

Irish Haemophilia Society

Strategic Plan

2015 - 2018

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



Introduction

The new Society Strategic Plan from 2015 – 2018, sets out an ambitious programme of work for the organisation. The plan sets out four broad goals, forty one objectives and one hundred and ninety seven strategies. It follows on from our previous successful strategic plan from 2010 – 2014, which was largely achieved. Over the course of the next three years, we are facing a very exciting and innovative time in terms of haemophilia treatment. We will have available on the market new longer acting factor concentrates. Progress will be made in clinical trials, in innovative areas such as gene therapy. We also hope to see the eradication of hepatitis C infection in our community well within the time frame of this strategic plan. We will look at broadening the community and offering some services and support to people with thrombophilia, Idiopathic Thrombocytopenic Purpura and platelet disorders. We will work to ensure that on a continuing basis through a challenging economic environment. We will advocate for optimum haemophilia treatment and we will work constructively with the health authorities to ensure that this is delivered in a cost effective and efficient manner. We will work to ensure that we represent all people with haemophilia and related bleeding disorders and that no sub-group of people with bleeding disorders, are marginalised or left behind. We will continue to work constructively with all external bodies and agencies and represent the interests of our community. We will look forward to our 50th anniversary year in 2018, with renewed confidence and hope for a brighter future for all people with haemophilia and inherited bleeding disorders.

Strategic Plan 2015 - 2018

Goals

There are four goals in the Strategic Plan:

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 development of haemophilia care globally.



Goal 1

The provision of optimum support and services for all people with haemophilia and related bleeding disorders and their families.

Objectives

1. To provide optimal support to ageing people with haemophilia.
2. To provide optimal support to children and families.
3. To provide optimal support to teenagers with haemophilia.
4. To provide optimal support to young adults with haemophilia.
5. To provide optimal support to people with von Willebrand's Disease.
6. To provide optimal support to women with bleeding disorders and carriers.
7. To provide optimal support to people with rare bleeding disorders and platelet disorders.
8. To provide optimal support to all members with HIV and/or hepatitis C.
9. To provide optimal support to all persons with inhibitors.
10. To provide optimal support to people with mild and moderate haemophilia.
11. To provide optimum services and support to non-nationals with bleeding disorders resident in Ireland.
12. To ensure our programmes and activities meet the needs of our members and their families.
13. To ensure our publications, website and social media profile meet the needs of our members and their families.
14. To collect data to demonstrate the benefits of treatment and living positively with a bleeding disorder.



Goal 2

To represent the interests of people with haemophilia with all external bodies and agencies.

Objectives

1. To ensure that the safest and most efficacious treatment is available to all members.
2. To work with the National Haemophilia Council to optimise the development of care for all with bleeding disorders.
3. To optimise our impact on the Consultative Council on Hepatitis C and other hepatitis forums.
4. To optimise liaison and collaboration with Comprehensive Care Centres.
5. To optimise liaison and collaboration with Haemophilia Treatment Centres.
6. To optimise constructive and effective engagement with the Department of Health, Health Service Executive and Hospital Groups.
7. To ensure the Society's views are considered on any relevant haemophilia or hospital infrastructure projects.
8. Constructive and effective engagement to ensure optimum haemophilia care in the new National Children's Hospital.
9. To ensure the Society is a repository of expertise in haemophilia care and related issues.
10. To implement effective media, public relations and political strategies.



Goal 3

To ensure the viability and development of our organisation in the future.

Objectives

1. The provision of defined services for people with thrombophilia.
2. The provision of defined services for people with platelet disorders and Idiopathic Thrombocytopenic Purpura (ITP).
3. To broaden area of work in hepatitis C.
4. To examine the feasibility of providing some services and support through the haemophilia HIV Trust (HHT).
5. To ensure board development and succession planning.
6. To optimise staff development, retention and future planning.
7. To optimise volunteer recruitment, development and retention.
8. To ensure level of core funding is optimised.
9. To develop new sources of funding to fund new programme areas.
10. To ensure governance continues to reflect best practice.
11. To broaden funding base.
12. To optimally utilise the Society's 50th anniversary to raise awareness.
13. To increase active membership in Society.



Goal 4

To ensure the Society plays a full and active role in the development of haemophilia care globally.

Objectives

1. To continue to work to develop haemophilia care in Vietnam.
2. To play a constructive role in developing haemophilia care in Europe working with European Haemophilia Consortium (EHC).
3. To play a constructive role in developing haemophilia care globally working with World Federation of Hemophilia (WFH).
4. To increase awareness among members on the reality of haemophilia care worldwide.



GOAL 1

The provision of optimum support and services for all people with haemophilia and related bleeding disorders and their families.

Objective 1:

Provide optimal support and services to ageing people with haemophilia.

Strategies

1. To work with the National Centre for Hereditary Coagulation Disorders (NCHCD) and selected GP's to produce and implement agreed protocols on monitoring and treatment.
2. To organise biennial conference.
3. To work with members and their families individually assisting them to maintain independence and quality of life.
4. Phone contact with each member annually.
5. To organise or facilitate a physical fitness programme and nutritional advice.
6. To identify the feasibility of peer practical assistance programme.
7. To establish a link with the centre for successful ageing and work with the Comprehensive Care Centres (CCC's) on service provision.
8. To produce a publication in collaboration with NCHCD for ageing members to give to their GP.
9. To provide resources from the Society for this including appointing an advocate if necessary.
10. To identify and assist with psychological vulnerabilities where possible.

Objective 2:

To provide optimal support and services to children and their families.

Strategies

1. To organise the Parents Empowering Parents (PEP) programme.
2. Systematic outreach to families at designated time intervals to provide support, check on progress and collect outcome data on living with haemophilia.
3. To provide structured and systematic on-going educational opportunities for children at our conferences.
4. To provide support and services to parents with newly diagnosed children.
5. To encourage and facilitate the development of support groups for mothers and fathers in Cork.
6. Systematic development of new services and tailor existing services based on need.



7. To liaise with Comprehensive Care Centres to identify requirements and target resources.
8. Systematically collect the views of the children and obtain feedback on activities.
9. To collaborate with Our Lady's Children's Hospital Crumlin (OLCHC) and Cork University Hospital (CUH) on outreach activities to increase inclusion of new and non-engaging families.
10. To attend specified clinics at OLCHC and CUH.
11. To organise father/son and mother/daughter event at Parents Conference.

Objective 3:

Establish teenagers group and plan appropriate activities.



Strategies

1. Educational and personal development programme for 15-17 year old group with haemophilia.
2. Appropriate personal development programme for 13-14 year old group with haemophilia.
3. To provide an opportunity for teenagers input into policy and governance.
4. Planned education programme for teenagers at Society conferences.

Objective 4:

To provide optimal support and services to young adults with bleeding disorders.

Strategies

1. A structured cumulative approach to education at conferences.
2. To increase appropriate use of social media tools.
3. The provision of appropriate career advice.
4. Mentoring and leadership by established young adults.
5. To increase involvement of young adults in governance of organisation.
6. The provision of advice and assistance on financial, tax and insurance issues.

Objective 5:

To provide optimal support and services to people with von Willebrand's Disease (vWD).

Strategies

1. To organise a specific conference or event in collaboration with Comprehensive Care Centres (CCC's).
2. To increase the number of persons with von Willebrand's Disease on our mailing/membership list.
3. To ensure views of von Willebrand's Disease community are known at board level.
4. To provide posters at CCC's on vWD.

Objective 6:

To provide optimal support and services to women with bleeding disorders (WBD's) and carriers.

Strategies

1. To organise specific conferences and events for carriers and women with bleeding disorders.
2. The provision of relevant updated information to maternity hospitals.

Objective 7:

To provide optimal support and services to rare bleeding disorders (RBD's) including platelet disorders.

Strategies

1. To carry out survey of requirements of RBDs and platelet disorders in collaboration with NCHCD.
2. To increase the number of people with RBD on our mailing/membership lists.
3. To carry out survey of requirements of people with Idiopathic Thrombocytopenic Purpura in collaboration with CCC's.
4. To examine the feasibility of organising a conference/meeting or specific event for this group.

Objective 8:

Provide optimal support and services to people with hepatitis C and HIV.

Strategies

1. Work to ensure the eradication of Hepatitis C in all persons with haemophilia and related bleeding disorders.
2. To provide regular updates on advances in treatment.
3. To organise an annual conference as required to provide information and peer support.
4. To facilitate peer support among members.
5. To provide optimum support to members undergoing treatment and following completion of treatment.
6. To liaise with members to ensure they are getting optimum benefit from HAA Card.
7. To provide written communication updates to members on tax and finance issues.
8. To ensure members with haemophilia who have received liver transplants are not excluded from access to services for haemophilia.
9. Work to optimise utility of new Hepatology Unit in St. James's hospital for people with haemophilia.
10. To assist members in finalising their interaction with the compensation tribunal/legal process.
11. Education on the impact of HIV on co-morbidity development and the complexity of pharmacology.

Objective 9:

To provide optimal support and services to people with inhibitors.

Strategies

1. To identify the needs of people with inhibitors.
2. To produce specific and appropriate education.
3. Integrate proposed services into broader European initiatives if feasible.
4. To provide appropriate support to individuals and the family.

Objective 10:

To provide optimal support and services to people with mild and moderate haemophilia.

Strategies

1. To provide information on accessing emergency care.
2. To provide education on management and disclosure issues and coping strategies.
3. Work with CCCs to examine changing therapeutic requirements and individual treatment protocols.

Objective 11:

The provision of optimum support to people with haemophilia and their families where english is not the first language.

Strategies

1. To identify materials requiring translation and languages into which they should be translated.
2. To collaborate with CCC's to identify number of individuals and families requiring translation services.

Objective 12:

To ensure our programmes and activities meet the needs of members and their families.

Strategies

1. To ensure that all members are contacted by phone at least on an annual basis to ascertain their needs.
2. To identify members and families who require home visits and carry this out systematically.
3. To increase capacity for staff to outreach to members.
4. To organise specific topic meetings where required to optimise attendance and benefit to members.
5. To work with the HHT fund to optimise assistance and activities for members with HIV.
6. To ensure conferences are continuously evaluated to ensure continued relevance with strategic objectives.

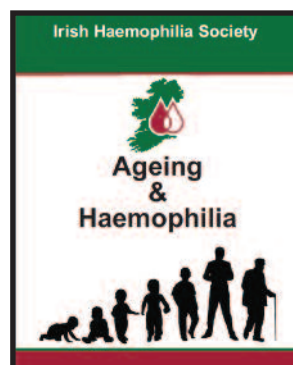


Objective 13:

To ensure our publications, website and social media profile meet the real and changing needs of our members.

Strategies

1. A planned schedule of specific targeted publications for a 4 year period.
2. To work with medical teams at CCC's to ensure timely medical input into publications.
3. To ensure regular publications reflect demographic diversity.
4. To carry out regular surveys and data collection and publish results where beneficial.
5. To increase electronic distribution of publications and increase electronic mailing list.
6. To optimise our utilisation of social media as an educational tool.



Objective 14:

Collect data to demonstrate benefits of treatment and of living positively with a bleeding disorder.

Strategies

1. Selection and assessment of key outcomes from patient perspectives.
2. To collaborate with CCC's where possible on data collection.

Goal 2

To represent the interests of people with haemophilia with all external bodies and agencies.

Objective 1:

To ensure that the safest and most efficacious treatment for haemophilia continues to be available to all people with haemophilia.

Strategies

1. To ensure new generation of longer acting factor concentrates are available to all members.
2. To work in collaboration with the Haemophilia Product Selection and Monitoring Board (HPSMAB) to ensure the country purchases the safest and most efficacious product.
3. To identify and train volunteers and/or staff who will develop expertise required to represent IHS on HPSMAB in the future.
4. To maintain and update knowledge in relation to new product developments and EU procurement law.
5. To ensure the Society are involved in Health Technology Assessments (HTA) or economic assessments of relevant products and engage proactively with relevant agencies and people.
6. To examine the feasibility of inclusion in gene therapy trials for factor VIII.
7. To organise a specific conference or event on haemophilia B.
8. To support and to optimise participation in gene therapy clinical trials on haemophilia.

Objective 2:

To work with the National Haemophilia Council (NHC) to optimise the development of care for people with bleeding disorders.

Strategies

1. To ensure our representation on and work with the NHC is optimal.

Objective 3:

To optimise representation of our members on Consultative Council on Hepatitis C and other Hepatitis forums.

Strategies

1. To work proactively with Consultative Council on Hepatitis C on development of services.
2. To work proactively with the HSE and Hepatitis C Liaison Officers to ensure members appropriate requirements are met.
3. To work proactively with liver transplant centres to ensure the requirements of members are understood and integrated.
4. To maximise the number of people with Haemophilia/vWD who contribute to the Hepatitis C database.
5. To work with other organisations where interests of the Society are met.
6. To maintain active engagement in Irish Hepatitis C Outcomes Research Network.



Objective 4:

Optimise liaison and co-operation with Comprehensive Care Centre's (CCC's).

Strategies

1. Scheduled regular team meeting with all CCC's.
2. To work with CCC's on collection of patient outcome data and research projects.
3. To work with CCC's on optimising use of factor concentrates and collection of required data.
4. To arrange distribution of Irish Haemophilia Society publications to all on national register by National Centres.
5. To arrange for display of IHS publications at CCC's and display of specific publications, posters and event information at specific clinics and arrange restocking of publications by IHS staff.
6. To work with CCC's to encourage all people with haemophilia to co-operate and collaborate with data collection.
7. To examine the feasibility of having an official IHS attendance at specific clinics.
8. To work with CCC's to optimise individualisation of therapy.
9. To work with CCC's to optimise referral to and co-ordination with other medical services.

Objective 5:

To optimise liaison and co-operation with (non CCC) Haemophilia Treatment Centres.

Strategies

1. Scheduled annual team meeting with level 2 and selected level 3 Centre's (Galway, Limerick, Waterford, Letterkenny).
2. To establish collaboration with services in Belfast if possible.
3. The provision of appropriate publications to these centres.
4. To ensure an appropriate patient pathway is operational for people with haemophilia in these centres.

Objective 6:

Constructive engagement with the Department of Health (DOH), Health Service Executive (HSE) and hospital groups.

Strategies

1. Engagement with HSE in line with the Service Level Agreement.
2. Awareness of and engagement with on-going changes in organisation of health care system.
3. Positive engagement with DOH on health policy issues affecting people with haemophilia.
4. Engagement with CEO's and senior management of hospital groups.
5. Engagement with HIQA, Irish Medicines Regulatory Agency (IMRA) and other statutory health bodies as appropriate.

Objective 7:

Constructive and effective engagement to ensure optimum haemophilia care in new National Children's Hospital.

Strategies

1. To engage and contribute to the greatest possible extent with the design and development process.
2. To ensure planned service will provide state of the art National Paediatric Haemophilia Service with seamless planned transition to adult care.
3. To ensure liaison with CEO of development board.
4. To evaluate stated requirements of our members with regard to new facility.

Objective 8:

To ensure the Society's views are considered on any other relevant haemophilia related hospital infrastructure projects.

Strategies

1. To ensure patient journey is optimised in CCC's.
2. To ensure patient access is maximised.

Objective 9

To develop the IHS as a repository of expertise in haemophilia care and organisational development.

Strategies

1. To contribute to a safe and secure blood supply for all Irish people.
2. To ensure economic results of the Society's work on and with the Haemophilia Product Selection and Monitoring Advisory Board (HPSMAB) are communicated to appropriate bodies.
3. To ensure the Society's views on these issues are adequately explained to media and politicians.
4. To identify actions to maintain and develop expertise.

Objective 10:

To implement effective media, public relations and political strategies.

Strategies

1. To cultivate relationships with key journalists and media contacts.
2. Timely briefing and delivery of material to appropriate media.
3. To organise media coverage for specific publications aimed at target demographic groups.
4. To schedule regular meetings with government, opposition health spokespersons and the Oireachtas Health Committee.
5. To organise in house advocacy, lobbying and media training.

Goal 3

To ensure the viability and development of our organisation in the future.

Objective 1:

To examine the provision of defined services for people with thrombophilia.

Strategies

1. To establish a working group with NCHCD to identify reasonable and achievable actions the Society could consider undertaking to assist this population.
2. To establish the feasibility of producing a specific publication in collaboration with NCHCD.
3. To establish the feasibility and practicality of organising a specific conference or event.
4. To identify specific additional areas of funding for this work.



Objective 2:

The provision of defined services for people with Platelet Disorders including Idiopathic Thrombocytopenic Purpura (ITP)

Strategies

1. To develop an understanding of the needs of this population.
2. To identify specific requirements of the paediatric ITP population in collaboration with OLGHC and develop plan to meet major needs.
3. To identify reasonable and achievable actions the Society could undertake to assist this population.

Objective 3:

Broaden areas of work in Hepatitis C.

Strategies

1. To organise a specific conference for Irish patients with hepatitis C.
2. To organise a conference for European people with haemophilia and hepatitis C.
3. To identify additional sources of funding for this work.
4. To monitor the ongoing impact of treatment on members.

Objective 4:

To examine the feasibility of providing some services and support through the haemophilia HIV Trust (HHT).

Strategies

1. To examine the feasibility and practicality of providing some services or information to this group in collaboration with the NCHCD and other CCC's.

Objective 5:

To ensure board development and succession planning.

Strategies

1. To identify expertise available within the board and optimally utilise.
2. To identify expertise or demographic group voice which could be beneficial to board.
3. Induction training for new board members.
4. To educate members on the role and work of the board.
5. Annual review and provision of external or specific training required for the board.
6. To develop a timetable to allow an opportunity for specified members to observe the board in session.
7. To examine utility of term limits, board numbers increasing and training for future potential board members.

Objective 6:

To optimise staff development.

Strategies

1. To identify training required on an annual basis both in house and external.
2. Annual formal evaluation, performance review and discussion on specific roles and role development for all staff.
3. To facilitate team building to ensure optimum staff communication and sustain a dynamic work environment.
4. To create opportunities for formal interaction between staff and board to optimise interaction on policy development and thinking.
5. To create staff personal development plans in collaboration with staff and apply resources for continuous personal development.
6. To identify additional staff resources required to facilitate implementation of strategic objectives.



Objective 7:

To optimise volunteer recruitment development and retention.

Strategies

1. To appoint volunteer leaders for each stream at conferences.
2. Mentoring and motivation for work involving specific expertise.
3. To utilise the database of volunteer skills and educational qualifications.
4. To initiate annual volunteer awards.
5. To provide a grant for a volunteer to attend World Federation of Hemophilia International Conference or European Haemophilia Consortium Conference or other appropriate event.
6. To increase general recognition and appreciation of volunteers.

Objective 8:

To ensure the level of core funding is optimised.

Strategies

1. To demonstrate that funds provided are beneficially used by measuring outcome and impact of programmes and activities.
2. To ensure visibility with media and high impact representation on external sites.
3. To collect and publish outcome data on treatment, events, publications and programmes.

Objective 9:

To develop new sources of funding to fund expanded activities.

Strategies

1. To identify new source of funds for work on thrombophilia, ITP and HHT respectively.
2. To obtain increased core funding as required.

Objective 10:

To ensure governance continues to reflect best practice.

Strategies

1. To ensure compliance with provisions of new Charities Regulations.
2. To ensure continued constructive engagement with HSE on service level agreements.
3. To ensure historical legal and financial issues are resolved.

Objective 11:

To broaden the funding base.

Strategies

1. Broaden pharmaceutical funding to include companies in area of hepatitis C and thrombophilia, ITP and other bleeding disorders.



2. To increase general fundraising.
3. To promote giving through legacies and planned giving.
4. To increase funding from existing and new pharmaceutical companies.
5. To identify potential future capital project to optimise benefit to members.

Objective 12:

To utilise 50th Anniversary of the Society to optimal effect.

Strategies

1. To increase public awareness of Society and our work by publishing a history of the Society and optimally utilising the publication and launch.
2. To prepare chronology of 50 years for archiving.
3. Organise series of events for 50th year to raise profile including gala dinner, public events and event on World Haemophilia Day.
4. To establish 50th anniversary working group to plan programme of events.
5. To give golden anniversary awards to individuals who have made an outstanding contribution to Society.

Objective 13:

To increase active membership in Society.

Strategies

1. To arrange for IHS publications to be sent to targeted demographics by CCC's.
2. To increase public awareness by organising World Haemophilia Day events annually.
3. To arrange for CCC's to distribute information packs on IHS to all new registered patients.
4. To arrange media coverage of specific publications and conferences.
5. To arrange with CCC's for information packs to be given to non-English speakers attending the centres.
6. To utilise social media to increase membership.
7. To increase junior and youth memberships via targeted interactions.
8. Identification of selected demographic groups within current membership to increase interaction.



Goal 4

To ensure the Society plays a full and active role in development of haemophilia care globally.

Objective 1:

To continue to work to develop haemophilia care in Vietnam.

Strategies

1. To work to establish Vietnam as a priority development target for WFH.
2. To ensure employment and language classes projects are successfully initiated and managed.
3. To increase involvement of the Irish Embassy and involve the Irish Government Development Aid Agency.
4. To publish results and analysis.



Objective 2:

To play a constructive role in development of haemophilia care globally working with WFH.

Strategies

1. To assist WFH in distribution of donated factor worldwide.
2. To encourage and offer support to CCC's to consider involvement in a WFH twinning programme.
3. To provide assistance to other National Member Organisations if practical.

Objective 3:

To play a constructive role in developments in haemophilia care in Europe working with EHC.

Strategies

1. To play a leading role in achieving consensus on major issues in relation to blood and plasma.
2. To ensure our publications are available to other European countries.
3. To provide proactive input into relevant directives, guidelines and regulations from EU, Council of Europe or European Medicines Agency (EMA) directly or via European Haemophilia Consortium (EHC) or Plasma Users Group (PLUS).
4. To ensure more Society board, staff or volunteers are involved in working groups at European level.

Objective 4:

To increase awareness among IHS members of the reality of haemophilia care globally.

Strategies

1. To include a talk at IHS conferences annually on care in another country or region.
2. To include articles in our newsletters and website on care in developing countries and reports on our development work.
3. To examine opportunities to expose members to events relating to haemophilia care abroad.



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