

## Conference: Advancing person-centred and integrated care for rare diseases and complex conditions across Europe

Final Conference of the EU-funded INNOVCare project | [Innovcare.eu](http://Innovcare.eu) | #INNOVCare

**5<sup>th</sup> September 2018, 09:00 – 13:30**

**Résidence Palace, 155 Rue de la Loi, 1040 Brussels**

The event will also be livestreamed at <https://innovcare.eu/live/>

### ABOUT THE SPEAKERS



#### **Moderator:**

**John Bowis, Former Member of British Parliament, UK Health Minister and Member of the European Parliament**

John Bowis is a former Member of the European Parliament (1999-09) and Member of British Parliament (1987-97). A graduate of Oxford University, John served as MP for Battersea and served two terms in the UK Government as Minister for Health (1992-1996) and Minister for Transport (1996-1997). Later, he worked as international policy adviser for the World Health Organisation, before being elected to the European Parliament. In the EP, John was Spokesman for the EPP Group on the Environment and Health and led for the Parliament on a range of Reports, including establishing the European Centre for Disease Prevention and Control, Neglected Diseases, Mental Health and Cross Border Healthcare.

### Speakers and Panellists:



#### **Speaker and Panellist:**

**Ana Carla Pereira, Head of Unit Modernisation of Social Protection Systems, European Commission, Directorate-General for Employment, Social Affairs and Inclusion**

As Head of Unit for "Modernisation of social protection systems" at the Directorate General Employment, Social Affairs and Inclusion at the European Commission, Ana Carla Pereira is responsible for social protection policies related to access and adequacy of pensions, long-term care and health. Ana Carla is currently coordinating the work around the initiative "access to social protection", one of the concrete deliverables of the European Pillar of Social Rights. Prior to this, Ana Carla was responsible for skills and qualifications policies, including the New Skills Agenda for Europe. She has also worked more than ten years on the implementation of European Employment Strategy and several years in the private sector, as a business consultant specialised in human performance. She graduated in Economics at University of Coimbra (PT) and holds a MA in European Human Resources Studies from the College of Europe (BE). She is Portuguese mother tongue and fluent in English, French and Italian.



**Panellist:**

**Ana Rath, Director, Orphanet; coordinator of European Joint-Action on Rare Diseases (RD-ACTION)**

Ana Rath is a Medical Doctor with Surgery background and has a Master degree in Philosophy. Ana oriented her career to medical information in 1997 and joined [Orphanet](#) in 2005. At Orphanet, she has been in charge of the Orphanet encyclopaedia, the rare diseases database, and the Scientific Direction. She became Deputy director in 2011 and is acting as Director of Orphanet since May 2014. Ana Rath was the Coordinator of RD-ACTION, the EU Joint action on rare diseases (2015-2018). She is member of the Revision Steering Committee of the WHO's ICD11 and of the Topic Advisory Group for Rare Diseases. Ana is also the coordinator of the Scientific secretariat of the International Rare Diseases Research Consortium (IRDiRC).



**Panellist:**

**Anders Olauson, Chairman, Agrenska; Chair, RareResourceNet-European Network of Resource Centres for Rare Diseases**

Anders Olauson was involved in the founding of the Agrenska Centre for Rare Diseases, in Sweden, in 1989. He served as director until 2004 and has been Chairman since then. He also serves as Chairman of the Council of the Eesti Agrenska Foundation in Estonia and is a former Board Member and President (1999-2001) of EURORDIS. Anders was also a Board Member of the European Patients' Forum (EPF), having served as President between 2005 and 2016, when he was appointed Honorary President of EPF. He is also involved in the NGO Committee for Rare Diseases, at United Nations New York, where Agrenska is a member of the Inception Executive Board. For the last two years, Anders has been involved in the creation of RareResourceNet, the European Network of Resource Centres for Rare Diseases, and serves as Chair of the Interim Board of Directors since April 2018.



**Panellist:**

**Birutė Tumienė, Clinical geneticist, Vilnius University Hospital; Representative of Lithuania on the European Reference Network Board of Member States**

Birutė Tumienė works as a clinical geneticist and a coordinator for rare disease competence centres at Vilnius University Hospital Santaros Klinikos. Besides, Biruté gives lectures on clinical genetics and rare diseases at Vilnius University, Faculty of Medicine. In the field of rare diseases, Biruté has been working for the last 12 years (since 2006) and is currently involved in Orphanet (as a Coordinator of Orphanet Lithuania), in the European Reference Network Board of Member States (as a Lithuanian Representative and a leader of a WG on ERN National Integration), and in the RD-Action and European Joint Program on Rare Diseases. She is a Board member of European Society of Human Genetics and Baltic Society of Inherited Metabolic Diseases and a member of a number of other professional/scientific organizations.

**Panellist:**

**Brando Benifei, Member of the European Parliament, Group of the Progressive Alliance of Socialists and Democrats**



Brando Benifei, European Federalist, is one of the youngest Members of the European Parliament and is from La Spezia, Italy. Brando has been chair of European affairs for the Young Democrats and Vice-President of ECOSY - youth organisation of the Party of European Socialists (PES) - for 4 years and was part of the PES working group, which originally drafted the European Youth Guarantee. His main fields of legislative work in the European Parliament are Employment and Social Affairs and Foreign Affairs. Brando is co-chair of the Youth Intergroup and vice-chair of the Disability Intergroup. Among his parliamentary activities in the Committee of Employment and Social Affairs, he was responsible for key legislative and non-legislative reports on the social inclusion and integration of refugees into the EU labour market, on youth employment policy, as well as digitalisation and rights of persons with disabilities. Brando is a member of the Network of Parliamentary Advocates for Rare Diseases, an initiative launched by EURORDIS in 2017.

**Speaker and panellist:**

**Dorica Dan, President, Romanian Prader Willi Association, NoRo Resource Centre for Rare Diseases**



Dorica Dan's daughter lives with Prader Willi Syndrome, a rare disease. Dorica initiated the Romanian Prader Willi Association in 2003, of which she is currently the Chair, and established the Romanian National Alliance for Rare Diseases in 2007, which she currently Presides. Dorica also coordinates the Centre for Information about Rare Genetic Diseases and the NoRo Resource Center for Rare Diseases, where INNOVCare's pilot took place. Dorica has been a board member of EURORDIS since 2007, served as member of the European Union Committee of Experts in Rare Diseases and of the Commission Expert Group on Rare Diseases, and Presides the Romanian Rare Cancers Association. Having initiated the national plan for rare diseases in Romania, Dorica was also an advisor to the establishment of national plans for Rare Diseases across EU Member States.

**Panellist:**

**Encarna Guillen-Navarro, Clinical Geneticist, Hospital Clínico Universitario Virgen de la Arrixaca; Former Minister of Health of Murcia Region**



Encarna Guillén Navarro, MD, PhD, is Head of Medical Genetics Section-Pediatric Service (Rare Diseases Unit) in V. Arrixaca University Clinical Hospital, in Murcia (Spain). Encarna is also: Professor of Pediatrics /Clinical Genetics in University of Murcia; Head of the Rare Diseases and Genetics research group in Murcia Institute of Biosanitary Research (IMIB-Arrixaca, FFIS, CIBERER-ISCIIII - Madrid); Region of Murcia Representative in the National Rare Diseases Strategy; Member of the FEDER (Spanish Federation of Rare Diseases) Expert Committee; Member of the Spanish National Bioethics Committee; Member of the Spanish Personalized Medicine working group; Academic corresponding in Royal Academy of Medicine and Surgery of Murcia, Spain; Former President of the Spanish Society of Clinical Genetics and Dysmorphology; and Former Minister of Health in the Region of Murcia, Spain. As Regional Health Minister, Encarna has led the development and the start of the implementation of regional case management reforms.



**Speaker and panellist:**

**Irina Vana, Researcher on Work and Equal Opportunities, ZSI – Zentrum für Soziale Innovation**

Irina Vana is a researcher at ZSI – Zentrum für Soziale Innovation in Vienna and has been involved in several projects on social policies and social inclusion in academic contexts and applied social research.

Within INNOVCare, Irina was part of the research team assessing the challenges and opportunities to up-scale integrated care for rare diseases.



**Speaker and panellist:**

**Juliet Tschank, Researcher on Work and Equal Opportunities, ZSI – Zentrum für Soziale Innovation**

Juliet Tschank is a social scientist in the department of ‘Work and Equal Opportunities’ at the Centre for Social Innovation (ZSI) in Austria. She has been engaged at ZSI since 2012 focussing her research on the social inclusion of socially disadvantaged groups and (adult) education. Her core competencies are designing, planning, implementing and analysing quantitative surveys and experimental studies. Among others, she has led the evaluation of an intervention to prevent early school leaving in Italy and Spain as well as the evaluation and scientific accompaniment of a number pilots in the field of adult education. In the INNOVCare project, Juliet leads the team evaluating the social impact of the INNOVCare pilot.



**Speaker and panellist:**

**Peter Lindgren, Professor of Health Economics, Karolinska Institutet**

Peter Lindgren is professor of health economics at Karolinska Institutet and is the head of the Swedish Institute for Health Economics.

Since more than 20 years he has been involved in research studying the allocation of scarce resources in health care and the balance between investments and achieved health outcomes such as health related quality of life.

Peter has contributed and led projects in a wide range of areas including rare diseases such as haemophilia and Duchenne’s Muscular Dystrophy.

In INNOVCare Peter leads the team responsible for conducting the economic impact assessment of the pilot intervention.



**Speaker and panellist:**

**Raquel Castro, Social Policy Director, EURORDIS-Rare Diseases Europe**

Raquel Castro leads EURORDIS' activities to promote the integration of rare diseases social services and policies as well as integrated care for people living with a rare disease and their carers. Raquel also heads the EURORDIS Open Academy, which provides capacity-building programmes to patient advocates.

Raquel supported the elaboration of the *Commission Expert Group Recommendations to Support the Incorporation of Rare Diseases into Social Policies and Services*, while working within the European Joint-Actions for Rare Diseases (EUCERD Joint-Action, 2012-15; RD-Action, 2015-18). She also coordinated the mapping of social services, policies and good practices across Europe and supported the inclusion of these topics in national rare disease policies. Prior to joining EURORDIS, Raquel designed and coordinated the Portuguese rare disease Help Line, after working with development and capacity building projects in Europe and India.



**Speaker:**

**Terkel Andersen, President, EURORDIS-Rare Diseases Europe**

Terkel Andersen was elected President of EURORDIS in May 2003 and has been a member of the EURORDIS Board of Directors since 1997, when the organization was founded. A person with haemophilia himself, Terkel has broad experience in disability and health issues. Terkel served as president of the Danish Haemophilia Society 1985-2017. He was one of the founders of the Danish Alliance of Rare Disorders in 1986 and worked as the first Executive Director of the Centre for Rare Diseases and Disabilities of the Ministry of Social Affairs in Denmark, from 1990 to 2001. From 1992 to 2002, he served on the executive board of the World Federation of Hemophilia; and from 1993 to 1999, he was chairman of the European Haemophilia Consortium. In his professional capacity, Terkel is working with the Danish National Council for Volunteering.



**Speaker and Panellist:**

**Ursula Holtgrewe, Head of Work & Equal Opportunities, ZSI – Zentrum für Soziale Innovation**

Ursula Holtgrewe is the head of the department of Work and Equal Opportunities at ZSI – Zentrum für Soziale Innovation, Vienna and conducts research on social innovation, service work and organisation.

Within INNOVCare, Ursula contributed to the assessment of policies towards RDs and the challenges and opportunities to up-scale integrated care for rare diseases and to overall project management at ZSI.



**Panellist:**

**Victoria Hedley, RD-ACTION-European Joint Action for Rare Diseases Policy Manager, University of Newcastle**

Victoria Hedley has worked in the field of rare disease healthcare and research policy for the last 6 years. She was the Thematic Coordinator for the European Joint Action for Rare Diseases (RD-Action, 2015-2018), after having been part of the management team of the previous Joint Action (EUCERD Joint-Action, 2012-2015). As Thematic Coordinator, Victoria was responsible for facilitating the translation of the needs and priorities of the rare disease field into meaningful policies at the European level, whilst maximising impact at the national level. Victoria contributed to shaping policies, organised multi-stakeholder workshops and coordinated the State of the Art of Rare Disease Activities in Europe. Victoria also supports the implementation of European Reference Networks – she led the implementation of the RD-Action Matchmaking tool and coordinated the engagement of ERNs in RD-Action’s policy activities.



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*The information contained in this publication does not necessarily reflect the official position of the European Commission.*