

# IRISH HAEMOPHILIA SOCIETY

## STRATEGIC PLAN 2020 – 2024



# Identity

The name of the Society will remain unchanged, but we will add a tagline underneath to make it clear we provide support for people with von Willebrand's, rare bleeding disorders and all inherited bleeding disorders.

## Suggested:

### **Irish Haemophilia Society**

*Representing people with haemophilia, von Willebrand's & other inherited bleeding disorders*

This could work on the website if separate sections on vWD and RBD on Homepage

- Produce a business card which can be distributed at the centers and available at reception clearly stating that we support people with Haemophilia, von Willebrand's and all inherited bleeding disorders.
- The tagline would need to specifically include mention of von Willebrand's except for the website where vWD would be on the homepage

# Publications and Digital Media

Our publications and digital media / social media strategies should include optimizing synergy with the new patient portal. All of our content should be made available to the NCC for the portal and we will ask for all the portal content to be made available to the Society for our use and dissemination. There will be a move toward more digital content (podcasts, videos) for use on social media and website.

## Action Plan

- Focus group to be established with NCC to look at content and roll out of the patient portal
- Contract health care workers and individuals to write specific content for our newsletters and publications.
- Attach QR codes to future publications to facilitate downloading. This will be very relevant for centers where our publications are displayed.

## Specific publication requirements agreed:

- Booklet on Pre-pubescent girls and menstrual bleeding
- Leaflets on Tranexamic acid, DDAVP and Low FVII based on infographics and our previously published Rare Bleeding disorders booklet required
- Updated booklet on von Willebrand's required

Better mechanism to ensure systematic replacement and replenishing of our publications at the three comprehensive care centres

- Requirement for a new information pack for newly diagnosed patients
- Develop a simple explanation/infographic to explain the coagulation cascade.
- Develop infographics on VWD, inheritance, new therapies

## Website

- Website to be redesigned and content to be re-evaluated
- Develop a regular e-mail update (possibly weekly) for members on our electronic list

## Social Media & Digital Media

- Include hashtags for vWD and RBD
- Produce podcasts
- Develop strategy on production and use of videos and use of YouTube
- Develop capability and culture of producing short videos on a regular basis - interviews with clinicians, at conferences, visitors to the office
- Add 100 new subscribers to our Ezine over next 12 months
- Develop capability to produce or source animations

## Events

Master schedule of events was agreed as follows;

### Annual:

- Maintain AGM / Conference in current format
- Maintain October Conference with some thematic alterations:
  - Integrate a lifestyle theme
  - More workshops / Interactive sessions
  - Sessions to be no more than 45 minutes to 1 hour
  - Continue with debates
  - Add specific tracks for vWD, RBD or mild haemophilia as numbers increase
- Hold Mild Haemophilia and Haemophilia B Information symposia on same day
- Annual vWD information day

## Every 2 years:

- Women's Conference
- Ageing Conference (alternating with Women's Conference)

## Every 3 years:

- Parents Conference
- In 2024 - organize 2 night vWD Conference
- Young Adult Conference - Pilot conference in 2020 linked to WISH project, co-funded with EHC
- Supply QR codes for booking forms

## Events 2021-2024

### 2021

- AGM
- October Conference
- Mild & Haemophilia B Info Day
- VWD Info Day
- Ageing Conference

### 2022

- AGM
- October Conference
- Mild & Haemophilia B Info Day
- VWD Info Day
- Women's Conference – vWD track
- Parents Conference

### 2023

- AGM
- October Conference
- Mild & Haemophilia B Info Day
- VWD Info Day
- Ageing Conference

2024

- AGM
- October Conference
- Mild & Haemophilia B Info Day
- VWD Info Day
- Women's Conference

**To be decided:**

Frequency of conference for young adults and specific conference / information days for rare bleeding disorders

## Lifestyle

With the rapidly changing therapeutic environment for haemophilia, our focus should move away from solely dealing with or educating on bleeding but more proactively on lifestyle. People with haemophilia will have lower annual bleed rates, will be capable of being more active and should be optimizing their activity levels and quality of life. This focus should include information, education and event related activity on diet, BMI, exercise, mental health.

### Action list

- Healthy food at conferences for both adults and children
- Education on responsible consumption of alcohol
- Assisting members in developing enhanced lifestyle including diet and exercise. This will include:
  - Specific workshops/ lectures at conferences on diet, exercise, activity

### Exercise sessions at conferences

- Demonstrations to groups of members on use of gym equipment at hotel gyms during conferences
- Specific programme on lifestyle and exercise with physiotherapists to enable individuals to develop a plan to continue with appropriate exercise/ activity
- Work with physiotherapists to identify facilities members could use in their local area

### Set Activity Goals for 4 age groups

- Children – teaching good movements
- Young people – identifying sports they're interested in

- 20s-40s with possible target joints – adapting exercise with this in mind
- Older people – maintaining mobility

### **Mental health**

- Involve the psychologist from the centre
- Focus on Attitude readjustment
- Organize sessions or courses on Mindfulness and meditation

## **Von Willebrands Disease**

There is a clear need for the Society to focus more on vWD. There are approximately 1200 people with vWD in Ireland. We have 120 on our mailing list. The major obstacle in the past has been the reluctance of the centres to send unsolicited mail from the Society out to those with vWD on their register.

### **Action list**

- A mechanism has been agreed with CHI Crumlin to make our information available to all with vWD on their register
- A mechanism has been agreed to send our booklets and meeting info to all with vWD who are enrolled in the 2 vWD studies (290 people)
- Appoint 2 members to vWD Research group at RCSI / NCC
- We need to advocate to change the official designation to von Willebrand Disorder
- Continue annual vWD information days
- As numbers increase, consider separate vWD track at our major conferences
- Consider organising pilot vWD programme in collaboration with EHC & AFFIRM project by Board member
- Increase number of people with vWD on our mailing list and/or membership list to enable us to organize a full weekend vWD conference by 2024
- New tagline and business card for centres to promote vWD
- Work to encourage centres to produce clear protocols for vWD treatment and care, to include examination of options for home treatment or prophylaxis
- Produce new booklet on vWD
- Utilise ethnographic videos on vWD
- Consider dedicated section in magazine on vWD
- Consider separate vWD E-Zine
- Highlight role of Irish treaters as leaders of vWD Research globally
- Highlight vWD, as theme of our World haemophilia day event in 2020

## Rare Bleeding Disorders

Similar actions to those taken with vWD should be applied to rare bleeding disorders. We need to increase engagement of those with deficiencies in FV, FVII, FX, FXI or FXIII. In addition the 2 largest cohorts under RBD in Ireland (with more than 200 people in each cohort) are Platelet disorders and bleeding disorders of unknown aetiology.

### Actions

- A mechanism has been agreed to send our rare bleeding disorders publications to all relevant families on CHI register
- Produce specific leaflets on DDAVP, Tranexamic acid and low FVII levels
- Produce specific leaflets and infographics on each individual factor deficiency
- Requirement to liaise with state authorities (HSE, Dept. of Social Protection) to recognize severe RBD similar to severe haemophilia

## Women with Bleeding Disorders

### Actions

- Produce booklet on pre-pubescent girls and menorrhagia
- Work with Dr Lavin on the *Knowyourflow* website and expand to *TikTok* and other platforms as required
- Add leaflet to new information pack on girls with haemophilia /carriers
- Link with EHC and EAHAD activities and publications in this area
- Lecture on girls with mild haemophilia at parent's conference
- Women and Bleeding disorders conference every second year

## Ageing

### Actions

- Send Ageing and Haemophilia booklets to primary care centres
- Provide assistance, support and information for members dealing with issues including wills, retirement planning, nursing homes
- Discuss "Men's Matters" issues including bowel and prostate cancer
- Develop programme or strategies to assist members in developing resilience

- Develop pilot programme for older men with haemophilia looking at positive lifestyle changes - diet and exercise
- Identify new title for Ageing conference
- Organize ageing conference every second year with a non- conference event in the other year
- Establish ageing working group to meet three times per year
- Work with NCC to clearly define protocols from NCC for dealing with ageing and haemophilia

## Teenage Boys

### Actions

- Produce specific publication for teenage boys
- Consider specific event- in conjunction with Centres
- Liaise with NCC regarding outcomes of their focus group for teenage boys

## Advocacy and External influence

### Actions

- Cultivate relationships with new people in DOH, Hospitals etc. (New Minister, Oireachtas Health Committee, Opposition Spokespeople, Paul Reid)
- Reiterate strong message that haemophilia is a major success story – massive savings have been made due to ongoing work of HPSMAB. This should lead to re-investment in comprehensive care
- Work to optimize availability of beds for people with Haemophilia and inherited bleeding disorders in H and H ward in St. James's
- Work to optimize availability of timely access to orthopaedic surgery
- Work to ensure that haemophilia service in national centre is not diminished or integrated with wider benign haematology services
- Work to clarify and / or establish separate funding streams for haemophilia - Treatment products and operational as national line items
- Organise meetings with DOH / HSE and relevant people to examine mechanisms for access to gene therapy when licensed.
- Establish relationships with key individuals in new structures which will replace HSE
- Work to optimize benefit of IPATH and von Willebrand research projects to members
- Ensure members use Home treatment app and Bleeding disorders alert cards



# Enhanced service to members

## Actions

- Designated Haemophilia / BD information stand at new children's hospital
- I.H.S. staff attendance at clinics at new Children's hospital

# Therapeutic Environment

## Actions

- Continue production of novel therapies newsletter twice per year in collaboration with EHC
- Produce information on Current and Novel Therapies in a more accessible form - infographics, animations, videos etc.
- Continue strong work of HPSMAB and ensure Society role in and influence on decisions is maximized to ensure access to safest and most effective treatment options in a timely manner
- Provide ongoing comprehensive and comprehensible information on treatment options to members via educational materials at different levels and conferences/ meetings
- Organise ongoing specific product or therapy class (e.g. Gene Therapy) meetings for members as developments warrant
- Work to ensure clearer treatment protocols and pathways to care for those with vWD
- Ensure access to new generations of therapy including Gene Therapy as required
- Measure impact of new and existing therapies on quality of life and utilize outcome measures for advocacy for continued access to best available therapies

# Human Resources and Governance

## Volunteers

## Actions

- Facilitate attendance of volunteers at conference lectures- planned in advance to allow all interested volunteers to choose a session they would like to attend
- Maintain updated database of volunteer skills and qualifications

- Volunteers to be encouraged to fill out evaluation form after each event
- Carry out a volunteer drive (colleges, nursing and dental schools, grant recipients, friends and family)
- Ensure volunteers are valued and supported

## Board

### Actions

- Co-opt two additional people to the board after AGM in 2020
- Email staff after monthly board meetings with all relevant decisions made.

Invite new board members into the office to be introduced to staff.

Organise social interaction for board and staff once a year.

- Put staff and board photos up on blue stands with a short bio at main conference
- Consider adding a board member who does not have haemophilia. (volunteer)

## Staff

### Actions

- Circulate staff roles to the board.
- Succession planning
- Encourage members to call in to the office to meet staff
- Implement faster training for staff when roles change
- Provide basic level of knowledge to all staff on benefits and entitlements for members for dealing with queries

## Finance / Viability

### Actions

- Purchase additional house or apartments for Society in location convenient to St. James's / new children's hospital
- Continue effective work on HPSMAB. Measure impact on an ongoing basis and ensure DOH and HSE are aware of impact of this work
- Obtain additional volunteer or staff expertise to broaden base of knowledge in vital area of product knowledge and selection