

European Haemophilia Consortium Round Table of Stakeholders

Tenders and Procurement of Coagulation Factor Concentrates: A European Survey of 38 Countries

Monday, 15th June 2015, 15:30 to 18:30
Residence Palace, Brussels, Belgium

Speakers' biographies

Brian O'Mahony

President, European Haemophilia Consortium (EHC)

Brian O'Mahony is the Chief Executive of the Irish Haemophilia Society. He represents the Society on the statutory National Haemophilia Council and he is the Vice-Chair of the Tender Commission, established by the Irish Government for the Procurement of factor concentrates. He previously served as Chair of the Irish Haemophilia Society for 17 years and as President of the World Federation of Hemophilia (WFH) for 10 years. He continues to work as a volunteer with the WFH. Among his activities are writing, advocating, and facilitating training. His publications for the WFH include Monographs on Advocacy, Developing Haemophilia Organisations, Economics and Health Technology Assessments and a Guidebook on National Tender Systems.

A medical scientist by profession, he is a Fellow of the Institute of Biomedical Sciences (UK) and a Fellow of the Academy of Medical Laboratory Sciences (Ireland). He has post-graduate qualifications in Management and in Occupational Health and Safety. He spearheaded the advocacy initiatives in Ireland, which resulted in the availability of prophylaxis for children and recombinant products for all people with haemophilia, compensation and life insurance for those affected by transfusion transmitted infections and a formal role for the Haemophilia Society in decisions on national haemophilia health care policy.

He is the convenor of the Platform for Plasma Users (PLUS), which advocates on plasma and blood related issues with European Institutions on behalf of several non-governmental organisations. He has served on the Steering Committee of the European Haemophilia Consortium (EHC) from 2007 to 2011. He was elected President of the EHC in 2011 and currently holds this position.

Brian has severe haemophilia B.

Mr Declan Noone

Chair, EHC Data and Economics Committee

Declan Noone served on the Irish Haemophilia Society (IHS) committee for three years before stepping down in 2008 to take up a full-time position as staff member of the IHS. Among his roles, he represents the IHS on the Haemophilia Product Selection Monitoring and Advisory Board (HPSMAB), which chooses the products used in Ireland for the treatment of haemophilia and other related conditions. He also works on Hepatitis C and access to treatments. He regularly contributes to the development of new publications for the IHS.



In 2014, he became a member of the World Federation of Hemophilia (WFH) and currently sits on its Educational Materials Committee, Data and Demographics Committee and Safety and supply Committee. He is also the current chair of the European Haemophilia Consortium (EHC) Data and Economics Committee.

He has co-authored papers on the quality of life in people with haemophilia, surveys on access to haemophilia care in Europe and the WFH Monograph entitled “An Introduction to Key Concepts in Health Economics for Haemophilia and a recent paper on European procurement methods.

Mr Noone trained as a medical mechanical engineering and completed a Master’s degree in medical engineering.

Prof Paul Giangrande

Chair, EHC Medical Advisory Group

Prof Paul Giangrande is the chair of the European Haemophilia Consortium (EHC) Medical Advisory Group (MAG), he has been in this position since 2013.

Prof Giangrande has recently (June 2015) retired from his position as consultant haematologist at the Oxford University Hospitals NHS Trust where he was also the Director of the Oxford Haemophilia Centre.

Prof Giangrande qualified in Medicine from the University of Manchester in 1979 after previously obtaining a First Class Bachelor of Science (BSc) degree in pharmacology. After obtaining postgraduate qualifications in both adult and paediatric medicine, he trained in haematology in various major hospitals in London. He obtained a research doctorate in 1991 for his work at the Royal Free Hospital in London on immunological aspects of haemophilia treatment. He subsequently worked at the Milan Haemophilia Centre with Professor Mannucci between 1989 and 1990, before being appointed to his position in Oxford in 1991.

He served as elected Vice President (Medical) of the World Federation of Hemophilia (WFH) from 2000 to 2008 inclusive and has wide international experience in the field.

Prof Cédric Hermans

Head of the Haematology Service, Cliniques Universitaires Saint Luc

Professor Cedric Hermans currently works at the Haemostasis and Thrombosis Unit, Division of Haematology at the Catholic University of Louvain, Brussels, Belgium.

Cedric completed his medical training and specialisation in general internal medicine at the Medical School and the Saint-Luc University Hospital of the Catholic University of Louvain. He obtained his PhD in Biomedical Sciences, specialising in Toxicology, in 1999. In 2000 he took up a one-year fellowship in the Haemophilia Centre and Haemostasis Unit of the Royal Free Hospital, London.

Cedric was appointed Associate Professor at the Medical School of the Catholic University of Louvain in 2003, Clinical Professor in 2009 and Ordinary Professor in 2012. He is currently heading the Division of Haematology and the Haemostasis and Thrombosis Unit of the Saint-Luc University Hospital, Brussels.

Cedric has published over 120 articles in international journals and is a member of several scientific societies and advisory boards. He is the Vice-President of the European Association for Haemophilia and Allied Disorders (EAHAD).



Presently, his main research interests lay in the area of haemostasis and thrombosis, especially clinical studies on the treatment of haemophilia, new anticoagulants, and the management of thrombosis.

Mr Miguel Crato

President, Associação Portuguesa de Hemofilia

Miguel Crato is currently President of the Portuguese Haemophilia Society.

Mr Crato has been contributing as a volunteer to the activities of the European Haemophilia Consortium (EHC) with regard to access to therapy. In 2014, he spoke at the World Haemophilia Day event held in the Paul-Ehrlich-Institut in Langen, Germany where the Kreuth III recommendations on minimum standards for haemophilia treatment were presented.

Mr Crato is a regular contributor to the EHC newsletter, where he often outlines the negative effects of the financial crisis on haemophilia care in his country. He also reports on events organised by the Portuguese National Member Organisation.

He is now leading efforts to increase the sharing of knowledge and experience when it comes to the treatment of haemophilia, with a new focus on patient care and communication. He has a strong interest in finding new ways in which haemophilia patients and their families can be equipped better to deal with their condition.

Dr Edward Laane

Senior Consultant Haematologist – Lecturer, North Estonia Medical Centre Foundation

Dr Edward Laane holds the position of Senior Consultant Haematologist and Lecturer at the North Estonia Medical Centre Foundation. At present Dr Laane is a research scholar at the Dana-Farber Cancer Institute in Boston, USA.

Dr Laane graduated in Medicine at Tartu University where he also completed his training in haematology. Dr Laane holds a PhD from the Karolinska Institute in Stockholm in oncology and experimental oncology. He also holds a PhD from Tartu University on flow cytometry studies in haematology.

Since 2006, Dr Laane has been working at the North Estonia Medical Centre where he headed the Department of Haematology from 2008 to 2012. Since 2008, Dr Laane has also been appointed as Lecturer at Tartu University.

Throughout his professional career, Dr Laane has focused on the improvement of haemophilia care. He introduced the first independent haemophilia nurse position in Estonia. He also started a clinic for people with bleeding disorders.

Dr Laane served as the President of the Estonian Haematology Society from 2010 to 2013. Since 2014, Dr Laane is working together with Helsinki University Hospital Coagulation Centre as part of a Twinning Program of the World Federation of Haemophilia.

Dr Laane is a member of numerous scientific organizations and has given scientific advice to the European Medicine Agency. Dr Laane has organised multiple international educational meetings, including with the European Haematology Association Type I Tutorial on Thrombosis, Haemostasis and Iron in 2014. Furthermore, he has organised many educational days for patients in Estonia.



Mr Jaroslav Kračún

Legal Officer, Unit Innovative and e-procurement, DG GROW, European Commission

Jaroslav Kračún has been working at the European Commission, Directorate General for Internal Market and Services (DG GROW) since 2008. His main focus has been public procurement legislation and enforcement as well as innovation policy. He is currently responsible for the Czech Republic, Slovakia and Slovenia.

Mr Kračún holds a Master's Degree in International Business Law from the Université Paris 1, Panthéon-Sorbonne in Paris and a Postgraduate degree in International Business Law from the ESSEC Business School in France.

Prior to joining the European Commission, Mr Kračún worked at the Gide Loyrette Nouel International Law Firm in Prague.

Prof Flora Peyvandi

Director, Haemophilia and Thrombosis Centre Angelo Bianchi Bonomi

Prof Flora Peyvandi was born on 29 November 1964 in Iran. In 1984, Flora moved to Italy and enrolled as a student in the Faculty of Medicine at the University of Milan. She obtained her MD degree in October 1991. Flora trained at the distinguished Department of Medicine, Ospedale Maggiore, University of Milan, under the supervision of Professor Mannucci, qualifying in 1996 as a specialist in Haematology.

Flora, aware of the lack of knowledge in Europe of rare haemostatic disorders, and their increased frequency in her mother country Iran and other Middle East countries, initiated a research project on Rare Coagulation Disorders. One aspect, Factor VII deficiency, became the initial focus of her PhD thesis. In 1996, after phenotype characterisation in Milan, of an international patient group, Flora characterised the underlying genetic mutations at the Royal Free Hospital, University College, London. This molecular characterisation was performed during 1996-1998 at the Katharine Dormandy Haemophilia Centre, and led to the publication of a number of peer reviewed manuscripts in leading haematological journals. However in order to characterise the functional effects of these diverse mutations and molecular lesions Flora trained (again) under the supervision of Professor Kenneth Bauer at Boston, VA Hospital, Harvard University. Between 1998-1999 Flora performed in vitro expression analysis, recombinant protein production and subsequent characterisation of the most interesting factor VII gene mutations.

In May 1999, Flora returned to the Angelo Bianchi Bonomi Centre, Fondazione Luigi Villa, University of Milan, Ospedale Maggiore to continue and expand her research on rare bleeding disorders. Flora developed a new research field and laboratories in the Centre. A molecular biology laboratory with facilities for expression studies was created. Flora also returned to clinical activity forming a link between patient and clinical science.

In February 2005 Flora was awarded the Associate Professorship of Internal Medicine at the University of Milan, organising a course in Molecular Medicine. Flora leads the group at the Molecular and Cell Biology laboratory of the Angelo Bianchi Bonomi Centre, Fondazione Luigi Villa, focussing on the molecular characterization of patients with haemophilia, thrombophilia, thrombotic thrombocytopenic purpura (TTP) and those affected by rare coagulation disorders.



Dr Paul Rübzig*Member of the European Parliament*

Paul Rübzig, born in Upper Austria, has been a member of the European Parliament (EP) since 1996 and belongs to the European People's Party (EPP). He is the owner of an Austrian blacksmith company and has a degree in Business administration, marketing and production engineering from the University of Linz, Upper Austria. He is married and has two children.

Paul Rübzig is the Vice-Chair of the EP's Delegation for relations with the Korean Peninsula. He is a member of the EP's Committee on Industry, Research and Energy and of the Committee on Budgetary Control. He is a substitute member of the Delegation for relations with Switzerland and Norway and of the EU-Iceland Joint Parliamentary Committee and the European Economic Area (EEA) Joint Parliamentary Committee, as well as a substitute member of the EP's Committee of Development.

Paul Rübzig is very active in the field of the small-scale business promotion. He is president of SME Global, a working group of the International Democrat Union (IDU), whose objective it is to support small and medium-sized enterprises (SME) and to improve their business environment. Paul Rübzig is also Chair of STOA (Science and Technology Options Assessment), an official body of the European Parliament that is supported by external experts such as universities, scientists or research institutes.

