

RETHINKING ALZHEIMER'S DISEASE

RETHINKING Alzheimer's disease: Detection and diagnosis

Launch event of the White Paper

24 January 2023, 12:30 - 14:00

Programme

Time	Topic	Speaker
12:30 - 12:40	 Welcome & Introduction	 MEP Sirpa Pietikäinen EPP, Finland
12:40 - 12:50	 Presentation of the RETHINKING Alzheimer's disease White Paper: Detection and diagnosis	 Frédéric Destrebecq Executive Director European Brain Council
12:50 - 13:00	 Patient testimony Value of an early diagnosis	 Helen Rochford-Brennan Vice Chair Irish Dementia Working Group
13:00 - 13:30	 Experts' panel discussion and Q&A Moderated by  Laura Campo Sr Director International Corporate Affairs, Alzheimer's disease Eli Lilly and Company	 Kristian Steen Frederiksen Co-chair EAN Scientific Panel Dementia and Cognitive Disorders  Maria Teresa Ferretti Chief Scientific Officer Women's Brain Project  Linus Jönsson Associate Professor Karolinska Institutet

Time	Topic	Speaker
13:30 - 13:55	 Policy panel Moderated by:  Frédéric Destrebecq Executive Director European Brain Council	 MEP Tomislav Sokol EPP, Croatia  MEP Deirdre Clune EPP, Ireland  Andrzej Rys Principal Scientific Adviser Directorate-General for Health and Food Safety (DG SANTE), European Commission  Dr Neerja Chowdhary Technical Officer, Brain Health Unit – Department of Mental Health and Substance Use World Health Organization (WHO)
13:55 - 14:00	 What next?	 Frédéric Destrebecq Executive Director European Brain Council



Background

RETHINKING Alzheimer's disease (AD) is a research-driven project offering policy recommendations to make tangible changes with the aim to improve the lives of people living with Alzheimer's disease across Europe.

About Alzheimer's Disease

Alzheimer's disease is a neurodegenerative disease that progresses in stages, beginning with a long silent phase before symptoms occur. It is the underlying cause in 70% of people with dementia. Dementia, which is not a specific disease but an overall term that describes a group of symptoms, is characterised by a decline in memory, thinking, behaviour and the ability to perform everyday activities.

It is estimated that 9.7 million people in Europe alone already live with Alzheimer's disease and dementia. With a rapidly ageing population, it is a growing public health concern worldwide as this number is projected to rise to a staggering 14 million by 2030.

The societal and economic cost of dementia in Europe is also very high and estimated to increase over EUR 250 billion by 2030 (with over 5% of this due to informal care costs), the equivalent of the whole GDP of Finland. AD is thus not only a debilitating and progressive disease affecting the daily lives of people, their families and carers, but also a huge burden for our economy and European nations' healthcare and social care systems. Healthcare systems in Europe currently lack the capacity to detect, diagnose and treat AD effectively.

RETHINKING Alzheimer's disease

EBC and EFPIA will collaborate with experts from different European countries to build an interdisciplinary consensus around practical and sustainable policy responses to Alzheimer's disease that will aim to improve the lives of people living with it.

Now is the time to rethink Alzheimer's disease to improve Alzheimer's disease care pathway and the lives of people living with it.



*Calling for change
in Alzheimer's care*

Speakers' biographies



MEP Sirpa Pietikäinen
EPP, Finland

Ms. Sirpa Pietikäinen is a Finnish member of the European People's Party (EPP) in the European Parliament. Ms. Pietikäinen is a former Finnish Minister of Environment (1991-1995). Her career at the Finnish parliament is extensive, ranging from the year 1983 to 2003.

At the European Parliament, Ms. Pietikäinen is a member of the Economic and Monetary Affairs Committee and the Women's Right and Gender Equality Committee as well as a substitute member of the Environment, Public Health and Food Safety Committee. She is active in several organizations. Her positions of trust include Chairmanship of the Globe EU and membership in board of Alzheimer Europe. Ms Pietikäinen is a strong advocate of health issues in the European Parliament and was recently a co-rapporteur in the Parliament's report on European care.

A graduate from the Helsinki School of Economics, Ms. Pietikäinen has MSc in Business.



Frédéric Destrebecq
Executive Director, European Brain Council

Frédéric Destrebecq is the Executive Director of the European Brain Council since October 2014. In this capacity, he is responsible for providing strategic direction and leadership while managing the day to day operations of EBC and its ongoing relationships with its member associations and other stakeholders, as well as representing the organisation in various European and national forums.

Fred holds a Master Degree in Political Science and International Relations from the Université Catholique de Louvain (Belgium). He also studied at the Institut d'Etudes Politiques (Paris) and University of Wales College (Cardiff), in the framework of the former EU Socrates exchange programme. Prior to EBC, Fred served the European Union of Medical Specialists (UEMS) as Chief Executive Officer, and previously as Director for European Affairs.



Kristian Steen Frederiksen
Co-chair, EAN Scientific Panel Dementia and Cognitive Disorders

Dr Kristian Steen Frederiksen is a consultant neurologist and director of the Clinical Trial Unit at the Danish Dementia Research Centre, Rigshospitalet. Dr Frederiksen conducts research on a number of topics related to Alzheimer's disease and Lewy Body Dementia including development biomarkers for the early diagnosis of dementia disorders and the clinical application of biomarkers. Dr Frederiksen also co-chairs the European Academy of Neurology Scientific Panel on Dementia and cognitive disorders.



Maria Teresa Ferretti
Chief Scientific Officer, Women's Brain Project

Maria Teresa Ferretti is a neuroscientist and neuroimmunologist, an expert in Alzheimer's and gender medicine. In 2016, she co-founded the non-profit organization "Women's Brain Project" (of which she is currently Scientific Director), a world leader in the field of the study of sex and gender specificities and the importance of precision in neurological and psychiatric diseases.

She graduated in Pharmaceutical Chemistry and Technologies at the University of Cagliari (Italy), then studied and worked in England, Canada (where she earned a PhD in Pharmacology and Pharmacological Therapy at McGill University in Montreal), Switzerland and Austria. Her articles have been published in numerous journals, including Nature and PNAS, and she is regularly invited by major scientific conferences to lecture on Alzheimer's disease, precision medicine and the differences between men and women in neurology and psychiatry.

She has taught in numerous university courses and is currently lecturer in the 'Certificate for Advanced Studies in gender medicine' course at the University of Zurich and 'External Teacher' at the Medical University of Vienna; in addition, she is responsible for continuous medical education modules for doctors and health professionals in the field of gender and precision medicine.

Passionate about scientific dissemination and animated by the desire to break the taboo on mental and brain diseases, she was a TED-x speaker in 2019 and 2021. She wrote in 2021, 'A headless girl' together with Antonella Santucci Chadha, and in 2022 'Alzheimer Revolution', books that explain the complexity of brain disorders to the lay public.



Linus Jönsson
Associate Professor, Karolinska Institutet

Dr Linus Jönsson is associate professor of health economics at the Karolinska Institute in Sweden. His research focuses on economic evaluation of diagnostic technologies and treatments for Alzheimer's disease (AD) and other neurodegenerative disorders. Dr Jönsson has authored of over 100 original publications, reviews and book chapters, he serves on the Swedish government gerontology research council and has acted as scientific advisor to the National Board on Health and Welfare. He is coordinator for national and European research collaborations developing methods for assessing the value of new technologies to diagnose, treat and prevent AD (JPND-ADDITION, PREDEM). He co-chairs the International Pharmacoeconomic Collaboration on Alzheimer's Disease (IPECAD), and teaches health economics, outcomes research and decision analysis at the Stockholm School of Economics and Copenhagen University.



Helen Rochford-Brennan
Vice Chair, Irish Dementia Working Group

Helen Rochford-Brennan is a Global Dementia Ambassador, former Chair, and currently Vice Chair, of the Irish Dementia Working Group; and currently a member, (formerly Chairperson), of the European Working Group of People with Dementia and its nominee to the Board of Alzheimer Europe. Helen sits on the Monitoring Committee of Ireland's first National Dementia Strategy and is a panel member of multiple advisory groups in Ireland and Europe.

**Laura Campo**

Sr Director International Corporate Affairs, Alzheimer's disease, Eli Lilly and Company

Laura Campo is responsible for the out-of-US relationships with Patient Associations and Health Professionals in the Global Corporate Affairs division at Eli Lilly and Company. In her role, Laura coordinates Lilly's efforts to engage the external environment in Alzheimer's disease, Migraine and Pain. Before joining the International Corporate Affairs role, Laura served as Corporate Affairs Market Access Manager at Eli Lilly Italia, supporting the Regional access plans in the Oncology, Cardiovascular, CNS, and other therapeutic areas, with a special focus on the partnership programs with Regional Institutions on the optimization of NHS processes. During the years in the Italian Corporate Affairs Division, Laura also covered the role of Country Leader for two major Lilly efforts in the environment engagement space, raising the attention to public policy issues that limit the access to patient's care in the Oncology area and in the Alzheimer's disease area. In the previous years within Eli Lilly and Company, Laura covered other National and International roles as Marketing Manager in the Attention Deficit & Hyperactivity Disorder area in Lilly Italia, European Regulatory Affairs Manager in the UK and Research Scientist in the Lilly Research Laboratories (Indianapolis). Laura pursued a post-doctoral fellowship at the University of Alabama at Birmingham and her graduate school in Italy where she currently lives.

**MEP Tomislav Sokol**
EPP, Croatia

Tomislav Sokol was born in Zagreb in 1982. He obtained his first degree in law at the Faculty of Law, University of Zagreb, in 2006, magna cum laude. He then obtained a Masters of Law (LL.M.) specialising in European Union Law at the Katholieke Universiteit Leuven (KUL), Belgium, in 2009, magna cum laude. He defended his PhD at KUL, dealing with free movement of cross-border health care services in the EU and its impact on national health insurance systems in 2014.

He was an Assistant Minister in the Ministry of Science and Education in 2017, after which he became a Member of the Croatian Parliament. He was a Member of the Croatian Parliament until July 2019, when he became a Member of the European Parliament. He is a Member of the Committee on the Internal Market and Consumer Protection (IMCO), Special Committee on the COVID-19 pandemic: lessons learned and recommendations for the future (COVI) and also EPP Vice Coordinator in COVI Committee, and a Substitute Member of the Committee on the Environment, Public Health and Food Safety (ENVI) and Committee on Regional Development (REGI) in the European Parliament.

So far, he has published around 20 papers and 1 book on issues concerning EU law, including several articles in European journals, such as the European Law Review and the European Law Journal. He has presented papers at many international conferences and worked on different research projects. Previously, he worked in a legal practice and is currently a Senior Lecturer at the Zagreb School of Economics and Management where he has taught Introduction to European Union and Principles of Law courses since the academic year 2010/2011. He is also an assistant professor at the Catholic University of Croatia where he has taught since the academic year 2016/2017. His areas of professional interest include the law of the European common market, EU health law, competition law, International and European social law and International and European trade law.



MEP Deirdre Clune
EPP, Ireland

Born in 1959 in Cork, Ireland. Ms Clune qualified as a Civil Engineer at University College Cork in 1980 and has worked with Delap & Waller, Roughton & Partners and Arup. She also obtained a Higher Diploma in Environmental Engineering in 1996.

Ms Clune is a former Member of the Irish Parliament (1997-2002, 2007-2011) and the Upper House of Parliament (2011-2014). She was elected Lord Mayor of Cork in 2005.

During her time in parliament, she was Deputy Spokeswoman on Enterprise with special responsibility for innovation. She was also the Fine Gael Spokeswoman on Environmental Information and Protection, Arts, Heritage, 'Gaeltacht' and the Islands.



Andrzej Rys
Principal Scientific Adviser, Directorate-General for Health and Food Safety
(DG SANTE), European Commission

Dr. Andrzej Rys is a medical doctor specialised in radiology and public health, graduated from Jagiellonian University, Krakow, Poland. In 1991, he founded the School of Public Health at the Jagiellonian University that he ran as Director until 1997. Thereafter, from 1997 to 1999, he served as Director of the Krakow's City Health Department. Between 1999 and 2002, he continued his career as Deputy Minister of Health in Poland where he developed a new system of emergency medical service and reformed the education system for the health professionals. At the same time, he was a member of the Polish EU accession negotiators team for the harmonisation of the Polish Health Care Law with the EU's Acquis Communautaire. After becoming Senior Consultant of "Health and Management Ltd" for the World Bank, WHO and EAR in Serbia in 2002. In 2003 he founded the "Center for Innovation, Technology Transfer and University Development" (CITTRU) at the Jagiellonian University where he assumed the role of Director until 2006. From 2004 to 2005, he was also Director of Development at "Diagnostyka Ltd". In 2006, he became Director for Public Health and Risk Assessment at the Directorate-General for Health and Consumers (DG SANCO), in the European Commission. From 2011 to September 2022, Dr. Andrzej Rys was the Director responsible for Health Systems, Medical Products and Innovation in DG SANTE, in the European Commission in Brussels, Belgium, where he is now Principal Scientific Adviser since 1 October 2022.



Dr Neerja Chowdhary
Technical Officer, Brain Health Unit – Department of Mental Health and
Substance Use World Health Organization (WHO)

Dr Neerja Chowdhary is a technical officer in the Department of Mental Health and Substance Use at the WHO headquarters. A psychiatrist by training, she works in the Brain Health team.

Her role includes supporting implementation of the Global action plan on the public health response to dementia 2017-2025.

She led the development of the WHO dementia risk reduction guidelines. She is also the focal point for WHO's maternal mental health work.

About us



European Brain Council (EBC)

The European Brain Council (EBC) is a network of key players in the “Brain Area”, with a membership encompassing scientific societies, patient organisations, professional societies and industry partners. A non-profit organisation based in Brussels, its main mission is to promote brain research with the ultimate goal of improving the lives of the estimated 179 million Europeans living with brain conditions, mental and neurological alike.



www.braincouncil.eu



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European Federation of Pharmaceutical Industries and Associations (EFPIA)

The European Federation of Pharmaceutical Industries and Associations (EFPIA) represents the biopharmaceutical industry operating in Europe. Through its direct membership of 37 national associations, 38 leading pharmaceutical companies and a growing number of small and medium-sized enterprises (SMEs), EFPIA’s mission is to create a collaborative environment that enables our members to innovate, discover, develop and deliver new therapies and vaccines for people across Europe, as well as contribute to the European economy.



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