IRISH HAEMOPHILIA SOCIETY

# STRATEGIC PLAN 2025 - 2028



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*Cumann Haemifile Na hEireann*

*The Society have agreed a practical 4-year strategic plan which will run from the beginning of 2025 to the end of 2028. This will encompass a time of exciting therapeutic innovation and significant change to the comprehensive care landscape, with the planned opening of the new National Children's Hospital. We will work to ensure that underserved groups in our inherited bleeding disorders community are recognised, and actions are taken to improve their status and involvement in the community.*

*This plan is designed to be practical and easily measurable with a mixture of objectives, strategies and some detailed tactics included, all designed to achieve our strategic goals of optimising treatment, care, education and support for all with inherited bleeding disorders and their families.*

# Events

***Strategies:***

- The Annual General Meeting and Conference (AGM) will continue to be held in March annually.
- The October Members' Conference will continue to take place annually.
- The Ageing Conference will continue every second year.
- The Women and Girls with Bleeding Disorders (WGBD) Conference will continue every second year. Increased emphasis will be placed on those aged 18 to 25 years.
- The Parents Conference will take place every third year.
- The Annual von Willebrand Disorder (VWD) Information Day will be subsumed into the AGM/Conference and October Members' Conference as a parallel session, together with rare bleeding disorders (RBD). The RBD sessions will alternate between factor deficiencies and platelet disorders.
- The annual Mild Haemophilia Information Day will be subsumed into the AGM/Conference and October Members' Conference as a parallel session.
- A day event for parents of newly diagnosed children with bleeding disorders will be held in year 1 and this could be advanced to an overnight event in year 3.
- Potential collaboration on events with Haemophilia Northern Ireland will be considered, including for World Haemophilia Day events.
- A parent/child overnight event will be organised on at least 2 occasions in the 4-year period.
- Gene therapy information meetings will be organised at various venues around the country, targeted at individuals who may be or are eligible for gene therapy. The concept will be small group meetings, followed by individual ongoing consultation and discussion to help individuals make fully informed decisions and prepare them for substantive engagement with the gene therapy hub and spoke centres.
- To encourage a culture of members dropping into the office, 3 to 4 coffee mornings will be organised in the office annually. The Society will also attend and work with Children's Health Ireland (CHI)/St. James's Hospital on their coffee morning for parents.
- Regional meetings for members to be held as and when required based on an annual evaluation of need and potential venues, with at least one held in Cork and Galway annually, linked with a visit and team meeting at Cork University Hospital (CUH).
- A community event at Fota Wildlife Park in Cork for members will be considered for the region.
- Additional informational events may be required depending on the availability and licensing of new therapies, and any major changes in the delivery of comprehensive care e.g. opening of the new children's hospital.

# Event Schedule*

**2025**

- AGM & Conference
- October Members' Conference
- Ageing Conference
- Memorial Service
- Parent/Child Overnight Event
- Women & Girls with Bleeding Disorder Information Day
- Newly Diagnosed Information Day
- Gene therapy meetings
- Coffee mornings


**2026**

- AGM & Conference
- October Members' Conference
- Parents Conference
- Women & Girls with Bleeding Disorders Information Day
- Gene therapy meetings
- Coffee mornings

**2027**

- AGM & Conference
- October Members' Conference
- Ageing Conference
- Parent/Child Overnight Event
- Newly Diagnosed Information Day
- Gene therapy meetings
- Coffee mornings

**2028**

- AGM & Conference
- October Members' Conference
- Women & Girls with Bleeding Disorders /
- Von Willebrand Disorder Conference
- Youth Conference
- Gene therapy meetings
- Coffee mornings

**This event schedule may change due to staff capacity, budget, or organisational priorities*

# Publications and Digital Media

***Strategies:***

- Our publications and digital content strategies should include optimising synergy with the MyIndici patient portal and the paediatric EPIC portal, if developed.
- A working group should be established early in 2025 to work with the National Coagulation Centre (NCC) to agree on a joint approach to content development for the MyIndici portal and a joint approach to producing the required content.
- Look at the feasibility of installing a digital device at each comprehensive care centre to facilitate non-members in contacting the Society to express interest in joining as members or on our mailing lists.
- Information produced by the NCC for the portal should be shared with the Society for our potential use and all content produced by the Society should also be made available for consideration for the portal.
- The portal is envisaged as a combined and collaborative project.
- The current quarterly magazines and Annual Report will continue to be produced.
- A specific required publication list will be agreed on an annual basis.
- Initially targeted publications will include a publication on menarche in young girls; an updated sports and activity publication; orthopaedic surgery; benefits and entitlements (website); transition to adulthood and sex and intimacy.
- Infographics will be produced as required.
- Consideration will be given to the translation of specific information/publications/leaflets or summaries into Ukrainian, Arabic and Russian.
- Members will be contacted as part of routine contact and asked to confirm if they no longer wish to receive hard copy publications (especially the quarterly magazine) and if they prefer to receive a PDF by email. Attempts will also be made to minimise duplicate copies going to the same address if possible. These steps should help make a saving in postal costs.
- Work will continue to attempt to get publications sent by the comprehensive care centres to individuals with inherited bleeding disorders who are non-members, with the postage costs borne by the Society.
- An updated newly diagnosed information pack will be produced in collaboration with the team at CHI.
- In addition to publication stands at the comprehensive care centres, each publication will be additionally advertised with a one-page QR code which links to the Society website.
- Increase use of WhatsApp for different demographic groups of members – establish WhatsApp as a method of communication to different groups of members of the Society.
- Provide more information on travel/emigration/careers.
- Add relevant content and optimise SEO of website.
- Layout/navigation of the desktop version of the website needs re-evaluation and to update and improve content.
- Consider Bluesky account.
- Increase use of LinkedIn.
- Look at using TikTok – use panel of younger members to advise on optimum use.

# Advocacy and External Influence

### *Strategies:*

- Continue to advocate for optimised access to beds in the Haemophilia and Hepatology ward at NCC for people with inherited bleeding disorders.
- Advocate for optimised access to orthopaedic surgery and general surgery at St. James's Hospital and dental care at all 3 centres.
- Make CHI the dental home for children with bleeding disorders.
- Work directly and collaboratively with the directors of the haemophilia service at CUH and CHI to highlight and address long standing deficiencies in human resources identified by sequential external audits.
- Work with CHI specifically, to advocate for funding for a link between the MyIndici and EPIC information systems.
- Work collaboratively with the management of the new National Children's Hospital to ensure the best possible service with minimal disruption for children with inherited bleeding disorders.
- Work collaboratively with the management of St. James's Hospital, the new National Children's Hospital and the coagulation centres to ensure optimum synergy in services for people with bleeding disorders on the St James' campus.
- Ensure that the national role of the Haemophilia Product Selection and Monitoring Advisory Board (HPSMAB) continues to be recognised and implemented.
- Work collaboratively within the National Haemophilia Council (NHC) to achieve a national line item in the annual HSE budget for haemophilia and inherited bleeding disorders.
- Work with the NHC to position haemophilia and inherited bleeding disorders as a national programme recognised by the HSE.
- Work constructively with the Hepatitis C Consultative Council to advance the needs of our members with hepatitis C.
- Work to expand access to the Long-Term Illness Card to all with inherited bleeding disorders.
- Maintain and develop strong collaborative relationships with the Blood and Tissue Policy team at the Department of Health (DoH) and at the HSE.
- Develop relationships as required with new hospital groups.
- Work with the DoH/HSE as required to facilitate access to gene therapy reimbursement for those who wish to avail of it.
- Advocate for more information on menstruation and heavy menstrual bleeding to be made available to all schools at 4th class level and older. This should include information from knowyourflow.ie, including an infographic.
- Organise regular team meetings at least twice annually for NCC and CHI and at least annually with CUH and University Hospital Galway.


# Therapeutic Environment

***Strategies:***

- Advocate for access to newly licensed therapies as required, both within the HPSMAB and externally with the DoH or HSE, if required.
- Continue to encourage access to high quality clinical trials for members.
- Organise a training course for selected members on concepts in therapy to identify potential future members to represent the Society on the HPSMAB.
- Measure the impact of new therapies and changes of therapies using surveys and specific quality of life assessment tools.
- Produce educational materials on new therapies in an accessible format, including videos and infographics.
- Circulate a list of acute hospitals which can provide emergency treatment for bleeding episodes – include a step-by-step guide on what to do in case of emergency.

# Haemophilia A and B

***Strategies:***

- Provide appropriate educational materials and meeting opportunities with members to deal with the complex and changing therapeutic environment.
- Ensure that the focus on haemophilia is not significantly diminished at the NCC compared to non-inherited bleeding disorder conditions.

# Von Willebrand Disorder

***Strategies:***

- Ensure this topic is covered at all main events.
- Send information materials and booklets out to non-members with VWD via comprehensive care or treatment centres, where possible.
- Increase the number of people with VWD on our membership and mailing lists.
- Work with comprehensive care centres to communicate clear treatment protocols, including for access to prophylaxis.
- Work with the HPSMAB to secure a budget uplift from the HSE for VWD treatment, as required.
- Consider a periodic separate e-zine on VWD.

# Rare Bleeding Disorders

***Strategies:***

- Ensure this topic is covered at all main events.
- Send information materials and booklets out to non-members with RBDs via comprehensive care or treatment centres, where possible.
- Increase the number of people with RBDs on our membership and mailing lists.
- Work with HPSMAB to secure a budget uplift from the HSE for RBD treatment, as required.
- Consider a periodic separate e-zine on RBDs.
- Produce updated material on RBDs.
- Provide specific services and support for each RBD as identified and as required.

# Women and Girls with Bleeding Disorders

***Strategies:***

- Produce and circulate a booklet on menarche in young girls to include information for parents on the potential requirement for hormonal therapy.
- Provide education to young girls and teenagers, and their parents, on menstruation.
- Organise a specific conference every second year.
- Organise webinars on relevant topics, as required.
- Provide free period products at all IHS events.
- Update current WGBD publications.
- Advocate for a gynaecology service at each comprehensive care centre and work with the centres to assist with this objective.
- Advocate for a required physiotherapy service for WGBD.
- Produce informative media for WGBD at each stage of life including menstruation, peri-menopause and menopause.

# Ageing

***Strategies:***

- Establish a peer support group to offer ongoing suggestions on programmes, events and advocacy and offer the opportunity for peer support.
- Provide relevant information via publications, website or events on nursing home issues, wills and probate, retirement issues and other relevant issues.
- Ensure there are pathways to access treatment for co-morbidities, co-ordinated by the NCC.
- Work with the centres to ensure that physiotherapy and care protocols are suited to the needs of an ageing population, including issues such as pain management, spinal stenosis and retaining mobility.
- Produce a new information booklet on Ageing and Haemophilia for targeted GPs who have patients with haemophilia, to include people with mild haemophilia.

# Mental Health

***Strategies:***

- Provide information on our website on mental health/psychology services available at the comprehensive care centres and advice on access to generic services.
- Liaise with the new psychologist at the NCC.
- Review options for mental health initiatives for the group aged 16 to 18 with inherited bleeding disorders.
- Review the requirement for peer support online and/or in person to include specific support for neurodivergent people.
- Look at options for including the topic of mental health at all of our conferences.

# Youth Activities

***Strategies:***

- Reorganise youth activities at conferences to optimise their benefit.
- Consider the Youth Group when planning educational sessions in the adults programme for main conferences.
- Work with centres to ensure the smooth transition from paediatric to adult services.
- Provide educational content on inherited bleeding disorders and living with the conditions during youth programmes at conferences.
- Identify potential new volunteers from the attendees at IHS events.
- Link information from the specific Trinity College website (www.steppingup.ie) to the IHS website.

# Children's Activities

***Strategies:***

- Reorganise and optimise children's programmes to include a full review of effectiveness, content and the opportunity for the introduction of educational content.
- Organise parent/child overnight events which could include activities designed to allow families to reset expectations on physical activities.

# International Developments

***Strategies:***

- Agree new twinning programme with another national member organisation (NMO) through the World Federation of Hemophilia (WFH).
- Identify appropriate volunteers, board members and staff members who would benefit from attending WFH, European Haemophilia Consortium (EHC) or other events, including youth training events.
- Agree details of collaboration with Haemophilia Northern Ireland of future collaboration, including a memorandum of understanding.

# Succession Planning

***Strategies:***

- Develop a succession plan for senior staff roles.
- Develop a plan for Board succession including a required skills review.

# Board

***Strategies:***

- Ensure, insofar as possible, age, gender, demographic and bleeding disorder variation in the community is reflected when candidates are considered for the Board.
- Consider active volunteers as a potential source of nominees for the Board.
- Introduce more formal induction training for new Board members.
- Integrate different Board members into work commitments with external bodies as required and on a planned basis.
- Utilise the skills of Board members to work with staff on specific projects.
- Introduce an exit interview/questionnaire for Board members when leaving the Board.

# Staff

***Strategies:***

- Continuously review staffing requirements in line with our strategic plan implementation requirements.
- Evaluate the need for an additional staff member to work on events.
- Ensure that staff receive appropriate training and upskilling required to allow for the evolution of roles within the team.
- Integrate different staff members into work commitments with external bodies as required and on a planned basis.
- Review and update policies, procedures and staff contracts, at least on an annual basis.
- Review and optimise requirements for outreach to members.

# Volunteers

***Strategies:***

- Develop a database of volunteer skills and qualifications.
- Ensure that volunteers have the opportunity to attend relevant lectures at conferences where feasible.
- Develop the work of the volunteer working group to be a strategic resource for the Society.
- Recognise the contribution of our volunteers with volunteer awards.
- Organise special needs training as required.
- Provide certificates for LinkedIn profiles.
- Assign a volunteer leader for each group and define their roles.

# Finance

***Strategies:***

- Maintain a strong and collaborative relationship with the HSE.
- Purchase an additional apartment close to St. James's Hospital before the opening of the new National Children's Hospital.
- Organise a new campaign on 'Planned Giving' to increase member participation.
- Encourage members to consider the Society when writing wills and legacies.
- Conduct an annual review of investment strategies and objectives for reserve funding.
- Include additional staff/Board members for meetings on pharmaceutical funding as required.
- Evaluate if the planned schedule of events for the 4-year period of the plan is achievable within our current or planned budget.
- Look into corporate finance/in-kind sponsorship from non-pharmaceutical companies, including from social media companies.

# Outreach

***Strategies:***

- Develop a tool to allow us to ascertain members' requirements in relation to outreach.
- Evaluate and plan requirements for home visits.
- Develop a regular outreach plan to new demographic groups within the membership, including families with bleeding disorders from Ukraine, Syria and Gaza.
- Link our outreach strategy to regional meetings where possible.

# Lifestyle

***Strategies:***

- Maintain and develop physiotherapy and online pilates classes for members.
- Assist members in building healthier lifestyles, via information and practical demonstrations, including on the topics of diet, exercise and physical activity.
- Demonstrate to groups of members the use of gym equipment during conferences.
- Look at the feasibility of doing aqua aerobics/swimming/hydrotherapy or similar activities for adults at conferences.

# Future Proofing

***Strategies:***

- Develop clear and proactive succession planning for key staff and Board roles.
- Work to increase our membership, particularly from those with VWD, RBDs, including platelet disorders, WGBD and those with mild bleeding disorders.
- Ensure that additional staff and/or Board members are upskilled to maintain and develop links with key contacts in the DoH, HSE, comprehensive care and treatment centres, pharmaceutical companies and other stakeholders.
- Develop risk register/mitigation strategies, including a section on adequate governance and oversight.

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