

Society Fondly Remembers Lost Friends

NEWS RELEASE

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SOCIETY FONDLY REMEMBERS LOST FRIENDS

THE Irish Haemophilia Society held a press briefing and reception in its offices on Monday evening to mark the 25th anniversary of a landmark Dáil debate on haemophilia and HIV which led to the 1989 general election.

The reception was attended by the Minister for Public Expenditure and Reform, Brendan Howlin, people with haemophilia, family members and health care workers.

Twenty five years ago this week the debate in Dáil Éireann focused on the plight of people with haemophilia who contracted HIV.

A total of 106 people with the hereditary blood clotting disorder were infected in the 1980s through infected blood products supplied by the State. By 1988, the full impact of AIDS was starting to become apparent and four members of the Irish Haemophilia Society (IHS) had died.

Concerned for those affected and their devastated families, the society set out a clear and unambiguous case for limited financial assistance from Government but no progress was made. Over several months, the IHS – a registered charity – made every effort to get the then administration to agree to the setting up of a fund to provide much-needed help.

Eventually, following three further deaths, the issue was brought to Dáil Éireann as a Private Members' Bill, by the Labour party and Brendan Howlin, TD, on 25-26 April 1989. The Government forced the issue to a vote which it lost by 72 votes to 69.

The Government, led by Charles J Haughey, called a general election in which they lost a significant number of seats. The new Fianna Fail-Progressive Democrats coalition, following further discussions, implemented a trust fund of £1 million administered by the Haemophilia HIV Trust (HHT).

This fund, initially chaired by Justice Mella Carroll, now continues under the chairmanship of Mr Justice Roderick Murphy. The trust has provided invaluable emergency financial support and assistance to people with haemophilia with HIV.

Reflecting this week on that traumatic episode of 25 years ago, IHS chief executive, Brian O'Mahony, remarked: "We fought hard for our members at that time knowing that HIV was a catastrophe."

Now, 25 years later, the full impact of HIV on people with haemophilia is apparent. A total of 70 of the 106 individuals infected have died, leaving behind devastated and grieving families and friends. A further 37 people with haemophilia have died in the same time period from Hepatitis C, also contracted from infected blood products.

Mr O'Mahony added: "The society and our members vividly recall those difficult days. We will always remember our members and those who have died. The burden of HIV and Hepatitis C in our community, on our members, on families, on individuals and on their dependants has been immense.

"Treatment for HIV and Hepatitis C are now much more successful and the surviving members can look to the future with increased confidence," stated Mr O'Mahony, who was chairman of the IHS at the time of the debate in 1989.

He added: "None of our members who have died from HIV or Hepatitis C, or a combination of both, will be forgotten by the society.

"The many battles we had to fight to obtain better treatments, to seek compensation for their families and to seek recognition of the appalling events which consumed them were the basis for the strong and active society we have today."

Current treatment for haemophilia in Ireland is excellent with safe and effective factor replacement therapy available. A child born now with haemophilia in this country will have a normal life expectancy and live a near normal quality of life.

Mr O'Mahony added: "We thank the politicians who supported our cause at that incredibly difficult time 25 years ago and great progress has since been made. New treatments for Hepatitis C, approved by Health Minister James Reilly on World Haemophilia Day in 2012, have resulted in a successful cure for eight people with haemophilia to date and even more successful therapies for Hepatitis C will shortly be available which, it is hoped, will result in an even higher cure rate."

Several of the young men who died as a result of HIV and Hepatitis C, leaving behind grieving and bewildered families and young children, now have grandchildren whom they will never meet.

Some of these grandchildren themselves have haemophilia but their reality now is an experience of excellent treatment, wonderful support and a near normal quality of life. From the suffering of the earlier generation has come the motivation, the fight for and the reality of a better future for all with haemophilia.

Some of those who died were children who will never know the freedom from pain and suffering which now characterises haemophilia. Some were older men with haemophilia who had to endure the end of their life in a crucible of suffering, fear and regret for the life un-lived.

Mr O'Mahony said: "We remember them at every conference where people with haemophilia gather to celebrate the strong sense of community and mutual concern for each other they helped foster.

"We remember them when every advance in treatment is announced. We speak of them often, remembering their humour and their ability to endure.

"We remember them when we speak with their surviving family members or glimpse their face in the face of their child or grandchild. We hope they are all in a better place. Wherever they may be, in the words of John McGahern, we hope that they may face the rising sun. "

For further information or a free-to-publish opinion piece, contact Brian O'Mahony, Chief Executive, Irish Haemophilia Society.

Brian@haemophilia.ie

01-6579900 / 087-2515325