec.)	31.50	
Career Projects (60.00	
North Star Meetings (2)	32.25	
Relate .50		
World Federation of Haemophiliacs	24.67	
Union of Voluntary Organisations for the Handicapped	<u>15.00</u>	40.17
Presentation to .	10.00	
Visit to Cork (32.14	
Cork Seminar	5.50	
Dublin Seminar	<u>5.50</u>	247.21
Being Balance per Pass Book	213.30	<u>235.28</u>
Interest to 15/11/75 as advised	<u>21.98</u>	
	<u>235.28</u>	

 I have on hands 17 Engraved Bracelets at an original cost of 26.35
 148 Unengraved " " " " " " 155.64
 181.99





1976 and 1977

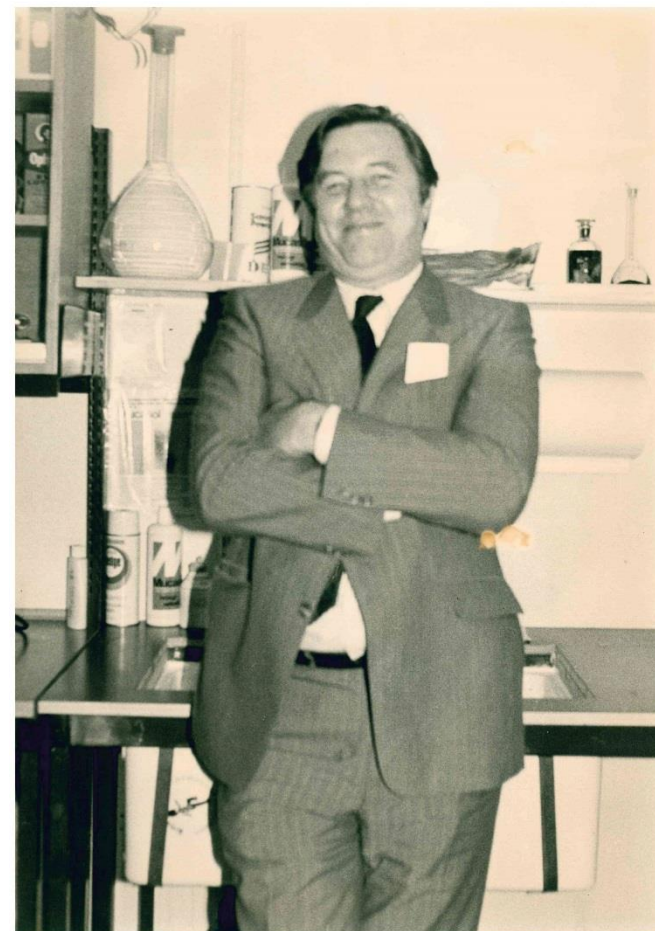
1976

- **Chairperson:** 1976-1978
Jack Downey
- Concerns about long delays (up to 5 hours) at National Centre
- PWH missing a lot of time from work or school

1977

- Society agrees to transfer of National adult centre from Meath to St. James's Hospital
- Centre moves to Top Floor, hospital 1
- Nurse finally allowed to give treatment Breda Joyce followed by Margaret King

Centre moves to St. James's, 1977





1978 and 1979

1978

- **Chairperson**: 1978-1980
Frank Bird
- National Haemophilia Services Co-ordinating Committee established (NHSCC)
- Committee included: PKM Carey, Vincent Hendron, John Buckley, Con Curtin, Philomena Byrne

1979

- Haemo Wallet cards provided
- Concerns about orthopaedic service
- Meeting with Northern Ireland
- No newsletter during the year
- AGM guests included Dr. Paula Cotter from Cork



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I.H.S. Services – supporting members in hospital

- Paid for television rental in the Meath 4 bed “Haemophilia” ward
- Board games and card table for never ending poker games!
- Rudimentary treatment - Plasma, cryoprecipitate and some factor concentrate
- Tooth extraction involved admission for 5 days with diet of jelly, ice cream and cold milky tea
- People: Nurse Duignan, Joan Mc Keever, Jimmy the Porter (Meath)
 - : Lorette Kiernan, Social Worker (Harcourt Street)
 - : Dr. Egan (Galway), Dr. O’Donoghue, Dr. Cotter (Cork)



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



1980

- **Chairperson:** 1980-1982
Joseph Nolan
- Deficiencies at centre included lack of wheelchairs and crutches
 - Society provided some of each
- Jack Downey met orthopaedic surgeon from Oxford who spoke at the AGM:
 - Requirements: *Blackboard and chalk*
- Continued engagement with Union of Voluntary Organisations for the handicapped (UVOH)



1981

- Activities - Flag days, Insurance
- Bill O'Sullivan on NHSCC: *"The agenda was very full and comprehensive but very little of a worth while nature was discussed about haemophilia."*
- Committee included: Margaret Dunne, Tommy Davenport, Shay Farrelly
- Meetings arranged with Cork Branch





1982

- **Chairperson**: 1982-1984
Philomena Byrne
- Fundraiser- Knit in, attended by Health Minister and Prof. Temperley
- Centre temporarily moved to Mercers while Hospital 1 refurbished
- Plan to send delegation to UK to look at centres in 1983 – Report 1983 by Shay Farrelly and John Scallan
- Eddie Murphy Chair of Cork Branch
- Committee included; John Scallan, Michael Kelly, Noel O’Leary, Sharon Dixon, Brian O’Mahony



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AGM 1982



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1977-1982: Treatment

- Treatment starting to improve - Factor concentrates became more available - FVIII and PCC for FIX deficiency
- Home treatment initiated - primarily due to long delays in accessing treatment in hospitals outside Dublin
- By 1980 - BTSB talking about self sufficiency from Irish plasma to make FVIII and FIX – did not happen until 1986
- With home treatment and more factor, future starting to look brighter - normal quality of life more realistic ambition
 - the calm before the storm of HIV and Hepatitis C



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



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11/10 - 1/11 1101 1101

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.
Temperley 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.



Personal Memories: Treatment 1968-1982

- Mercy Hospital Cork for whole blood in emergency only
- Standard “treatment” for bleeds was ice and later crepe bandages to support joint post bleed
- First factor infusion in Harcourt Street in 1972
- Train from Killarney to Dublin for Plasma 1972-1975
- Moved to Dublin for college in 1975
- Treatment in Meath Hospital - 4 bed ward
- Home treatment in late 1970's





Personal Memories: Society 1968-1982

- Briefly on board in 1978 but could not commit due to college exams
- Joined board after AGM in October 1982
- Small, friendly group - limited activities and funds
- Annual fundraising flag day and raffles a big deal
- Board meetings often semi formal
- Newsletter sub committee - work often stopped to play poker!
- Dedicated group of parents and people with haemophilia
- Paternalistic care - Society not involved or consulted on major decisions
- Advocacy confined to individual cases - no lobbying or political contacts
- **Friendships formed which have endured**

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

2018 Strategic Plan Goals

1. The provision of optimum support and services for all people with haemophilia and related bleeding disorders and their families.
2. To represent the interests of people with haemophilia with all external bodies and agencies.
3. To ensure the viability and development of our organisation in the future.
4. To ensure the Society plays a full and active role in the development of haemophilia care globally.



Irish Haemophilia Society **Strategic Plan** **2015 - 2018**

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





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