

European Haemophilia Consortium

World Haemophilia Day 2017

Wednesday 19 April 2017

**EDQM
Strasbourg, France**

Speaker biographies

Dr Susanne Keitel

Director, EDQM

Dr Susanne Keitel is a licensed pharmacist with a PhD in pharmaceuticals. Following ten years of experience in the pharmaceutical industry, she held various senior positions at the German Federal Institute for Drugs and Medical Devices (BfArM). In October 2007, Dr Keitel was appointed Director of the European Directorate for the Quality of Medicine & HealthCare (EDQM), a directorate of the Council of Europe in Strasbourg.

Mr Brian O'Mahony

President, EHC

Mr Brian O'Mahony is the chief executive of the Irish Haemophilia Society (IHS). He represents IHS on the statutory National Haemophilia Council and is the vice-chair of the Tender Commission, established by the Irish government for the procurement of factor concentrates. He previously served as IHS chair for 17 years and as president of the World Federation of Hemophilia (WFH) for ten years. He continues to work as a volunteer with the WFH by writing, advocating, and facilitating trainings. 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, Mr O'Mahony is a Fellow of the Institute of Biomedical Sciences (UK) and 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 of the IHS in the decision-making of national haemophilia health care policies.

He is also the convenor of the Platform for Plasma Users (PLUS), which advocates on plasma and blood related issues within European Institutions on behalf of several patient organisations. He served on the Steering Committee of the European Haemophilia Consortium (EHC) from 2007 to 2011. He was elected as president of the EHC in 2011 and re-elected in 2015.

Mr O'Mahony has severe haemophilia B.



Prof Wolfgang Schramm

University of Munich

Prof Wolfgang Schramm has been working on haemostasis and haemophilia since 1973. He has received certifications for internal medicine (1980), habilitation (1982) and transfusion medicine (1997). In 1982, he became a professor at the Faculty of Medicine of the University of Munich, after having been appointed as head of the department of haemostaseology the previous year. Since 1997, he led the combined departments for transfusion medicine and haemostaseology at the university of Munich, until he retired in 2011.

Prof Schramm serves on many national and international regulatory bodies and committees, such as expert groups focusing in haemophilia within the Deutsche Arbeitsgemeinschaft für Blutgerinnungsforschung (DAB) / Gesellschaft für Thrombose-und Hämostaseforschung (GTH), as well as many regulatory advisory boards both in Germany and at European level. He has served as member and chairman in several scientific and humanitarian societies, including DAB/GTH, the advisory board of the German Haemophilia Society and is associate editor for the *Journal of Thrombosis and Haemostasis* and "Bayerische Kinderhilfe Rumanien."

His particular scientific interest in the field of haemostasis is haemophilia care. In clinical research, he initiated several patient-outcome studies, cost-effectiveness evaluations and meetings to enhance optimal use of blood and plasma-derivatives at national and international level (Wildbad Kreuth Initiatives I-IV).

He is the author of more than 300 papers published in books, international or national scientific journals and conference proceedings.

Dr Marie-Emmanuelle Behr-Gross

Scientific Officer, EDQM

Marie-Emmanuelle Behr-Gross is a pharmacy graduate of the University of Strasbourg, France. After her Pharm D and a short spell in pharmaceutical practice, she began teaching science and undertook a fundamental research project in biology. Having spent several years working at the Regional Blood Centre of Strasbourg (EFS Alsace), she was awarded a PhD in Pharmacology and became a lecturer at the Faculty of Pharmacy (University of Strasbourg). After further experience in the development and control of health products, she joined the EDQM (1997), where she has been involved in the Biological Standardisation Programme, an applied research programme co-sponsored by the European Union and the Council of Europe on the establishment of reference preparations and methods for the quality control of biomedicines.

From 2007 to 2010, Dr Behr-Gross was the Scientific Administrator in charge of the organ transplantation steering committee (CD-P-TO) of the Council of Europe. From 2007 to 2012, she was also the Scientific Administrator of the blood transfusion steering committee (CD-P-TS) of the Council of Europe. As such, she coordinated efforts on policy advice (drafting of non-mandatory legal instruments), publications (Blood Guide), annual enquiries, organisation of specialised symposia and management of ad hoc working groups in charge of various topics (e.g. procurement of rare blood, pathogen inactivation, blood components supply management, transfusion safety).

In 2013, she began working on the Biological Standardisation Programme.



Prof Margit Serban

University Clinic, Timisoara

Margit Şerban, MD PhD, is the head of the IIIrd Paediatric University Clinic and the head of the Bone Marrow Transplant (BMT) Center in Timisoara, Romania.

She is the founding president of the “Cristian Şerban Foundation for Children and Adolescent Aid”, a non-profit, non-governmental organization that aimed and succeeded in building and establishing a hospital for evaluation, education, therapy and rehabilitation of children with diabetes, haemophilia and other chronic diseases. Known as the Evaluation and Rehabilitation Clinic Center for Children and Adolescents “Cristian Şerban”, the hospital is the only one of this kind in Romania.

Professor Serban is a member of the Romanian Medical Academy, the Romanian Academy of Scientists, and eight national Scientific Societies focusing on paediatrics, genetics, immunology, onco-paediatrics, haematology, hepatology, gastroenterology, thrombosis and haemostasis. She is also a member of many international medical societies, including the International Society for Paediatric Oncology (SIOP) and Gesellschaft fuer Thrombose und Haemostasis (GTH). She is the president of the Medical Society Timișoara Medicală - branch Pediatrics and of the Medical Academy - branch Timișoara.

She is the honorary president of the Romanian Haemophilia Association.

Mr Daniel Andrei

President, EHC Romanian NMO

Daniel Andrei is a graduate of Babes-Bolyai University in Cluj-Napoca, Romania. He holds a Master's Degree in Child and Family Welfare, Social Policies and Social Services. Mr. Andrei is licensed in Social Work and Special Psycho Pedagogy with emphasis on children with disabilities.

Mr. Andrei is the President of the Romanian Haemophilia Association.

Mr Cees Smit

EGAN

Cees Smit studied business economics at the Free University in Amsterdam.

From 1978 till now, he has been a member of the research project ‘Haemophilia in The Netherlands’ at the Leiden University Medical Centre (LUMC). From 1987 till 1998, he was co-ordinator of the Netherlands Haemophilia Society, after which he worked in the mental health area.

In January 2003, he received an honorary doctorate from the College of Deans of the University of Amsterdam in recognition of his work on patient participation, haemophilia and medical biotechnology.

At ZonMw (The Netherlands Organisation for Health Research and Development), he is on the Commission for Translational Gene Therapy and Stem Cell Therapy. He is also chair of the Policy Board of the Biobank of Radboud UMCN.

In recent years, he wrote several books on ageing with chronic diseases, like haemophilia and HIV. ‘Ageing with haemophilia’ was published in English in 2007. The book ‘Ageing with HIV’ is written in Dutch and was published on December 1, 2009 - World Aids Day.

In September 2015, together with Annemarie de Knecht – van Eekelen, he published the book ‘De macht



van de patiënt, baas over je eigen ziekte’, which would translate in English as ‘The power of the patient, boss of your own disease’. One of the issues covered in this book is the increasing cooperation between patients, researchers and industry in the drug development process (Patient 3.0).

Mr Gerry O’Reilly

Board member, Irish Haemophilia Society

Mr O’Reilly resides in County Kilkenny, Ireland. Gerry is 56 years old and was born with severe haemophilia A. Currently, he is serving as Board Member and Treasurer of the Irish Haemophilia Society.

During this event, he will be giving a presentation on living with haemophilia and of the contamination with HIV and hepatitis C through treatment in the mid-1980s and early 1990s.

Mr O’Reilly will also discuss efforts to control HIV, as well as two failed attempts to clear HCV.

Mr Zafar Yuldoshev

Project Coordinator, UNDP Ukraine

Naja Skouw-Rasmussen

Member, EHC Steering Committee

Naja Skouw-Rasmussen is a volunteer with the Danish Haemophilia Society (DHS), where she organises youth meetings, women’s weekend and the DHS annual meeting. She was actively involved in the DHS project to promote telemedicine in haemophilia treatment. For the last seven years, she has been on the DHS’s board of directors. While she has an interest in working on activities to promote the wellbeing of all of those affected by bleeding disorders, the issues closest to her heart is improving the life of women affected by bleeding disorder in terms of improving diagnose, treatment options, social acceptance and support.

Internationally, she has worked on Young Voices India, a project focusing on supporting and motivating the young leaders with a bleeding disorder in India. Furthermore, she has actively participated in several conferences organised by the World Federation of Hemophilia (WFH), as well as the EHC youth workshops, EHC leadership workshops and EHC annual meetings.

She holds a Master in Geography and a Master in Development Studies and works at the National Council for Volunteering (Denmark).

Naja Skouw-Rasmussen has von Willebrand disease.

Prof Cédric Hermans

President, EAHAD

Cedric Hermans is head of the Division of Haematology, the Haemostasis and Thrombosis Unit and the Haemophilia Centre of the Saint-Luc University Hospital in Brussels, Belgium. He was appointed Associate Professor at the Medical School of the Catholic University of Louvain in 2003 and Full Professor in 2012.

Prof Hermans has published over 125 original articles in international journals and is a member of several scientific societies and advisory boards. Presently, his main research interests lie in the area of



haemostasis and thrombosis, especially clinical studies on the treatment of haemophilia, new anticoagulants, and the management of thrombosis.

Mr Mirko Jokic

Member, EHC Inhibitor Working Group

Mirko Jokic is actively involved in the Serbian Haemophilia Society (SHS), especially in the field of Inhibitors. He initiated the establishment of the Inhibitor Group within the SHS, which deals with inhibitor-related topics and events. He is the coordinator of this group and works closely with other parts of the SHS. In addition, he is responsible for the online activities of the SHS, such as raising awareness on haemophilia through the social networks.

Since 2015, Mr Jokic is a member of the EHC Inhibitor Working Group, which aims to develop the European Inhibitor Network - a network to combat social isolation and improve the wellbeing of people living with inhibitors, their families and caregivers. The EHC Inhibitor Working group is also developing the European treatment guidelines for people with bleeding disorders and inhibitors.

Dr Radoslaw Kaczmarek

Member, EHC Steering Committee

Dr Radoslaw (Radek) Kaczmarek is an assistant professor at Hirsfeld Institute of Immunology and Experimental Therapy in Wroclaw, Poland. His research interests involve glycobiology and transfusion medicine.

Dr Kaczmarek is a board member of the Polish Haemophilia Society and a member of the European Haemophilia Consortium (EHC) Steering Committee. He has been a volunteer with both organisations and the World Federation of Hemophilia for many years. Dr Kaczmarek has been involved in many advocacy efforts for improvement of haemophilia care, both in his home country and at the European level, representing the EHC vis-à-vis the European Medicines Agency and other relevant institutions.

Radek has severe haemophilia A.

Prof Paul Giangrande

Chair, EHC Medical Advisory Group

Paul Giangrande is the chair of the EHC Medical Advisory Group (MAG) since 2013. In 2015, Prof Giangrande retired from his position as consultant haematologist at Oxford University Hospitals NHS Trust (UK), where he was also the director of the Oxford Haemophilia Centre.

Prof Giangrande studied medicine at the University of Manchester (UK) 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 (UK) on immunological aspects of haemophilia treatment. He subsequently worked in Italy at the Milan Haemophilia Centre with Professor PM Mannucci between 1989 and 1990, before being appointed to his position in Oxford in 1991.

He served as elected WFH vice-president (medical) from 2000 to 2008 inclusive and has wide



international experience in the field.

