

European Haemophilia Consortium

Round Table on 'Outcome Measures in Haemophilia'

Monday, 28 November 2016, 15:00 to 17:00

European Parliament

Brussels, Belgium

Speaker biographies

Mrs Norica Nicolai

Member, European Parliament

Mrs Norica Nicolai is the vice-chair of the Alliance of Liberals and Democrats for Europe (ALDE) party in the European Parliament and one of the strongest liberal voices in Romanian politics. Mrs Nicolai has been a member of the European Parliament since 2009. Until 2014, she headed the Romanian Liberal Delegation and since 2015 she has been one of the three independent Romanian Members of the European Parliament (MEPs) in the ALDE group.

Mrs Nicolai has been active, amongst other, in the European Parliament's (EP) Foreign Affairs Committee and in the Committee for Security and Defence, which allowed her to take part in numerous election observation missions throughout Africa. In addition, starting with her mandate in 2014, she became a member of the EP Fisheries Committee.

Mrs Nicolai started her political career in the position of deputy-minister in the Romanian Ministry of Labour in 1995 where she was in charge of, amongst other policies, gender equality. Furthermore, while in this position, she actively promoted and integrated the *acquis communautaire* in her country, creating and implementing many laws addressing women's rights and gender equality.

From 2000 to 2008, she was a member of the Romanian Senate where she sat on the Judicial Committee, the Defence Committee and held the position of vice-president of the Senate for one year.

Mrs Nicolai holds a degree from the School of Law of the University in Bucharest in Romania.

Mr Jamie O'Hara

Chair, EHC Data and Economics Committee

Mr Jamie O'Hara is an economist by training, with expertise in practical and technical applications of the discipline across industries. He has worked with a range of organisations across the public, private and third sectors, including European Institutions as well as charities such as the World Federation of Haemophilia, the European Haemophilia Consortium and the UK Haemophilia Society.



Mr O'Hara has been central to the development and validation of policy at EU level. He has provided specialist health economics and outcome research (HEOR) advice in the development of multi-billion dollar patient and market access initiatives with some of the world's largest pharmaceutical companies.

He is currently the health economic lead on an expert panel piloting proof of concept for the development and implementation of a global haemophilia registry. He is also a senior lecturer in Health Economics at the University of Chester in the United Kingdom.

Prof Frits Rosendaal

Leiden University Medical Centre

Prof Rosendaal M.D. Ph.D., is professor of clinical epidemiology at the Leiden University Medical Center, the Netherlands, where he chairs the Departments of Clinical Epidemiology and is co-appointed at the Department of Thrombosis and Haemostasis.

He studied medicine in Rotterdam, the Netherlands, and obtained his PhD at Leiden University, with a thesis on haemophilia, in 1989. His main research interests are haemostasis and thrombosis. He published over 700 papers in the field. In the field of thrombosis, he designed the Leiden Thrombophilia Study (LETS) and the Multiple Environmental and Genetic Assessment of risk factors for venous thrombosis (MEGA), that have been instrumental in the identification of a series of risk factors for thrombosis, amongst which factor V Leiden, prothrombin 20210A and fibrinogen gamma 10034T. In the field of haemophilia, he has coordinated the national surveys 'Haemophilia in the Netherlands' since 1985.

Within the general field of aetiology of disease, he has a specific interest in genetics and in side-effects of medicinal drugs. With regard to the latter, he published on the increased inhibitor risk with the use of a particular concentrate in the Netherlands and Belgium in 1993, an increased risk of myocardial infarction with the use of short-acting calciumblockers, an increased risk of venous thrombosis with third-generation contraceptives and with fourth-generation (drospirenone-containing) oral contraceptives, an increased risk of venous thrombosis with postmenopausal hormones, and the risk of bleeding with oral antithrombotic agents.

He has been chairman of the Council of the International Society for Thrombosis and Haemostasis (ISTH) and was president of the 24th ISTH Congress in Amsterdam in 2013.

Currently, he is editor-in-chief of the *Journal of Thrombosis and Haemostasis*. He is an elected member of the Netherlands Royal Academy of Arts and Sciences and the German Academy Leopoldina.

Dr Pratima Chowdary

Consultant Haematologist, Katharine Dormandy Haemophilia Centre & Thrombosis Unit, The Royal Free Hospital

Dr Chowdary is co-centre director for the Katharine Dormandy Haemophilia Centre and specialises in the management of adult patients with haemophilia and related bleeding disorders. She is also the coagulation lead for health services laboratory in London and serves as a treasurer for the United Kingdom Haemophilia Centre Doctors Organisation (UKHCDO).

She has received her basic medical degree from Osmania Medical College in India and completed her haematology training in London. She has been a consultant haematologist for ten years and is the lead for



the adult haemophilia multidisciplinary team. Her major research interests include personalised management, haemophilia outcomes, musculoskeletal complications of haemophilia, and lab assays for monitoring of replacement therapy. She has been an investigator on multiple clinical trials of novel and extended half-life products in severe haemophilia. She has set up a biobank for the department and has a special interest in biomarkers for joint disease. She is the chairperson of the UKHCDO working party on musculoskeletal issues in patients with haemophilia and a panel member for the National Institute for Health Research, Health Technology Assessment Programme.

She is author or co-author of more than 30 journal articles and textbook chapters. She is a member of numerous professional societies including the International Society on Thrombosis and Haemostasis, the British Society of Haemostasis and Thrombosis, the European Association of Allied Bleeding disorders and the World Federation of Haemophilia.

Mr Jason Booth

Associate Director, Global HEOR, Shire

Jason Booth joined Shire as associate director, Global Health Economics and Outcomes Research (HEOR) in June 2015 and has worked in the pharmaceutical industry for 13 years.

His current role focuses on management of global HEOR strategy for Shire's haemophilia A products to ensure the best outcomes for patient access. The role involves researching, analysing and presenting relevant clinical data, input into clinical trial design, collecting evidence for and conducting economic evaluations and estimating the financial impact for payers.

In his previous role Mr Booth was Snr Health Economics Manager for Australia and New Zealand at Baxter working across all therapeutic areas including haematology, immunology, renal dialysis, and hospital/surgical products. Other previous roles included five years at Pfizer Australia as a Health Economist working primarily in specialty care including inflammation and rheumatology, endocrine care, infectious diseases (including vaccines), pulmonary vascular disease and ophthalmology.

Jason's tertiary qualifications include a Masters' degree in Public Health (University of Sydney), a Graduate Certificate in Pharmacoeconomics (Monash University) and a Bachelor degree in Medical Science (University of Wollongong).

Dr Maher Aasi

Associate Group International Medical Director, Hemophilia, at F. Hoffmann La Roche

Maher Aasi is a certified immunologist and rheumatologist. He is currently the global medical affairs director for the emicizumab Hemophilia program at Roche. His responsibilities include developing medical strategies, phase 3b/4 clinical studies, and generating real-world evidence supported with patient reported outcomes, in collaboration with therapeutic area experts and patient groups, that address data gaps and support the clinical evidence package.



Dr Radoslaw Kaczmarek

Member, EHC Steering Committee

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

Radek 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. Radek has participated in numerous local and international meetings on haemophilia and related bleeding disorders as an invited speaker, discussion panellist or chair. He 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.

