Dr Ricardo Baptista Leite  
*Member, Portuguese Parliament*

Dr Baptista Leite is a member of the Portuguese Parliament, head of public health at the Catholic University of Portugal and city councillor of the city of Cascais in Portugal.

He trained as a medical doctor with a specialty in infectious diseases and he is a guest lecturer at both the NOVA Medical School and at the NOVA Information Management School, NOVA University in Lisbon, Portugal. Dr Baptista Leite is also a member of the European Leadership Network and of the European Young Leaders (Friends of Europe).

Dr Baptista Leite is a PhD candidate in public health at Maastricht University in the Netherlands and the founder of 'Creating Health – Research and Innovation Funding.' Dr Baptista Leite is the main author of the book 'Citizenship for Health,' amongst other publications.

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Mr Heinz Becker  
*Member, European Parliament*

Mr Becker has been an Austrian member of the European Parliament (MEP) since 2011 representing the European People’s Party (EPP). As an MEP he is a member of the committee on Civil Liberties, Justice and Home Affairs, and is a substitute of the committee on Employment and Social Affairs.

Mr Becker has a long experience representing the rights of senior citizens and the elderly population. He is active both in Austria, where he is secretary-general of the Austrian Senior Citizens’ Association (ÖSB) and at the European level where he is a co-chair for the European Parliament’s Interest Group on Carers, and a member of the European Parliament’s group on Intergenerational Solidarity and Family Policies.

He was recently elected as the vice-president of the European Seniors’ Union (ESU).

Mr Becker has also supported the EHC’s work in the past hosting a Round Table discussion on inhibitors in haemophilia A.
Piet de Kleijn

Physiotherapist, University Medical Centre (UMC) Utrecht

Mr de Kleijn graduated as a physical therapist in 1979 in Utrecht, the Netherlands and has since been involved in haemophilia care. Since 1988, he is fully responsible for the physiotherapy of visiting haemophilia patients at the Van Creveldkliniek located in the University Medical Centre of Utrecht.

Mr de Kleijn is the co-author and author of various scientific articles. He has also been a member of the World Federation of Hemophilia (WFH) Musculo-Skeletal Committee (MSK). Additionally, he has given numerous presentations during the WFH world congresses and workshops. In 2012 he was awarded the Vincenzo Pietrogrande award of the WFH MSK.

Mr de Kleijn has been active in several WFH Twinning Programs including the twinning between the Van Creveldkliniek and the Dr Kandou Hospital in Manado, Indonesia, which received the award of Twin of the Year in 2011. As a member of an International Haemophilia Training Centre, he supervised numerous trainees and foreign physiotherapists over the years.

In 2007 he initiated a Global Physiotherapy Initiative, an effort to implement basic physiotherapy in haemophilia treatment centres world-wide, based on the concept of ‘train the trainers.’ Moreover, he introduced the International Classification of Functioning as well as the ‘functional milestones’ as a model and practical approach to realise this goal. For his efforts he received the WFH ‘Health Care Volunteer of the Year’ award in 2012, being the first non-medical healthcare professional to receive this award.

In 2012 a Dutch four-year project, the PHYSical therapy in haemophilia in the NETHerlands (PHYSHNET) started. The objective of this project was to implement and collect evidence for the additional value of physical therapy. This project, which will end this year (2016), could be used as a model for a European approach in gathering evidence for the added value of physiotherapy.

Mr de Kleijn is also a board member of the Physiotherapy Working Group of the European Association for Haemophilia and Allied Disorders (EAHAD), an organisation representing European healthcare professionals active in the area of haemophilia and other bleeding disorders. Through this committee, he hopes to improve access to physiotherapy for patients in both chronic and acute situations. In his opinion: “In time physiotherapy has to be accepted and formally implemented as part of the daily care of people with haemophilia of all ages, hence ensuring ‘all treatment for all.’”
Prof Geoffrey Dusheiko

Professor, University College London

Prof Dusheiko, MD, MB, BCh, is emeritus professor of medicine at the Royal Free Hospital and University College School of Medicine, London, United Kingdom (UK).

He earned his bachelor of medicine, bachelor of surgery degree from the University of Witwatersrand in Johannesburg, South Africa. After graduating, he completed his internship at Baragwanath Hospital in Johannesburg and his residency at Johannesburg Hospital. His fellowships were conducted at the Johannesburg Hospital Liver Unit and the National Institutes of Health in Maryland and the University of Minnesota (United States).

Prof Dusheiko’s research interests include the management and treatment of hepatitis B and C and small hepatocellular carcinoma; he has a special interest in research in viral hepatitis, focused on viral genotyping, applied molecular virology, the natural history of chronic viral hepatitis, and antiviral therapies.

He has served on editorial boards for the *Journal of Viral Hepatitis, Hepatology, and Best Practice and Research: Clinical Gastroenterology, GUT* among others, and is the author of more than 330 published articles. He is currently a co-editor of *Alimentary Pharmacology and Therapeutics* and on the editorial board of the *Journal of Viral Eradication*.

A member of several organisations, including the International Association for the Study of the Liver (IASL), the American Association for the Study of Liver Diseases (AASLD) and the European Association for the Study of the Liver (EASL); Prof Dusheiko is also a fellow of the Royal College of Physicians, the Royal College of Physicians of South Africa, and the Royal College of Physicians of Edinburgh.

He served as Educational Councillor on the EASL Governing Board for four years and was the recipient of the EASL recognition award in 2014.

He is a guidelines writer for the World Health Organisation (WHO), a director of the Skipton Fund in the UK and has advised the National Institute of Clinical Excellence (NICE) in the UK.

Mr Zygmunt Gruszka

Member, Swedish National Member Organisation (NMO)

Mr Gruszka is a 69 year old who used to have a severe form of haemophilia B. Born in Poland, although living in Sweden for over 20 years, he experienced being a patient with haemophilia in an underdeveloped country and living without proper access to treatment. In fact, treatment used in Poland while he was growing up was solely plasma and even this treatment was not available often. When he was 22 years old, he moved to Sweden and was finally able to access much better treatment, although his joints had already been badly affected and greatly damaged.

Once he finished his Masters’ degree in mathematics, Mr Gruszka started to work in IT for the banking sector. A few years ago, he developed liver cancer due to hepatitis C (HCV). Fortunately, he did not have to wait long for a liver transplant, which was very successful.

Mr Gruszka has been an active member of the Swedish Hemophilia Society for over 20 years and he sat on its board for 15 years. During these last few years he mostly has dedicated his time to the elderly members of the society and to issues linked to HCV such as compensation and access to new treatments.

Mr Gruszka is married and has a daughter who has moderate haemophilia B.
Mr Radoslaw Kaczmarek

*Member, EHC Steering Committee*

Mr Kaczmarek is a PhD candidate at the Ludwik Hirszfeld Institute of Immunology and Experimental Therapy in Wroclaw, Poland. His research interests involve glycobiology and transfusion medicine.

Mr Kaczmarek is a board member of the Polish Haemophilia Society and a steering committee member of the European Haemophilia Consortium (EHC). He has been a volunteer with both organisations and the World Federation of Hemophilia (WFH) for many years.

He has participated in numerous local and international meetings concerning 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 (EMA) and other relevant institutions.

Mr Kaczmarek has severe haemophilia A.

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Mr Goran Kapetanovic

*Director, Kapetanovic Productions AB*

Mr Kapetanovic was born in 1974 in Sarajevo, Bosnia and Herzegovina. He studied film direction at the Dramatiska Institutet in Stockholm.

His last four films have been given 23 international awards. Amongst these, his film 'Kiruna-Kigali' was shortlisted for the Oscars as best foreign drama.

Between 2005 and 2010 Mr Kapetanovic worked as a producer and mentor with people from the Rwanda Film Centre in Kigali, Rwanda. The resulting movies from this collaboration premiered at the Tribeca Film Festival in 2007.
Mr Achim Kautz

Executive partner, Leberhilfe Projekt

Mr Kautz is a patient advocate representing the interests of people affected by liver diseases.

He was one of the founding members of the European Liver Patient Association (ELPA) in which he served in various positions such as Vice-President and policy consultant. He is also the founder and executive partner of Leberhilfe Projekt an organisation looking to tackling liver diseases by developing economic models to make the eradication of hepatitis C (HCV) viable, promoting early diagnosis of liver diseases and providing education for better management of HCV. Additionally, Mr Kautz sits on various boards and committees consulting on how to best tackle liver diseases.

In the past few years, he has worked with organisations such as World Health Organisation, the German Ministry of Health and the World Hepatitis Alliance towards better prevention and management of liver diseases.

Mr Kautz holds a Bachelor in advertising and communication from the private University of Tertia (Bonn). He is the author and co-author of many publications including a manual for the development and assessment of national viral hepatitis plans published last year by the WHO and ‘The eco-report: A macroeconomic overview of viral HCV in Germany,’ published on the www.leberhilfe-projekt.de website.

Dr Maria-Elisa Mancuso

Clinical assistant, University of Milan

Dr Mancuso (MD, PhD) is a haematologist working as a clinical assistant at the Angelo Bianchi Bonomi Haemophilia and Thrombosis Centre in Milan (Italy).

She obtained a post-degree in clinical and experimental haematology and a PhD in clinical methodology.

She is involved in clinical research and has published several original articles in peer-reviewed journals as Blood, Journal of Thrombosis and Haemostasis, Haematologica, Thrombosis and Haemostasis, British Journal of Haematology and Haemophilia.

She is a member of several scientific societies such as the International Society for Thrombosis and Haemostasis (ISTH), the World Federation of Hemophilia (WFH), the American Society for Hematology (ASH) and the European Association for Haemophilia and Allied Disorders (EAHAD).

She has been involved as co-investigator in several clinical trials, and she takes care of both children and adults with haemophilia with a specific scientific interest in inhibitors and chronic hepatitis C.
Dr Eveline P Mauser-Bunschoten

Haematologist, University Medical Centre (UMC) Utrecht

Dr Mauser-Bunschoten studied medicine at the University of Groningen, the Netherlands, where she graduated in 1978. Since 1979 she has been working at the Van Creveldkliniek, Department of Haematology, University Medical Centre Utrecht in the Netherlands where over 1,000 people with haemophilia and allied bleeding disorders are treated. The Van Creveldkliniek was founded in 1964 and is one of the first comprehensive care haemophilia centres in the world; which includes also special outpatient clinics for both children and adults with orthopaedic problems.

Her medical interests are hepatitis C infections in haemophilia patients, co-morbidity (orthopaedic and age related) in elderly haemophilia patients, bleeding tendency in carriers and improvement of care in developing countries. In 1995 she received her PhD at the University of Utrecht. Her thesis focused on ‘Complications in haemophilia care.’

She has been involved in twinning programmes with the haemophilia organisations and centres in Lahore Pakistan, and Manado Indonesia and participated in workshops to promote and improve comprehensive care in developing countries.

She is editor of the several books including ‘From Care to Coaching,’ ‘Rare Bleedings in Haemophilia,’ ‘Aging with Haemophilia,’ and ‘Sexuality and Bleeding Disorders.’ Furthermore she was editor of the Dutch Guidelines for Haemophilia Treatment.

She has written guidelines for the World Federation of Hemophilia (WFH) on bleeding tendency in haemophilia carriers and participated in the revision of the WFH treatment guidelines.

Evelien participated in a twinning programme with a hospital in Manado, Indonesia, which was awarded the WFH Twinning of the Year award in 2012. In 2015 a Twinning program between Utrecht, Yogyakarta and Solo, Indonesia started.

Dr Miroslav Mikolášik

Member, European Parliament

Dr Mikolášik is a Slovakian member of the European Parliament (MEP) since 2004, representing the European People’s Party (EPP). As a MEP he is a member of the committee on the Environment, Public Health and Food Safety, the subcommittee on Human Rights, and a substitute member of the committee on Regional Development.

Dr Mikolášik trained as both an anaesthesiologist and a general practitioner. Following his training, he pursued a career in government and politics. He worked at the Institute of Medical Ethics and Bioethics in Bratislava, was the vice-chairman of the District National Committee, was the head of the Department for International Relations at the Ministry of Health, and was the Chairman of KDH (Christian Democratic Movement). He then served as a member of the National Council of the Slovak Republic, where he was a member of the committee on Social Affairs and Health Care, the EU-Slovak Republic Joint Parliamentary Committee, and the Foreign Affairs Committee.

Dr Mikolášik is long standing supporter of the European Haemophilia Consortium (EHC), and has chaired various multi-stakeholder Round Table events on haemophilia.

He is also a Member of European Parliamentary Interest Group on Innovation in Health and Social care, and hence has extensive experience in discussing access to treatment in bleeding disorders, including haemophilia.
Mr Brian O’Mahony  
*President, European Haemophilia Consortium (EHC)*

Mr O’Mahony is the chief executive of the Irish Haemophilia Society (IHS). He represents IHS 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 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. Among his activities are 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, 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 IHS 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 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.

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 the 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 and the results as treatment failure.

Prof Kathelijne Peerlinck  
*Professor, University of Leuven*

Dr Peerlinck is professor at the centre for Molecular and Vascular Biology of the Catholic University of Leuven (KULeuven) in Belgium. She is also a staff member at the division of Heart and Vascular Disorders of the University Hospitals in Leuven and the director of the Haemophilia Comprehensive Care Center of the University Hospitals.

Dr Peerlinck received her medical degree at the University of Gent in Belgium. She specialised in Internal Medicine and Haematology both in Gent and in Leiden, the Netherlands. She obtained her PhD at the KULeuven with studies on von Willebrand’s disease and haemophilia.

Dr Peerlinck’s clinical and research interests include haemophilia, with special interest in mechanisms and treatment of inhibitors in haemophilia and evaluation of treatment in patients with coagulation disorders and a special focus on management of cardiovascular disorders in these patients.
Sirpa Pietikainen

*Member, European Parliament*

Ms Pietikainen has been a Finnish Member of the European Parliament (MEP) since 2008, representing the European People’s Party (EPP).

She is a member of the committee on Economic and Monetary Affairs, and a substitute for the committee on the Environment, Public Health and Food Safety and the committee on Women’s Rights and Gender Equality.

She has a background in economics and holds a Masters in Business Administration (MBA) from the Helsinki School of Economics.

Before becoming an MEP, she worked as member of the Finnish Parliament, was the Minister for the Environment and was the chairwoman for both the Finnish United Nations Association and the Citizens’ Security Council KATU.

Ms Pietikainen has extensive experience in the European health policy, especially in the domain of healthy ageing. She is member of the European Parliament’s Intergroup on Active Ageing and of the European Parliament’s group on Intergenerational Solidarity and Family Policies. She is a co-chair of the European Parliament’s Interest Group on Carers, and hence has taken part in many initiatives on ageing in both health and innovation.

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, and 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 on haemophilia (‘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.
Cees Smit

Patient advocate, VSOP/EGAN

Mr Smit studied business economics at the Free University in Amsterdam. From 1978 until now, he has been 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 Dutch Haemophilia Society and from 1998 to 2002, he worked in the area of mental health.

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

In recent years, he wrote several books on ageing with chronic diseases, like ‘Haemophilia and HIV.’ The book ‘Ageing with Haemophilia’ was published in English in 2007. The book ‘Ageing with HIV’ is written in Dutch and was published in 2009 during World AIDS Day (1st December).

In September 2015, he published together with Annemarie de Knecht – van Eekelen the book ‘De Macht van de Patiënt, Baas over je Eigen Ziekte.’ The book is so far only available in Dutch, but the English title would be ‘The power of the patient, boss of your own disease.’ One of the issues discussed in this book is the increasing cooperation between patients, researchers and industry in the drug development process (Patient 3.0).