







# RETHINKING **ALZHEIMER'S DISEASE**

Rethinking Alzheimer's disease: Moving towards a new Alzheimer's disease detection and diagnosis pathway in Sweden

> Virtual event 26 September 2023 | 09:00 - 11:00

### Discover the Programme\*

Time	Topic	Speaker
09:00 – 09:10	Introduction & Welcome address	Joakim Ramsberg, Head of Science and Society, Swedish Brain Foundation (SBF)  Prof. Suzanne Dickson, President, European Brain Council (EBC)
09:10 – 09:20	Keynote speech: Living with Alzheimer's disease in a daily life	Maria Cavalli, Co-founder, NADIO (Need, Ask, Develop, Implement and Organize)
09:20 – 10:00	Panel discussion and Q&A: From detection and diagnosis to innovative treatment and care  Moderated by:  Joakim Ramsberg, Head of Science and Society, Swedish Brain Foundation (SBF)	Frédéric Destrebecq, Executive Director, European Brain Council (Presentation of the Rethinking Alzheimer's Disease White Paper)  Linus Jönsson, Full Professor of Health Economics, Karolinska Institutet  Kaj Blennow, Professor, University of Gothenburg
10:00 – 10:10	Keynote address: Rethinking the Alzheimer's care pathway in Sweden	Moa Wibom, Senior Physician & Senior Manager, Ängelholm Hospital

 $<sup>^*</sup>$ Please note that this is a provisional programme which may still be subject to change.

Time	Topic	Speaker
10:10 -10:55	Panel discussion and Q&A: Healthcare system transformation: scaling up health systems' readiness  Moderated by:  Joakim Ramsberg, Head of Science and Society, Swedish Brain Foundation (SBF)	Laura Campo, Executive Director International Corporate Affairs, Alzheimer's disease, Eli Lilly and Company  Giovanni Frisoni, Full Professor of Clinical Neuroscience, Geneva University Hospital  Lina Nordquist, Member of Parliament, Swedish Liberal party  Gerd Lärfars, Chairwoman, Swedish Association of Local Authorities and Regions
10:55 – 11:00	Concluding remarks: What next?	Frédéric Destrebecq, Executive Director, European Brain Council

### Background

Rethinking Alzheimer's disease (AD) is a research-driven project, coordinated by the European Brain Council and supported by the European Federation of Pharmaceutical Industries and Associations, 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 7 million people in Europe alone already live with Alzheimer's disease. 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 50% 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.



Calling for change in Alzheimer's care

### Speakers' biographies



Joakim Ramsberg Head of Science and Society, Swedish Brain Foundation (SBF)

Joakim Ramsberg, Ph.D., is currently head of science and head of policy at the Swedish Brain Foundation. Before this he served for many years as chief scientific officer and project director at Vårdanalys (The Swedish Agency for Health and Care Services Analysis). He is an affiliated researcher at Karolinska Institutet. Additionally, Joakim is a senior Harkness Fellow in Health Care Policy and Practice and was a visiting scholar at Harvard medical school. Ramsberg has served as elected president of the Swedish Health Economics Association. He has been a member of several governmental, international, and research advisory committees e.g. for the Swedish government, the European Commission, the OECD, SBU and the Swedish Research Council. He received a Ph.D. in economics from the Stockholm School of Economics.



Prof. Suzanne Dickson
President, European Brain Council (EBC)

Professor Suzanne L Dickson is a neurobiologist and Professor of Neuroendocrinology at the University of Gothenburg. She graduated with a Ph.D. in Neuroendocrinology from the University of Cambridge in 1993, where she later became Senior Lecturer in Physiology. She is a leading figure in neuroendocrinology and works within many European Union and international organisations and societies to promote research, facilitate grant funding and training of Early Career Scientists. Her research into the neurobiology of appetite aims to unravel neurobiological pathways that respond to orexigenic signals, such as the hormone, ghrelin, and that drive feeding behaviours, not only food intake but also food choice, food anticipation, food reward and food motivation. This work involves mostly preclinical studies and includes behavioural tasks, viral vector mapping, chemogenetics and RNAscope. She is Secretary and Executive Board member of the European College for Neuropsychopharmacology, and also chairs ECNP's Workshop for Early Career Scientists in Europe. She also is founder and co-chair of ECNP's nutrition network and EBRA's BRAINFOOD cluster.



Maria Cavalli Co-founder, NADIO (Need, Ask, Develop, Implement and Organize)

Maria Cavalli is an accomplished social entrepreneur with a personal drive that stems from her father's diagnosis of early-onset Alzheimer's at age 50. Inspired to make a difference, she co-founded the Healthtech company NADIO in 2008. Their digital services for caregivers "En bra plats" and "Demenslotsen," can be found in 25 municipalities. "Alzheimerguiden" serves as a nationwide digital platform designed for those recently diagnosed with Alzheimer's.

Maria has an extensive background in dementia care as a Senior Manager and as a Project Manager in Healthcare Improvement. She held a board position with Alzheimer Sweden from 2003-2006 and is currently on the board of the BPSD-registry, a Swedish National Quality Registry. Maria is also a founding member of the Swedish Network for Young Caregivers (SNUA).



#### 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.



## **Linus Jönsson**Full Professor of Health Economics, Karolinska Institutet

Dr Linus Jönsson MD PhD, is 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, IHI-PROMINENT), and co-chairs the International Pharmacoeconomic Collaboration on Alzheimer's Disease (IPECAD).



# **Kaj Blennow**Professor, University of Gothenburg

Kaj Blennow is Professor and Academic Chair in Clinical Neurochemistry at University of Gothenburg, and Head of the Clinical Neurochemistry Lab at Sahlgrenska University Hospital, Gothenburg, Sweden. He holds a Specialist Competence in Psychaitry and in Clinical Chemsitry.

His main research interest is the development of new analytical methods for CSF and blood biomarkers for AD and other brain disorders, and the application of these to increase the understanding of AD pathophysiology, as well as for screening, diagnostics and in therapy monitoring in clinical trials.

Dr. Blennow has published more than 1900 original research papers and review articles in peer-reviewed journals, with more than 140.000 citations, and he has an H-index of 169. He is President of the Society for CSF analysis and Clinical Neurochemistry and head of the Alzheimer's Association QC program for CSF and blood biomarkers. He has received a series of research prizes, such as the Alois Alzheimer Research Award (Germany, 2001), the Henry Wisniewski Lifetime Achievement Award (2011), the Söderberg Price in Medicine (2016), and the Nordic Price in Medicine (2018).



#### Moa Wibom Senior Physician & Senior Manager, Ängelholm Hospital

Moa Wibom is a senior physician and senior manager at the unit for Cognitive Medicine at Ängelholm Hospital in Sweden. She holds a master's degree from the Karolinska Institute and is also a Silvia Physician. Moa is a prominent figure in public education and awareness regarding cognitive diseases, including Alzheimer's disease, vascular disease, and frontotemporal disease, with numerous appearances on television and other media. Since 2021, she has been the director of the Swedish BPSD registry. The well-being of children living with a parent with a neurocognitive disorder has become her mission, and she is a founding member of the Swedish Network for Young Caregivers (SNUA).



# Laura Campo Executive 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.



#### Giovanni Frisoni Full Professor of Clinical Neuroscience, Geneva University Hospital

Clinical neurologist, full professor of Clinical Neurosciences at the University of Geneva, Switzerland, and director of the Memory Center at Geneva University Hospital. Formerly scientific director at the National Alzheimer's Centre Fatebenefratelli in Brescia, Italy, leads a team of about 35 scientists and clinicians. Author of over 750 scientific papers listed in PubMed on the use of biomarkers for earlier and more accurate diagnosis and prognosis of Alzheimer's disease and other dementias. Biomarker editor for Neurobiology of Aging and founding editorial board member of The Lancet Neurology. Has led national and international projects funded by the European Commission, IMI, IMI2, the Alzheimer's Association, Italian Ministry of Health, Swiss National Science Foundation, and industry. Over the years, he has attracted over 35M euros in competitive research funds. Chairman of Alzheimer's Imaging Consortium at International Conference on Alzheimer's Disease in 2010 and 2011. Honorary member of the Austrian Neurological Society and of the French Society of Neurology, he has received the Investigator Award Winner of European Academy of Neurology in 2016.



# **Lina Nordquist**Member of Parliament, Swedish Liberal party

Lina Nordquist (1977) is a Swedish researcher and politician. She is an associate Professor in physiology with a research focus on blood pressure and diabetes. Since 2018, she serves as a member of the Swedish Parliament and spokesperson in healthcare for her party Liberalerna.



#### Gerd Lärfars Chairwoman, Swedish Association of Local Authorities and Regions

Assistant Professor Gerd Lärfars is Chairwoman for The Council for New Therapies (NT-council) at the Swedish Association of Local Authorities and Regions (SKR). The NT-Council negotiates managed access agreements for priority medicines on behalf of all regions.

### 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.



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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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#### Swedish Brain Foundation (SBF)

The Swedish Brain Foundation (SBF) works for a society where all brains reach their full potential, free from disease. It is by contributing to research that we can change the lives of even more people.

Since their start in 1994, they have distributed almost one billion kroner to Swedish brain research and they have no plans to slow down. There is much more to explore. They know that big change starts with giving each person the right conditions. That every person, every brain, gets a place.

In order to fulfill their vision, they work with the objectives: collecting and financing brain research as well as spreading knowledge and forming opinions in the area of the brain.



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Swedish Association of the Pharmaceutical Industry (LIF)

Läkemedelsindustriföreningen is the trade association for the research-based pharmaceutical industry in Sweden with about 90 members and associate companies. Lif Service AB (LIF) represents its members in issues of common concern, assisting and informing them on questions vital to the industry. They are members of the European trade association EFPIA and the international trade association IFPMA as well as of the European associations AESGP.



www.lif.se



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