TOWARDS A GLOBAL ALLIANCE ON EPILEPSY RESEARCH

Date: Tuesday 12 February 2019  
Time: 13:00 - 14:30  
Venue: MEP Salon (LOW)

LUNCH EVENT
Hosted by BRIAN HAYES MEP  
President, European Advocates for Epilepsy Group

Speakers will present on the unmet needs in the field of epilepsy and the status of epilepsy research priorities at a global level

OPENING REMARKS  
Brian Hayes MEP

INTRODUCTIONS  
Martin Brodie

SPEAKERS  
Francesca Sofia  
Frederic Destrebecq  
Philippe Rylin

CLOSING REMARKS  
Brian Hayes MEP
Brian Hayes MEP
Born in 1969, Mr Hayes studied history and sociology at the National University of Ireland, St Patricks College Maynooth. He served as a member of Dail Eireann (Irish Parliament) from 1997-2002 and 2007-2014. In 2011 he was appointed Minister of State at the Departments of Finance and Public Expenditure & Reform, a position he held until his election to the European Parliament in May 2014. He was appointed to the European Parliaments Economic & Monetary Affairs Committee, Development Committee and Budgetary Control Committee. He is also a member of the Delegations to Iraq and South Africa. He is President of the European Advocates for Epilepsy group.

Martin Brodie
Prof Martin Brodie is President of the International Bureau for Epilepsy (IBE). His involvement with IBE goes back more than 30 years, having served as a member of its board from 2005 to 2009. He qualified in Medicine at Glasgow University in 1971 and undertook his postgraduate training in London before returning to Glasgow where he directed the Epilepsy Unit in Glasgow, Scotland from 1981 until his retirement in 2017, providing a range of services for people with seizure disorders across the West of Scotland. He set up and chairs the Board of Trustees of the charity, Scottish Epilepsy Initiative. Prof Brodie’s research interests include antiepileptic drug neuropharmacology, randomised clinical trials, prognostic outcome studies, management of epilepsy and factors affecting antiepileptic drug response. He has published more than 450 editorials, chapters, reviews, proceedings and articles in peer reviewed journals.

Francesca Sofia
Dr Sofia is a molecular biologist with a Ph.D. in neuroscience. She specialized in healthcare economics and policy, working for 10 years as research program manager for a major Italian health foundation, dedicated to rare genetic diseases, where she was coordinator of the Patient Support Office and headed the intramural research institute. Her career path was straightforward until the moment her youngest daughter was diagnosed with a rare form of epilepsy, in 2011. So it was that her work and personal lives melted together gaining strength, drive and humanity. In July 2014, she joined the Italian Epilepsy Federation with the aim of fostering epilepsy research. Recently, she founded Science Compass an enterprise that provides services and tools for effective investments in the biomedical sector to non-profit health foundation and patient organizations. She is a member of the European Regional Executive Committee of the IBE and of Epilepsy Alliance Europe.

Frederic Destrebecq
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.

Prior to this position, Fred served the European Union of Medical Specialists (UEMS) as Chief Executive Officer, and previously as Director for European Affairs. 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.

Philippe Ryvlin
Dr Ryvlin is Professor of Neurology and Chair of the Department of Clinical Neurosciences at University Hospital of Lausanne (CHUV), Switzerland, and Director of the Epilepsy Institute (IDEE) in Lyon, France. He is President of the European Epilepsy Monitoring Association (EEMA), co-Chair of the Epilepsy Alliance Europe Joint Task Force, founder of the European Network for Epilepsy Research (ENER), and coordinator of the EU funded European pilot network of reference centres in refractory epilepsy and epilepsy surgery, (E-PILEPSY). He is the author or co-author of over 200 PubMed referenced papers on topics primarily related to epilepsy surgery, anti-epileptic treatments and Sudden Unexpected Death in Epilepsy (SUDEP). At CHUV, Philippe Ryvlin has developed NeuroTech, a clinical research infrastructure dedicated to the evaluation of novel technologies in patients with neurological disorders, with emphasis on mobile and connected devices as well as assisting robots.
WHO WE ARE

**International League Against Epilepsy**

With national chapters in 114 countries worldwide, the International League Against Epilepsy (ILAE), was founded in 1909 and is the world’s preeminent association of physicians and other health professionals working toward a world where no person’s life is limited by epilepsy. The goals of the ILAE are to advance and disseminate knowledge about epilepsy; to promote research, education and training; and to improve services and care for patients, especially by prevention, diagnosis and treatment.

*President: Samuel Wiebe*

[ilae.org](http://ilae.org)

**International Bureau for Epilepsy**

Established in 1961, the International Bureau for Epilepsy (IBE) is an international network of national epilepsy organisations (IBE chapters) that exists to provide support for a strong global network, encourage the development of new chapters in underserved areas of the world, and to encourage communication and collaboration among all members so as to meet our mission and vision.

IBE’s vision is a world where everywhere ignorance and fear about epilepsy are replaced by understanding and care.

*President: Martin Brodie*

[ibe-epilepsy.org](http://ibe-epilepsy.org)

**Epilepsy Alliance Europe**

Epilepsy Alliance Europe was established (2011) to highlight the need for increased research funding for new and novel treatments for epilepsy and improved treatment and care for the 6 million Europeans living with epilepsy. With a vision to have epilepsy as a health priority in Europe, its main objectives are the protection of the rights of people with epilepsy, the improvement of epilepsy care, the dissemination of awareness and knowledge about the complex spectrum of epileptic diseases, and the promotion of research in epilepsy and its comorbidities.

*Co-chairs: Philippe Ryvlin and Martin Brodie*

[epilepsyallianceeurope.org](http://epilepsyallianceeurope.org)

**European Advocates for Epilepsy Group**

The European Advocates for Epilepsy working group was created in April 2011, following the successful launch of the first European Epilepsy Day (now International Epilepsy Day), which was hosted in the European Parliament in Strasbourg by Gay Mitchell MEP. The aim of the group is to improve the quality of life of all people with epilepsy, their families, their care-givers and healthcare providers through European Union (EU) policy.

Currently, the group comprises 55 MEPS, lead by its President Brian Hayes MEP and Vice President Nathalie Griesbeck MEP.

*Brian.hayes@europarl.europa.eu*

Yesterday was International Epilepsy Day
It’s not too late to post your photo and message on social media with the hashtag #EpilepsyDay
Help us to raise awareness about epilepsy by showing your support for the 6 million people living with epilepsy in Europe

Towards a Global Alliance on Epilepsy Research Workshop
is organised by Epilepsy Alliance Europe
and hosted by Brian Hayes, MEP
and members of the European Advocates for Epilepsy Group

EUROPEAN ADVOCATES FOR EPILEPSY MEMBERS

PRESIDENT: Brian Hayes. VICE PRESIDENT: Nathalie Griesbeck.