

Benefits of Individual Communications Strategy From a National Haemophilia Society

Authors: Anne Duffy & Nina Storey
Irish Haemophilia Society

The Irish Haemophilia Society has an individual communication strategy which includes annual telephone calls to their members. The purpose of this strategy is to connect with members on a personal level in order to collate updated contact details and ascertain the needs of members with regard to all aspects of information and support required from and provided by the Society. The communication strategy is implemented by designated members of staff.

Communications Strategy in 2010

First implemented in 2010, 633 of 765 (81.70%) of the membership were contacted. This personal contact with individual members proved to be an invaluable source of information. This allowed the Society to provide new and improved services and support to it's members.

Communication Strategy in 2011

Following the success of the communication strategy in 2010, 733 of 857 (85.75%) of members were contacted in 2011. Priority was given to contacting members with Hepatitis C in 2011. As a result of the communications in 2011, the following vital information relating to members with Hepatitis C was collated:

- Establishing individual's genotypes.
- Previous Hepatitis C treatment and response to treatment.
- Increase in number of members reporting that they had been diagnosed with hepatocellular carcinoma which required liver transplantation.

This information proved invaluable to the Society in ensuring that the necessary guidelines and information meetings required for this cohort of members were in place.

Action Taken Based on Communications Strategy in 2011 relating to Members with Hepatitis C

- Collated vital information on members with Hepatitis C.
- Liaised with relevant medical specialists to optimise the guidelines for monitoring the progression to cirrhosis and to ensure early detection of hepatocellular carcinoma.
- Provided updated information on the new treatments available to members with Genotype 1.
- Encouraged members to access the home support and counselling services provided by the health authorities to enable them to maximise their chances of completing their treatments.

Other Actions

- Support to parents whose children were moving from IV access devices to peripheral vein self infusion.
- Success in encouraging members to attend conferences and meetings.
- Proactive identification of members requiring home visits and financial support.

Communication Strategy in 2012

By the end of May 2012, 394 of 887 (42.51%) of the Society's membership has been contacted. On a year to year basis new information is continually being sourced from the individual communication with members.



Irish Haemophilia Society: Services & Support



The Irish Haemophilia Society offers services and support to all members living with Haemophilia, von Willebrand Disease and Rare Bleeding Disorders. From the time of diagnosis there are many issues facing people with bleeding disorders. Support is offered to people with bleeding disorders, their parents, and families on issues such as how to recognise a bleed, treatment and care. Coming to terms with a diagnosis can be very difficult especially when there is no history of haemophilia in the family. Through our educational programmes, AGM & Conferences, Parents' Conference, Members' Conference, Information Meetings and Regional Visits, we give our members as much information as possible. We also provide publications and up to date information on our website. We constantly endeavour to help members with any queries or questions they may have.

EDUCATION

The following are a list of educational meetings and conferences held by the IHS:

- AGM & Conference
- Parents Conference
- Members Conference
- Relatives Days
- Regional Meetings
- Treatment Updates
- Conference for Young People
- Women and Bleeding Disorders Information Days
- Peer Group Meetings
- Conference for members with HIV and/or Hepatitis C



Information on the Health (Amendment) Act Card [HAA CARD]

Men, women and children who contracted Hepatitis C through the administration within the State of blood or blood products are entitled to a **Health (Amendment) Act Card (HAA Card)** under the Health (Amendment) Act 1996.

HAA Cardholders are entitled to avail of a range of services, *without charge*, including

- GP services
- prescribed drugs, medicines & appliances
- dental services
- ophthalmic services
- home support
- home nursing
- counselling services
- other services including physiotherapy and chiropody/podiatry services

In certain circumstances, terms and conditions may apply. If you have any queries about the HAA Card or the general operation of any of the services under the Health (Amendment) Act Card, please contact the Hepatitis C Liaison Officer – see list overleaf.

Any problems that arise in the course of providing a service to HAA cardholders can be resolved through the relevant Liaison Officer and not through the HAA cardholder.

