

Irish Haemophilia Society

AGM & Conference

ADULTS PROGRAMME

3rd - 5th March 2017

Slieve Russell Hotel, Co. Cavan



FRIDAY 3rd MARCH

- 5.30pm - 8.00pm **Registration** (*Cranaghan - Pre Conference Area*)
To allow members to register on Friday evening and to attend the buffet dinner and presentation, we will be keeping registration open for a longer period this year.
- 7.00pm - 8.00pm **Buffet Dinner** (*Cranaghan Suite 1*)
*An opportunity for everyone to come together for an informal buffet dinner. **Parents please note that no activity will take place on Friday evening for children. We would ask you to ensure that your child/children are supervised on Friday evening.***
- 8.00pm - 9.00pm **HISTORY OF THE IRISH HAEMOPHILIA SOCIETY** (*Cranaghan Suite 1*)
Speaker: Mr. Brian O'Mahony, Chief Executive, I.H.S.
Panel: Mr. Kieran McHugh, Mr. Jim O'Leary, Mrs. Hilary O'Sullivan.
Join us for this very interesting presentation and panel discussion on the history of our organisation.

SATURDAY 4th MARCH

- 9.15am - 10.00am **Registration** (*Cranaghan - Pre Conference Area*)
- 10.00am - 12.30pm **ANNUAL GENERAL MEETING** (*Cranaghan Suite 1*)
- 12.30pm - 1.30pm **Lunch** (*Cranaghan Suite 2*)
- 1.30pm - 2.30pm **iPATH: NEW RESEARCH PROJECT** (*Cranaghan Suite 1*)
Chair: Mr. Brian O'Mahony, Chief Executive, I.H.S.
Speaker: Professor James O'Donnell, National Coagulation Centre, St. James's Hospital.
Join us for this information session on the new iPath (Irish Personalised Approach for the Treatment of Haemophilia) Research Project which will involve researching fundamental questions on haemophilia.
- 2.30pm - 3.00pm **Tea/Coffee Break** (*Cranaghan - Pre Conference Area*)
- 3.00pm - 4.00pm **AN UPDATE ON HAEMOPHILIA CARE** (*Cranaghan Suite 1*)
Chair: Mr. Brian O'Mahony, Chief Executive, I.H.S.
Speaker: Dr. Barry White, National Director, National Coagulation Centre, St. James's Hospital.
The National Director will give updates on service developments, new treatments and information on the new National Coagulation Centre and the Lighthouse Project.
- 4.00pm - 5.00pm **OPEN FORUM WITH COMPREHENSIVE CARE CENTRES** (*Cranaghan Suite 1*)
Chair: Dr. Barry Harrington, Chairperson, National Haemophilia Council.
Panel: Dr. Barry White, National Director, National Coagulation Centre.
Dr. Beatrice Nolan, Paediatric Consultant Haematologist, O.L.C.H.C.
Dr. Alison Dougall, Consultant in Special Care Dentistry, Dublin Dental University Hospital.
Ms. Evelyn Singleton, Haemovigilance Officer, National Coagulation Centre.
Ms. Ruth Hunter Nolan, Quality Assurance Officer, National Coagulation Centre.



- 5.00pm **CRECHE, CUBS, KIDLINK & YOUTH GROUPS MUST BE COLLECTED BY PARENTS FROM THEIR RESPECTIVE ROOMS AT 5.00PM SHARP**
- 5.00pm **FAMILY TIME - VOLUNTEERS OFF DUTY FOR REST OF EVENING**
- 7.15pm **Gala Dinner** (*Cranaghan Suite 1 & 2*)
The evening will start with an Awards Ceremony, followed by dinner and entertainment. Parents please ensure that children are supervised and remain seated during the Gala Dinner.
- 11.00pm **AS PER THE I.H.S. CHILD PROTECTION POLICY, CHILDREN MUST VACATE THE FUNCTION ROOM BY 11.00PM.**

SUNDAY 5th MARCH

- 10.00am - 11.00am **VIETNAM: WHAT IS THE G.A.P. PROGRAMME?** (*Cranaghan Suite 1*)
Chair: Mr. Alain Weill, President of the World Federation of Hemophilia (W.F.H.)
Speakers: Dr. Nguyen Hoang Nam, Deputy Head of Clinical Haematology Department, National Children's Hospital, Hanoi, Vietnam.
 Mr. Alain Weill, President of the W.F.H.
Dr. Nam and Mr. Weill will update members on the W.F.H. G.A.P. (Global Alliance for Progress) programme that has commenced in Vietnam and which will improve haemophilia treatment for people with haemophilia in Vietnam.
- 11.00am - 11.30am **Tea/Coffee Break** (*Cranaghan - Pre Conference Area*)
- 11.30am - 12.30pm **CARRIERS DISCUSSION GROUP** (*Cranaghan Suite 1*)
Chair: Ms. Traci Marshall Dowling, Chairperson, I.H.S.
Speakers: Ms. Anne Duffy, Gestalt Therapist.
 Dr. Alison Dougall, Consultant in Special Care Dentistry, Dublin Dental University Hospital.
This session will start with a short presentation from Ms. Anne Duffy, followed by an informal discussion on carrier issues such as carrier testing, family planning, pregnancy, menopause, positive living and dental care.
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- INHIBITORS DISCUSSION GROUP** (*Claddagh Suite*)
Facilitators: Dr. Beatrice Nolan, Paediatric Consultant Haematologist, O.L.C.H.C.
 Mr. Jim O'Leary, Executive Board, I.H.S.
An informal discussion group which will give members with inhibitors an opportunity to meet other members, to ask questions and to learn from each other.
- 12.30pm - 1.45pm **WORKSHOP: NEW DEVELOPMENTS IN TREATMENT** (*Cranaghan Suite 1*)
Chair: Mr. Brian O'Mahony, Chief Executive, I.H.S.
Speaker: Dr. Beatrice Nolan, Paediatric Consultant Haematologist, O.L.C.H.C.
Join us for this very exciting workshop which will look into the improved treatments that are on the horizon or currently available, including gene therapy and extended half-life factor.
- 1.45pm **PARENTS PLEASE NOTE:**
CRECHE, CUBS, KIDLINK GROUPS TO BE COLLECTED FROM VARIOUS ROOMS AT 1.45PM SHARP.
YOUTH GROUP TO BE MET BY PARENTS AT THE END OF THE LAST TALK IN CRANAGHAN SUITE 1.
- 2.00pm - 3.00pm **Buffet Lunch** (*Cranaghan Suite 2*)

MEMBERS, PLEASE REMEMBER TO SIGN IN BEFORE ATTENDING EACH SESSION.

