



## Brain Awareness Week Event

“Patient Engagement in EU-funded Brain Research Projects”

16 March 2021, 12:30 - 14:00 CET

**#ILoveMyBrain**

# Programme

Time	Topic	Speaker
12:30 - 12:40	 <b>Welcome &amp; Introduction</b>	 <b>Joke Jaarsma</b> President European Federation of Neurological Associations (EFNA)   <b>Monica Di Luca</b> President European Brain Council (EBC)
12:40 - 12:55	 <b>Setting the scene: What are the challenges of engaging patients in research?</b>	 <b>Joke Jaarsma</b> President European Federation of Neurological Associations (EFNA)   <b>Irene Norstedt</b> Director, People Directorate, DG Research and Innovation European Commission   <b>Erik Van der Eycken</b> EU Research Project Officer Global Alliance of Mental Illness Advocacy Networks (GAMIAN - Europe)
12:55 - 13:25	 <b>Concrete Examples and Solutions</b>	 <b>Pierre Meulien</b> Executive Director Innovative Medicines Initiative (IMI)   <b>Paola Zaratina</b> MULTI-ACT Project - White Paper for innovative routes for patient engagement – call to action   Representative from the Belgian Centre for Evidence-based Medicine (CEBAM)

Time	Topic	Speaker
13:25 - 13:55	 <p><b>Panel Discussion and Q&amp;A</b></p> <p>Moderated by:</p>  <p><b>Frédéric Destrebecq</b> Executive Director, European Brain Council</p> <p>Focus on the importance of involving patients in research – the benefits and the pitfalls; reaction to examples of the work of IMI, proposed solutions of MULTI-ACT and CEBAM.</p>	 <p><b>Irene Norstedt</b> Director, People Directorate DG Research and Innovation European Commission</p>  <p><b>Erik Van der Eycken</b> EU Research Project Officer Global Alliance of Mental Illness Advocacy Networks (GAMIAN - Europe)</p>  <p><b>Joke Jaarsma</b> President European Federation of Neurological Associations (EFNA)</p>  <p><b>Tomislav Sokol (HR, EPP)</b> Member of the European Parliament</p>
13:55 - 14:00	 <p><b>Concluding Remarks</b></p>	 <p><b>Hilka Kärkkäinen</b> President Global Alliance of Mental Illness Advocacy Networks (GAMIAN - Europe)</p>



# Background

Patient engagement in research is an approach that involves meaningful and active collaboration with patients in the governance, priority setting, conducting and knowledge translation of research. While patient engagement is becoming increasingly popular and vital prerequisite in research projects, many researchers are still unsure or hesitant in the involvement of patients in their work and why such engagement is of value. The process is unclear to many and how to fully involve patients can be unclear. However, many patients are keen to be part of research – “nothing about us without us” –arguing that no research can be fully done without direct insight from the people actually living with these conditions every day.

For some time now, the European Commission, through its research programmes and related initiatives, has been increasing its encouragement of involving patients in research, particularly within the projects it funds. The Responsible Research and Innovation (RRI) approach has been highlighted throughout the objectives of the EU Horizon 2020 Programme. In health research this means to put the expectations of patients and society at the heart of research programs. European initiatives such as the Innovative Medicines Initiative (IMI) have spearheaded the growth of involving patients in European research, encouraging patient involvement in their activities and project, and involving patients as speakers and panellists in their events and consultations. Furthermore, H2020-funded projects such as MULTI-ACT were launched with the aim to increase the impact of health research on people with brain diseases and to create and implement a new model allowing for the effective cooperation of all relevant stakeholders.

However, most patients and patient representatives still feel like not enough support is given to have their voices fully heard in research—requests and demand for involving patients is growing but a pool of “patient experts” is still lacking. The discussion needs to shift from “we need to show that patients are on board” to “how can we best involve patients and why/ how are we involving them to the full benefit for the research conducted”. “What can be done concretely in EU funded health research projects to enforce patient engagement”? This needs to be more than a “box ticking exercise”.

This Brain Awareness Week looks to explore the current state of patient engagement in EU-funded Brain Research projects, looking at IMI and MULTI-ACT as concrete examples and solutions and analysing in discussion with key officials what has been done and what can still be done in order to guarantee change.



# Speakers' biographies



**Joke Jaarsma**

President, European Federation of Neurological Associations (EFNA)

Joke Jaarsma is EBC Treasurer and President of the European Federation of Neurological Associations (EFNA). In 2009 she started the European Alliance for Restless Legs Syndrome, an organization which now represents all major European patient groups for RLS. She still works with them as Director of External Relations. Furthermore, she also is a member of several scientific panels at the European Academy of Neurology.

In her working life, Joke Jaarsma was senior publisher at one of the major science publishers. She joined the Dutch Restless Legs Syndrome (RLS) patient association in 1999, and she is still active as Vice President of the Dutch group.

Having finished full-time paid employment, she decided to spend her retirement in helping give neurology patients a strong and collective voice.



**Monica Di Luca**

President, European Brain Council (EBC)

Monica Di Luca, EBC President, is Professor of Pharmacology and Head of Laboratory of Pharmacology of Neurodegeneration – DiSFeB at the University of Milano.

Her primary research interest is related to synaptic plasticity in physiological and pathological conditions, with the primary aim to apply basic findings to the cure of neurodegenerative diseases such as Alzheimer's and Parkinson's Disease.

She has been member of Council of several national and international scientific organizations including Federation of European Neuroscience Societies (FENS, President 2014-2016), the International Brain Research Organization (IBRO), EMBO and the European Dana Alliance for the Brain (EDAB).



**Irene Norstedt**

Director, People Directorate, DG Research and Innovation, European Commission

Irene Norstedt works at the European Commission where she is the Director responsible for the People Directorate within the DG for Research and Innovation.

Irene has been at the European Commission since 1996, and was instrumental in the creation of the Innovative Medicines Initiative (IMI) in 2008. From 16 December 2014 to 15 September 2015, Irene served as Acting Executive Director of the Innovative Medicines Initiative.

Prior to joining the European Commission, she worked for the Swedish life science company Biacore AB and at the Swedish embassy in London. Irene studied biotechnology and polymer science, and holds a Master of Science (MSc) in Chemical Engineering.



**Pierre Meulien**

Executive Director, Innovative Medicines Initiative (IMI)

Pierre Meulien is Executive Director of the Innovative Medicines Initiative (IMI), a €5 billion public-private partnership between the European Union and the European pharmaceutical industry. At IMI, he is responsible for the overall management of the program, which works to improve and accelerate the drug development process by facilitating collaboration between the key players involved in health research. Previously, Dr Meulien was president and CEO of Genome Canada, where he raised money and oversaw the launch of novel projects and networks in the field of genomics-based technologies. Prior to that, he was chief scientific officer for Genome British Columbia and was the founding CEO of the Dublin Molecular Medicine Center. Dr Meulien also worked with the French biotechnology company Transgene and with Aventis Pasteur (now Sanofi Pasteur). He has a Ph.D. in molecular biology from the University of Edinburgh and carried out a postdoctoral fellowship at the Institut Pasteur in Paris.



**Paola Zaratina**

MULTI-ACT Project - White Paper for innovative routes for patient engagement – call to action

Paola Zaratina joined Italian MS Society on February 2010 where she currently holds the position of Director of Scientific Research. Paola has deep experience in Neuroscience research and in Drug Discovery and Development, acquired in Public, Private and Patients' Organizations and in the last 20 years in the area of Multiple Sclerosis. Coordinator (2018-2021) of the EU Responsible Research Innovation H2020 MULTI-ACT project ([www.multiact.eu/](http://www.multiact.eu/)) Paola led the development of a new participatory governance model and guidelines to engage patients as key stakeholder in multistakeholder research initiatives. Co-chair of the Scientific Steering Committee (2019) of the global Patient Reported Outcomes Initiative for Multiple Sclerosis (PROMS, [www.aism.it/PROMS](http://www.aism.it/PROMS)). Member of the Scientific Steering Committee (2012) and of the Industry Forum (2014) of Progressive Multiple Sclerosis Alliance (PMSA, <https://www.progressivemsalliance.org>). Paola is author of more than 75 publications (1987-2021) and 9 patents (Linkedin [https://bit.ly/in\\_zaratina](https://bit.ly/in_zaratina) ; Twitter @paolazaratina; Research Gate [https://bit.ly/rg\\_zaratina](https://bit.ly/rg_zaratina)).



**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.

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.



**Tomislav Sokol (HR, EPP)**  
Member of the European Parliament

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.

During his studies, in 2004, Tomislav Sokol became a Member of the Croatian Democratic Union (HDZ). He climbed the party ranks during the next decade, always emphasising on Christian Democratic values as the cornerstone of its identity. He was an Assistant Minister in the Ministry of Science and Education, 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 and a Substitute Member of the Committee on Regional Development.

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, worked on different research projects and is currently taking part in a Jean Monnet project related to EU health law and policy. 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.



**Hilikka Kärkkäinen**  
President, Global Alliance of Mental Illness Advocacy Networks  
(GAMIAN - Europe)

Hilikka is a social worker by profession and she has retired from her job as Social Ombudsman in Sosiaalitalito in 2014. She is also a patient and an expert by experience having suffered reactive depression in 2002. She has worked both for the City of Helsinki and the City of Espoo in Child Welfare several years. Hilikka was a Senior Social Worker in Probation and After Care Association in Helsinki for seven years. As an office manager in Espoo Social Services in 1980's she was also in charge of a Horizon ECHO program for people with mental disorders. She was Executive Director of Finnish Central Association for Mental Health 1998-2002 and has been President and Vice President of Mieli Maasta, which is a patient association for those suffering from depression. She has worked for the City of Järvenpää as a Planner of Regional Mental Health Care. Hilikka was a Board Director of European Federation of Neurological Associations (EFNA) 2002-2004 and President of GAMIAN-Europe once before in 1999. She is a Board Director of European Brain Council (EBC), European Patient Forum (EPF) and European Psychiatric Association (EPA).

# 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.

With the aim to speak with one voice, EBC stands as the platform to foster cooperation between its member organisations and other stakeholders, consistently promoting dialogue between scientists, industry and society. As showcased by its growing portfolio of projects, research and policy papers, as well as events, EBC emphasizes the importance of continued interaction with the European Institutions to build strong European health policies, raising awareness and encouraging education on the brain and the repercussions of neurological and mental health conditions on society as a whole.



## European Federation of Neurological Associations (EFNA)

The European Federation of Neurological Associations (EFNA) is an umbrella group representing pan-European neurology patient groups.

Our slogan ‘Empowering Patient Neurology Groups’ encapsulates our goals as an Association. We strive to add capacity to our members – allowing them to be the most effective advocates possible in their own disease specific areas.

EFNA embraces the concept of Partnership for Progress – working at a high level with relevant stakeholders from the fields of policy, medical, scientific/research, industry, patient partners and other key opinion leaders.



## Global Alliance of Mental Illness Advocacy Networks-Europe (GAMIAN-Europe)

Global Alliance of Mental Illness Advocacy Networks-Europe (GAMIAN-Europe) is a non-profit patient-driven pan-European organisation, representing and advocating for the interests and rights of persons affected by mental ill-health. Our main activities include awareness-raising, education, and partnership and capacity building. Overarching themes in our work relate to anti-stigma, discrimination and patients’ rights.





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