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**Brain Awareness Week Event
"Patient Engagement in
EU-Funded Brain Research Projects"**

EBC in partnership with EFNA & GAMIAN-Europe

Digital Event – 16 March, 12:30-14:00

Programme:

Welcome & Introduction 12:30-12:40	Welcome by Joke Jaarsma, President, European Federation of Neurological Associations (EFNA) and Monica Di Luca, President, European Brain Council (EBC)
Concrete Examples and Solutions 12:40-13:20	<p>Pierre Meulien, Innovative Medicines Initiative (IMI)</p> <p>Paola Zarin, MULTI-ACT Project - White Paper for innovative routes for patient engagement – call to action</p> <p>Representative from the Belgian Centre for Evidence-based Medicine (CEBAM)</p>
Panel Discussion: 13:20-13:50 <i>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.</i>	<p>Irene Norstedt, Director, People Directorate, DG Research and Innovation, European Commission</p> <p>Erik Van der Eycken, EU Research Project Officer, Global Alliance of Mental Illness Advocacy Networks (GAMIAN - Europe)</p> <p>Donna Walsh, Executive Director, European Federation of Neurological Associations (EFNA)</p> <p>Tomislav Sokol (HR, EPP), Member of the European Parliament</p>
Concluding Remarks 13:50-14:00	Hilkka Kärkkäinen, President, Global Alliance of Mental Illness Advocacy Networks (GAMIAN - Europe)

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.