

Irish Haemophilia Society

Celebrating

50

Years



1968 – 2018



Foreword

We explored a variety of options and planned many different activities for our 50th Anniversary year in 2018. As you look through this souvenir booklet, I believe I am justified in saying that the year exceeded our expectations in terms of the events organised, the memories evoked, and the recognition gained by the Society.



I want to acknowledge the team who started planning the events with me in late 2016 – Traci Marshall Dowling, Mary Clare Delaney, Margaret Dunne, Debbie Greene and John and Geraldine O'Mahony. Our aim was to commemorate the past and celebrate the Society's achievements, while also looking to the future.

Our 50th Anniversary AGM had the highest ever attendance. The wonderful memory room featuring old photos and paraphernalia was greatly appreciated by members as a commemoration of the past, juxtaposed with the exciting developments in treatment and research highlighted at the conference. The presence of the Minister of Health at this celebration added to the occasion. This was followed by the lighting up in red of several major public buildings for World Haemophilia Day on April 17 - an initiative we hope to make an annual event. On the same day, we had a billboard unveiled in Dublin and a permanent art installation in the main lobby of St. James's Hospital which houses the NCC. The movie on the history of the Society 'Facing the Rising Sun', also premiered in April. In September, we organised a Gala Fundraising Dinner; a celebration of a community who have not just survived but prospered. Our entire 50th programme was recognised as we won Patient Organisation Project of the Year at the annual Irish Healthcare Awards in October.

2018 was a truly momentous one for the Society. It was moving and emotional to see so many members who are no longer with us being remembered. It was great to see some old friends who re-emerged to celebrate and commemorate with us. It was motivating and reassuring to see this community, who have weathered so many storms and tragedies together, emerge into the daylight as a strong, cohesive community who offer each other great support, friendship, kindness and real sense of family. It is immensely reassuring to be celebrating our 50th anniversary at a time of such profound change in treatment for haemophilia.

Roll on the 60th anniversary, I for one cannot wait.

Brian O'Mahony





50th Anniversary AGM & Conference

Our AGM and Conference in April had a record attendance of 350 members and was a great celebration of, and by our community.

In retrospect, Storm Emma did us a favour as we had to move the conference to April from the original March dates - and this was the beginning of an extraordinary week and month of April. At the conference - officially opened by Minister for Health, Simon Harris, TD - we awarded life memberships to our outgoing Chairperson, Traci Marshall Dowling and Teresa Mulvey, who made a major contribution as a member of the staff team in the difficult years of the 1990's; and to two doctors from abroad who have been stalwart supporters of the society and our events for many years; Dr. Bruce Evatt from Atlanta and Dr. Paul Giangrande from the UK. We also unveiled a memories room which featured artefacts, old newsletters, photographs and memories for so many in our community.





World Haemophilia Day

World Haemophilia Day followed the AGM on Tuesday April 17th and began with Society representatives appearing on national breakfast television; Ireland AM on TV3. Later that morning we unveiled a billboard on Macken St. Dublin with a specially commissioned artwork by renowned street artist Shane O'Malley. Following this, a permanent painting, also by Shane was unveiled in the main lobby of St. James's Hospital to mark our 50th Anniversary. This was an appropriate location as St. James's have journeyed with us on days of despair and hope and progress since 1977. The day culminated with several iconic buildings – incl. Liberty Hall, Dublin Convention Centre, RCSI, Stephen's Green Shopping Centre and more - being lit up in red to mark World Haemophilia Day 2018.



The same week, Brian took the reins of the @Ireland Twitter account with 67,000 followers, to tweet about the Society's history, hopes, 50th Anniversary and World Haemophilia Day, among other things.





Movie Premiere

Later in April, we had a cinema premiere for our movie on the history of the society 'Facing the Rising Sun'.

This movie, the product of countless hours of interviews, digitising, collating and reviewing archive footage and weaving together the story of the Society was directed by Academy Award nominated director Goran Kapetanovic from Sweden. The premiere at the restored Art Deco Stella Cinema in Dublin was a profoundly moving experience. The movie was previously premiered for all of our members at the AGM and physical copies were made available free of charge to all of our members, and to any person interested from our website.



Gala Fundraising Dinner

In September the Society hosted a 'Gala Fundraising Dinner'. The evening included an auction which contained some amazing sports memorabilia including a signed boxing glove from Muhammed Ali, a signed 'Grand Slam' 2018 Ireland rugby jersey, signed GAA county jerseys, signed ties or scarves from all political party leaders and many other items. A special thanks to Ger O'Reilly and Kieran McHugh for all their work on this, especially the auction.

The Member's Conference in October 2018 included a retrospective look at the commemorative events of the year and members were informed that the previous week, the Society had won an Irish Healthcare Award for patient organisation project of the year for our suite of 50th Anniversary programmes and commemorations.

