

Press Release

Date: February 6th 2014
From: The Irish Haemophilia Society
Subject: Funding in the Charitable Sector

The Irish Haemophilia Society (IHS) is extremely disappointed to learn of serious concerns regarding the governance and use of public funds by the organisation Positive Action which provides support to women infected with Hepatitis C through Anti-D injections.

As a registered charity of long standing, the Irish Haemophilia Society is in receipt of State funding. The amount allocated in 2013 was €532,966 which comprised 64% of our total funding. In addition, the Society receives funding from research funds, corporate donations, membership fees and targeted fundraising events.

The Society has very strong financial governance and accountability in place, overseen by our board of unpaid volunteers. We agree an annual detailed business plan with the Health Service Executive (HSE) and we were the first organisation receiving funds from the HSE in the area of Hepatitis C to sign a Service Level Agreement (SLA). Our funding from the HSE has been governed by Service Level Agreement since 2009 and we have been fully compliant with the requirements of the SLA.

The public funding provided by the HSE to the Society is managed via their Hepatitis C office, although the funding relates to all the diverse activities of the organisation.

IHS Chief Executive, Brian O'Mahony, stated: *"The Irish Haemophilia Society utilises the funding received from all sources in a prudent, accountable and transparent manner to provide the maximum support and services to all those with inherited bleeding disorders."*

He added: *"The HSE has acknowledged, in writing, the prudent manner in which the Society utilises the funding we receive"*.

Ms Michele Tait, the HSE's Hepatitis C National Co-ordinator stated that *"the Irish Haemophilia Society is a very efficient organisation"*.

She said: *"The IHS staff work extremely hard, are highly motivated and professional in their work, and they also engage in a highly positive manner with my colleagues and I in the HSE."*

In addition, the Society's innovative work on medication procurement with the haematologists, the HSE and Department of Health on the Haemophilia Products Selection and Monitoring Advisory Board, has resulted in savings to the exchequer in excess of €130 million from 2002 to 2013.

Brian O'Mahony stated: *"The savings we have achieved for the country are a multiple of the funding received by the Society. We remain committed to ensuring the provision of the safest and most efficacious treatment for haemophilia while achieving this at the lowest possible cost to the country."*

The Society also strongly welcomes the announcement of the appointment of a regulator to the charities sector and remains committed to continued proper, ethical and transparent use of all the funding received. The audited accounts of the IHS are published each year in the Annual Report and these are available on our website www.haemophilia.ie

About Haemophilia and the Irish Haemophilia Society

Haemophilia and von Willebrands disease are inherited conditions resulting from a deficiency in one of the proteins which assist the blood in clotting. The condition, if not adequately treated, results in excessive bleeding and can cause permanent and painful damage to joints and muscles. Treatment is via the administration of replacement therapy.

Up to 1991, unfortunately, many of the blood products used for treatment were contaminated with HIV or Hepatitis C. As a result, 106 people with haemophilia were infected with HIV and 220 with Hepatitis C. A total of 107 individuals to date have died as a result of the treatment provided in the past.

The Irish Haemophilia Society has been in existence since 1968. We provide a wide range of services and support to over 1,000 persons with

haemophilia, von Willebrands disease and other inherited bleeding disorders. These include advocating for optimum treatment and care, participation in selection and procurement of medications, education materials and educational conferences.

Information and education programmes are organised for individuals and their families to assist them in dealing proactively and positively with their haemophilia. People with haemophilia who were infected with Hepatitis C or HIV via their treatment receive a lot of additional services and support from the Society including specific publications and conferences with health care worker participation and peer support.

The Society provides services and support to our 1,074 members and also to non-members who have inherited bleeding disorders. The Irish Haemophilia Society is widely regarded as the most efficient and effective national haemophilia patient organisation in Europe.

For any further information, contact the Chief Executive, Mr. Brian O'Mahony on 01-6579900 / 087-2515325 or by e-mail at brian@haemophilia.ie