AGM & CONFERENCE 2020

MARCH 6TH – 8TH 2020 I SLIEVE RUSSELL HOTEL, CO CAVAN

ADULT PROGRAMME

Friday March 6th

17.00 – 19.00 Registration (Cranaghan Pre Conference Area)
19.00 – 20.00 Buffet Dinner (Cranaghan Suite)

Saturday March 7th

09.00 – 10.00 Registration (Cranaghan Pre Conference Area)
10.00 – 12.15 Annual General Meeting (Cranaghan Suite 1)
12.15 – 13.15 Lunch (Cranaghan Suite 2)

13.15 – 14.15 Gene Therapy (Cranaghan Suite 1)
A major area of development in haemophilia is in gene therapy. Gene therapy is intricate and complicated. Our guest speaker from the Royal Free Hospital in the UK will give an overview of this complex and fascinating subject.
Chair: Chair: Mr. Matthew McCabe, Member of I.H.S. Executive Board
Speaker: Emeritus Professor Edward Tuddenham MD, Royal Free Hospital, UK

14.15 – 15.15 Everything you need to know about Emicizumab (Hemlibra) (Cranaghan Suite 1)
Find out everything you need to know about this exciting new therapy for people with factor VIII deficiency. This new treatment option is a very significant step forward for people with haemophilia A.
Chair: Mr. Brian O'Mahony, CEO, I.H.S
Speakers: Dr. Niamh O'Connell, National Director & Consultant Haematologist, NCC
Dr. Beatrice Nolan, Paediatric Consultant Haematologist, OLCHC

15.15 – 15.45 Coffee Break (Pre Conference Area)

15.45 – 16.30 An Open Forum with the Comprehensive Care Centres (Cranaghan Suite 1)
Do you have a question to ask one of the team? Would you like to get clarification on something? Our panel will be happy to answer your questions in relation to haemophilia care in Ireland.
Chair: Mr. Brian Fitzgerald, Chairperson, National Haemophilia Council
Panel: Dr. Niamh O'Connell, National Director & Consultant Haematologist, NCC,
Dr. Beatrice Nolan, Paediatric Consultant Haematologist, OLCHC
Dr. Alison Dougall, Dentist, NCC

16.30 – 17.00 e-Health & Patient Portal Workshop (Cranaghan Suite 1)
An interactive workshop to discuss this new and advanced e-health system for people with inherited bleeding disorders. This patient portal will offer people the opportunity to see and contribute to their own medical records and to interact electronically with their health care team.
Speaker: Dr. Niamh O'Connell, Consultant Haematologist

CRECHE, CUBS, KIDLINK, YOUTH GROUPS MUST BE COLLECTED BY PARENTS FROM THEIR RESPECTIVE ROOMS AT 17.00 SHARP

17.00 – 19.15 Family Time - Volunteers Off Duty
19.15 – 23.00 Gala Dinner (Cranaghan Suite)

AS PER THE I.H.S. CHILD PROTECTION POLICY, CHILDREN MUST VACATE THE FUNCTION ROOM BY 11.00PM

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Sunday March 8th

10.00 – 10.45 Twinning with Jordan: A Progress Report (Cranaghan Suite 1)
The WFH Twinning Programme links haemophilia organisations and treatment centres in developing and developed countries and has improved treatment for people with haemophilia in many countries. The I.H.S. are currently twinned with the haemophilia organisation in Jordan. An update will be given on progress during this session.
Speakers: Mr. John Stack, Chairperson, I.H.S.
Professor Arafat Awajan, Vice-President, Jordanian Thalassemia & Hemophilia Society

10.45 – 11.30 iPATH – An Update on this Innovative Research Project (Cranaghan Suite 1)
The iPATH study seeks to revolutionise the current 'one size fits all' standard of treatment that has been in place for more than fifty years and develop a new personalised treatment approach that will tailor treatments based on the needs of the individual patient. The iPATH team will give an update on this pioneering project.
Chair: Mr. Brian O'Mahony, CEO, I.H.S.
Speakers: Professor James O'Donnell, Director, Irish Centre for Vascular Biology, RCSI
Professor Padraic Fallon, Professor of Translational Immunology, TCD
Ms. Megan Kennedy, BSc (Hons) Physiotherapist, TCD & St. James's Hospital

11.30 – 12.00 Coffee Break

12.00 – 13.00 Focus on Lifestyle (Cranaghan Suite 1)
Find out more on the effects that lifestyle has on your health. Lifestyle includes a wide range of activities including diet, exercise, stress and many other topics that will be discussed.
Speakers: Ms. Sheila Roche, Clinical Specialist Physiotherapist in Haemophilia, St. James's Hospital
Mr. Mark McGowan, Clinical Specialist Physiotherapist in Haemophilia, St. James's Hospital

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13.00 – 14.00 Lunch and Depart (Cranaghan Suite 2)

STAY CONNECTED WITH THE I.H.S.

Keep up-to-date with the latest from the Irish Haemophilia Society on:

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