

The Value of Innovation Series

**Enhanced engagement through  
public-private partnerships**

Sustaining therapeutic innovation  
to address patient needs

**21<sup>st</sup> November 2018**

**The EGG Brussels  
Rue Bara, 175 - 1070 Brussels, Belgium**

**#PublicPrivate  
#TherapeuticInnovation  
#PatientNeeds  
#IndustryDay  
#ILoveMyBrain**



## European Brain Council Brussels Office

Rue d'Egmont, 11  
BE-1000 Brussels  
Tel: + 32 (0) 2 513 27 57

[info@braincouncil.eu](mailto:info@braincouncil.eu)

 @EU\_Brain  
#PublicPrivate  
#TherapeuticInnovation  
#PatientNeeds  
#IndustryDay  
#ILoveMyBrain

[www.braincouncil.eu](http://www.braincouncil.eu)



## SUMMARY

|   |    |
|---|----|
| Introduction                                    | 4  |
| EBC - Who we are                                | 4  |
| Programme                                       | 5  |
| Keynote Speakers                                | 6  |
| Sessions  |    |
| • R&D Breakthroughs in Brain Health             | 8  |
| • The Value of Innovation - Interactive Session | 11 |
| • Engaging Patients in Their Care               | 11 |
| Speaker Biographies                             | 13 |
| Poster Session on Disease Awareness Initiatives | 19 |
| Acknowledgments                                 | 26 |
| Notes   | 27 |

## ■ INTRODUCTION

EBC is made up of a vast network of vital players in the Brain space; with a membership encompassing scientific societies, patient organisations, professional societies and industry partners. All play vital roles in research, advocacy, treatment, support and innovating for the brain and for those across Europe (and the world) living with brain and mental disorders. Today's event brings together this membership and gives all an opportunity to showcase their latest work and initiatives to the EBC constituency and other key stakeholders as well as to create a forum to establish a dialogue to improve outcomes for patients focused on 3 key areas – R&D in Neurology and Psychiatry, Patient Engagement and Disease Awareness. The anticipated outcomes of the day will be to foster a debate to define how we would establish valuable partnerships between industry and EBC stakeholders to improve outcomes for patients living with a brain condition.

## ■ EBC - Who we are

The European Brain Council (EBC) is a non-profit organization gathering patient associations, major brain-related societies as well as industries. Established in March 2002, its mission is to promote brain research in order to improve the quality of life of those living with brain disorders in Europe. 165 million Europeans live with a brain disorder, causing a global cost (direct and indirect) exceeding 800 billion euros for the National Health budgets. EBC's main action areas are:

- Fostering cooperation with its member organizations
- Promoting dialogue between scientists, industry and society
- Interacting with the European Commission, the European Parliament and other relevant international institutions
- Raising awareness and promoting education on the brain
- Disseminating information about brain research and brain diseases in Europe



## ■ PROGRAMME

- 10:30** Chairmen's Welcome & Presentations
- 11:00** **Keynote Lecture:** *The importance of the private sector in improving outcomes for brain health*
- 11:30** **R&D Breakthroughs in Brain Health**
- R&D Breakthroughs in Neurology
  - The potential of PET-MR in differential diagnosis and prediction of cognitive trajectory in mild cognitive impairment
  - Brain+ RECOVER: Digital Therapeutics app platform for brain rehabilitation
- 12:30** **Lunch Poster Session on initiatives to improve disease awareness**
- 14:00** **R&D Breakthroughs in Brain Health (continued)**
- How can we "crack" the code of Multiple Sclerosis (MS)?
  - Understanding the entorhinal cortex memory-system for novel biomarker and treatment development in Alzheimer's disease
  - The IMI PRISM project: a quantitative approach to neuropsychiatry
- 14:45** **The Value of Innovation - Interactive Session**
- 15:30** **Coffee Break**
- 15:45** **Keynote Lecture:** *The importance of engaging patients in their conditions*
- 16:15** **Engaging patients in their care**
- Patients and Psychiatrists working in partnership for developing trust and effective care – Why patient empowerment matters
  - Assertive outreach projects can improve treatment continuity and long-term outcomes for people with Schizophrenia
  - MS in the 21<sup>st</sup> Century: A model for better patient engagement
- 17:00** **Summary and meeting close**

## ■ KEYNOTE SPEAKER - The importance of the private sector in improving outcomes for brain health



**Sohini Chowdhury**

Deputy CEO, Michael J. Fox Foundation, USA

Sohini joined The Michael J. Fox Foundation in 2005. As Deputy CEO, Sohini oversees the Research Partnerships team and works closely with the Foundation's executive leadership and Board of Directors in building the organization's capacity as an unprecedented stakeholder in drug development – a nimble, resourceful, patient-focused problem-solver whose efforts are demonstrably accelerating progress toward treatment breakthroughs and a cure. Sohini was elevated to the role of Deputy CEO in 2017.

In her previous capacity as SVP, Research Partnerships at the Foundation, Sohini established and led the formal industry strategy, building ongoing relationships with pharmaceutical firms and biotechs as research partners and as sponsors of the Foundation's scientific and educational programs. She has led development of programs critical to increasing patient engagement in Parkinson's research including the Fox Trial Finder smart-match tool and Fox Insight. Sohini also is responsible for administrative and operational oversight of the MJFF-sponsored landmark clinical study PPMI, or the Parkinson's Progression Markers Initiative, launched by MJFF in 2010 to identify and validate Parkinson's biomarkers.

Prior to joining MJFF, Sohini worked at the World Economic Forum for five years. As the Senior Community Manager of the Forum's Technology Pioneers program, she was responsible for annually selecting and integrating innovative biotech, energy and IT technology companies into Forum activities. Sohini also worked directly for the Forum's CEO, acting as his liaison with key Forum stakeholders and overseeing several in-house projects.

Sohini graduated with an MA from Georgetown University, and holds a BA in International Studies from Vassar College.

@MichaelJFoxOrg

## ■ KEYNOTE SPEAKER - The importance of engaging patients in their conditions



**Prof. Guendalina Graffigna**

Associate Professor, Catholic University of the Sacred Heart of Milan, Italy

Guendalina Graffigna received a PhD in Social Psychology at the Catholic University of the Sacred Heart of Milan (Italy) where she actually is Full Professor. At the same university she teaches "Consumer Food Psychology", "Qualitative Methodology" and "Psychology for Social Marketing", she coordinates the Research Center "EngageMinds Hub: Consumer & Health Research Center" and she is a member of the Coordination Committee of the PhD School in Psychology. Furthermore, she is currently Director of the Study and Training Centre of ASSIRM (Italian Association of Marketing Research Institutes).

Before her actual appointments, Guendalina was a Post Doc fellow (A.A. 2007-2008) and a visiting professor in Qualitative Methods (A.A. 2008-2009) at the International Institute for Qualitative Methodology, University of Alberta, with which she still collaborates for several research and teaching initiatives. In July 2012, Guendalina was awarded with the prize of Qualitative Health Research Leadership 2012 from the Global Congress for Qualitative Health Research Committee.

Her research and scientific activities are mainly devoted to patient engagement in health and wellbeing, healthcare organization innovation and digital health. She has spent the last 10 years of activity in constructing bridges between scientific/academic knowledge and professional practice, particularly in the sectors of consumer and health research. At present, she is coordinating and intra- and inter-university reflection for contributing to priorities and policy discussions at the European Level on patient health engagement.

@entropiapura

## ■ SESSION 1 - R&D Breakthroughs in Brain Health

This session showcases major developments – be they diagnostic, therapeutic or digital – with potential to change the course of brain conditions that illustrate public-private and multi-stakeholder involvement.

**Chaired by:** **Dr. Pierre Meulien**, Executive Director, Innovative Medicines Initiative (IMI) and **Prof. Patrice Boyer**, Vice-President, European Brain Council (EBC)

### R&D Breakthroughs in Neurology

**Prof. Wolfgang Oertel**, Hertie-Senior- Research-Professor and Professor for Neurology, Philipps University Marburg, Germany and Vice-President, European Brain Council (EBC)

### The potential of PET-MR in differential diagnosis and prediction of cognitive trajectory in mild cognitive impairment

**Dr. Christopher Buckley**, Senior Imaging Technology Leader, GE Life Sciences R&D

Patients presenting with mild cognitive impairment (MCI) present a challenge to their physician as the early stages of neurodegenerative diseases such as Alzheimer's disease, vascular dementia, frontotemporal dementia and Lewy body disease have overlapping symptoms. However, early insights to the disease etiology via the combination of MRI and PET amyloid imaging can provide valuable diagnostic and prognostic information. Baseline MRI and amyloid PET images were analyzed in a 3-year clinical outcome study and the findings (and algorithm-based predictions) are compared to the actual outcomes. The results show the utility of PET-MR imaging exams in MCI.

### Brain+ RECOVER: Digital therapeutics app platform for brain rehabilitation

**Mr. Ulrik Ditlev Eriksen**, Chief Science Officer & Co-founder, Brain+ ApS, Copenhagen, Denmark

Brain+ helps people, who have suffered brain injury or are suffering from a brain disorder to restore their fundamental brain functions to full health and functionality, by engaging the patient in self-training on a clinically validated mobile app platform with computer games that are purpose-built for clinical neurorehabilitation, and with digital behavioral therapy. Healthcare professionals and family caregiver work becomes more effective while freeing up their time.

The Brain+ RECOVER app is undergoing Phase 2 randomized controlled trials in Parkinson's disease, major depressive disorder, traumatic brain injury and Alzheimer's Disease, with Oxford University, Copenhagen University, Aarhus University, Nottingham University, Alzheimer Europe, The European Brain Council, the Danish National Center for Brain Injury, the Danish National Center for Neuropsychiatric Research, funded by the Danish Innovation Fund and the European Commission, Horizon2020.

Brain+ calls the exercises neuro-games because the training is so challenging to the brain's cognitive system that it stimulates the damaged neurological structures to rewire and rebuild.

This is possible because the training is targeted, intense, highly adaptive, and personalized to the patient's specific needs and specific cognitive deficits.

### How can we "crack" the code of Multiple Sclerosis (MS)?

**Danny Bar-Zohar**, Global Head of Neuroscience Development, Novartis

MS is a complex, heterogeneous disease with a poorly understood disease course. Currently, classic clinical phenotypes define disease entities; however, these do not allow either individual prognosis or optimized treatment regimens or target populations in clinical trials. Irreversible disability progression starts earlier than thought previously but is ill defined and hard to detect early. Healthcare and drug development for people with progressive disease is specifically impacted.

Our project: Novartis has initiated a multi stakeholder collaboration to leverage its combined high quality clinical, imaging and biomarker clinical trial data of more than 35,000 MS patients across all age groups and MS types. Using advanced analytics methodology on this unique dataset, we aim to better characterize the MS disease continuum, enable better prediction of the individual disease course as well as early diagnosis of progression. Further, we will improve prediction of treatment response and refine or define trial populations and outcome measures for MS clinical trials with focus on progressive MS.

The goal: Influence clinical practice, health care of people with MS and optimize MS clinical development.

### Understanding the entorhinal cortex memory-system for novel biomarker and treatment development in Alzheimer's disease

**Menno P Witter, Christian Doeller, Clifford Kentros** - Kavli Institute for Systems Neuroscience, NTNU Norwegian University of Science and Technology, Trondheim, Norway

The entorhinal cortex (EC) is involved in integration of space and time as the key contextual components underlying episodic memory. In subjects with mild cognitive impairment or early Alzheimer's disease (AD), EC shows volume loss and selective degeneration of layer II-neurons, even before a memory-based clinical diagnosis of AD is possible. A high percentage of EC-layer II-neurons contains the protein Reelin and we obtained evidence that these neurons selectively accumulate intracellular A $\beta$ -42 (iA $\beta$ ).

Prof. Menno Witter will present new approaches to study mnemonic functions of the entorhinal cortex using specific fMRI tests in humans, develop comparable tests in animal models, and study alterations in network functions in early stages of increased iA $\beta$ . Together this will result in novel, mechanistic biomarkers for the early detection of Alzheimer's disease. Further, data on our developed and patented new neuronal intervention approach (EDGE) will be presented. This allows to selectively interfere with the initial phases of disease process.

This research is part of a National Norwegian center for Neurodegenerative diseases, a Nordic consortium on the relevance of expression of iA $\beta$  and an international (Denmark, Japan, USA) consortium on the development of clinical applications.

## The IMI PRISM project: a quantitative approach to neuropsychiatry

Hugh Marston, Head of Translational Neuroscience, Eli Lilly UK

The current nosology of neuropsychiatric provides a pragmatic framework for treatment choice, regulation and clinical research. This approach does not though provide the insights into biological mechanisms vital for innovative discovery research. The PRISM project aims to address this weakness by developing a quantitative biological approach to the understanding and classification neuropsychiatric disease. PRISM is performing a deep phenotyping exercise using innovative technologies in carefully stratified Alzheimer's and schizophrenia patients exhibiting the common symptom of social withdrawal. These results will be combined with an analysis of existing major clinical data sets. If successful, with this meaningful biological starting point, new hypotheses and approaches for reverse translation into pre-clinical research should emerge. While with patients and regulatory agencies, clear routes for the future translation and regulatory approval of new treatments are under way. Together it is hoped to provide new solutions to the challenges of psychiatry and neurology.

*The PRISM project ([www.prism-project.eu](http://www.prism-project.eu)) leading to this application has received funding from the Innovative Medicines Initiative 2 Joint Undertaking under grant agreement No 115916. This Joint Undertaking receives support from the European Union's Horizon 2020 research and innovation programme and EFPIA. This publication reflects only the authors' views neither IMI JU nor EFPIA nor the European Commission are liable for any use that may be made of the information contained therein.*

*Other authors that contributed to this project and presentation:*

**Prof. Martien Kas**, University of Groningen, Groningen Institute for Evolutionary Life Sciences, Groningen, The Netherlands

**Prof. Dr. Brenda Penninx**, Department of Psychiatry and Amsterdam Neuroscience, VU University Medical Center, Amsterdam, The Netherlands

**Dr. Bernd Sommer**, Boehringer Ingelheim International GmbH

**Prof. Alessandro Serretti**, Department of Biomedical and NeuroMotor Sciences, University of Bologna, Italy

**Prof. Celso Arango**, Hospital General Universitario Gregorio Marañón, CIBERSAM, IISGM, Universidad Complutense, School of Medicine, Madrid, Spain



## INTERACTIVE SESSION - The Value of Innovation

This interactive session aims at engaging with the audience and encourages a discussion on how industry and EBC stakeholders should collaborate to advance and accelerate access to major medical breakthroughs in CNS conditions and enhance the speed of translation of science to clinical application.

The session is introduced and moderated by Donna Walsh, Executive Director of the European Federation of Neurological Associations (EFNA), on the Value of Innovation.

## SESSION 2 - Engaging Patients in Their Care

This session focuses on patients programmes that empower and engage patients and their carers to be active participants in the healthcare decision making process, the management of their condition, enabling engagement and access to resources to maximize their health state. They represent multi-stakeholder engagement in design, development and execution, working to engage patients as partners in the research process – including input on focus, design and conduct of research studies.

**Chaired by:** **Andrew Powrie-Smith**, Executive Director of Communications & Partnerships, European Federation of Pharmaceutical Industries and Associations (EFPIA) and **Joke Jaarsma**, Treasurer, European Brain Council (EBC) and President, European Federation of Neurological Associations (EFNA)

### Patients and Psychiatrists working in partnership for developing trust and effective care – Why patient empowerment matters

**Prof. Silvana Galderisi**, President, European Psychiatric Association (EPA) and **Hilkka Kärkkäinen**, President, Global Alliance of Mental Illness Advocacy Networks (GAMIAN) - Europe

Mental health care can only be effective if patients and mental health workers develop trust and establish a good therapeutic relationship. This will require an understanding of each other's expectations, powers and limitations. There has been little systematic investigation of the mutual experiences of patients and clinicians and how these interact throughout the care process.

Against this background, the mental health patient led organisation GAMIAN-Europe and the European Psychiatric Association (EPA) joined forces to explore innovative ways of involving and empowering patients.

The joint EPA-GAMIAN-Europe presentation will address person-centred care and patient – clinician communication issues. Concrete examples will be provided on shared decision making and joint psychiatrists - patients collaboration to develop trust, empowerment and self-management of patient conditions.

## Assertive outreach projects can improve treatment continuity and long-term outcomes for people with Schizophrenia

Dr. Stefan Pype, Neuroscience Medical Affairs Lead, Janssen Benelux

The long-term outcome for people with schizophrenia is known to benefit from continuous integrated treatment. As pharmacological approach, Long-acting Antipsychotic Treatments (LATs) have shown superior effectiveness in terms of preventing psychotic relapse, rehospitalisation and mortality. To further boost the continuous use of LATs, Janssen set up an assertive outreach project in collaboration with 15 Belgian Psychiatric hospitals and with Remedus, a private partner specialised in ambulatory care. The program started in 2015 and now supports over 260 patients treated with LATs. Patients who choose to participate in the programme are contacted prior to each LAT injection, and they have the option for home administration. The programme coordination is done by Remedus, in close collaboration with the hospitals. We present preliminary data on the added value of the Belgian programme. Outcomes from similar international projects suggests that patients benefit through improved treatment satisfaction, continuity and outcomes.

## MS in the 21<sup>st</sup> Century: A model for better patient engagement

Vanessa Pott, Director, Patient Advocacy & Strategic Partnerships Global Healthcare Government & Public Affairs, Merck, together with David Yeandle and Pieter van Galen, MS in the 21<sup>st</sup> Century Steering Committee Members

The MS in the 21<sup>st</sup> Century initiative is led by an international steering group of people with multiple sclerosis (PwMS), neurologists and other healthcare professionals involved in MS care. They work closely together to develop programmes designed to increase standards of care, and increase patient engagement in their own disease management. This presentation features two members of the MS in the 21<sup>st</sup> Century Steering Group, David Yeandle OBE and Pieter van Galen, who will describe the activities and outputs of the group, including peer reviewed publications and educational initiatives. They will share their personal perspectives on how these initiatives provide a platform for PwMS to increase awareness of unmet patient needs and to work with other stakeholders to develop patient-centric solutions.

Vanessa Pott Director of Patient Advocacy; Strategic Partnerships at Merck KGaA, will also describe how this innovative partnership in the field of MS is important to bring attention to the need of MS patients and improve standards of care.

## Summary & Meeting Close

Prof. Monica Di Luca, President, European Brain Council (EBC)

## ■ SPEAKER BIOGRAPHIES

### Session Chairs



**Dr. 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 post-doctoral fellowship at the Institut Pasteur in Paris.

@IMI\_JU



**Prof. Patrice Boyer** is Vice-President of the European Brain Council and a past President of the European Psychiatric Association (EPA). He is Professor of Neurosciences and Psychiatry at the University Paris-Diderot (France) and Professor of Psychiatry and post graduate studies (geographical) at the University of Ottawa, Ontario, Canada. He is the Secretary General of the French Congress of Psychiatry, a member of the International Scientific Advisory Board of the main foundation for research in psychiatry in France (Fondamental) and a member of the editorial board of European Psychiatry. Prof. Boyer was previously the co-Chairman of the Master and Doctorate courses for neurobiology at the Universities of Paris 5 and Paris 7 and the advisor for psychiatry in the then newly created INSERM thematic institute (ITMO Neurosciences).

@EU\_Brain



**Mr. Andrew Powrie-Smith** is Communications Director at EFPIA, the European Federation of Pharmaceutical Industries and Associations. He previously worked for ABPI, the Association of the British Pharmaceutical Industry, where he served as a Director responsible for the creation and delivery of the association's reputational strategy, as well as for the management of the ABPI Scotland office team. Andrew Powrie-Smith is also a former Director of the British Lung Foundation, after working in the UK and abroad for the British Red Cross, Amnesty International and Scope.

@EFPIA



**Ms. Joke Jaarsma** is Treasurer of the European Brain Council 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.

@joke\_jaarsma  
@EUneurology  
@EU\_Brain

## Session 1: R&D Breakthroughs in Brain Health



**Prof. Wolfgang Oertel** is Vice-President of the European Brain Council and sits in the European Affairs Sub-Committee of the European Academy of Neurology. He is Hertie-Senior-Research-Professor (2014-2022), Professor for Neurology and former Chairman (1996-2014) at the Dept. Neurology, Philipps University Marburg, Germany. Prof. Oertel has served as president (2007-2011) of the German Parkinson Society (DPG), as board member (2009-2014) and president (2011-2012) of the German Society for Neurology, treasurer (2001-2002) of the International Movement Disorder Society (MDS), chairperson (2007-2009) of the European section of MDS and president (2013-2015) of the International REM-Sleep Behaviour Disorder Study Group, an organization he founded in 2009. He is treasurer of the European Restless Legs Syndrome (RLS) Study group (2014-2017). He coordinates the European Affairs Sub-committee (EASC) of the European Academy of Neurology (EAN). Since 2015 he is member of the high-level advisory group "Scientific Panel for Health (SPH)" to the European Commissioner for "Research and Innovation". Prof. Oertel's main field of scientific interest are neurodegenerative disorders such as Alzheimer dementia, Parkinson's disease (PD) and related disorders. In parallel he also keeps a strong interest in RLS. He has reviewed over 750 scientific publications.

@EU\_Brain  
@EANeurology



**Christopher Buckley** is Senior Technology Leader in Imaging Technology, Medical Diagnostics at GE Healthcare. He received his BSc in Physics from Queen Elizabeth College, London University and his PhD from King's College, London University. In his role as Senior Technology Leader, Dr. Buckley coordinates all neurological PET, CT, SPECT & MRI imaging projects, leading and providing support to R&D initiatives across the neurology, cardiac and pulmonary portfolio. Previously he was Technology Leader - Imaging at GE Healthcare, providing image science leadership, guidance, support and input into phase I-IV clinical imaging studies for neurology



including PET, CT, MRI & SPECT. Prior to working at GE Healthcare, Dr. Buckley was Senior Consultant at RSI-UK and Lecturer in Physics & Astrophysics at King's College London.

**Prof. Menno P. Witter** is Fulltime Professor of Neuroscience and Director of the Norwegian Research School in Neuroscience at the Norwegian University of Science and Technology (NTNU) in Trondheim, Norway. He is the initiator and current director of the Norwegian Research School in Neuroscience since 2013. He is elected member of the Royal Norwegian Society of Sciences and Letters, and The Norwegian Academy of Science, member of the European Dana Alliance for the Brain and received the Olav Thon Foundation International Research Award (2016).

His current work focuses on the functional anatomy of the lateral and medial entorhinal cortex. His group also works on the mechanisms of Alzheimer's disease, using animal models. For more information and full publication list, go to [www.ntnu.edu/employees/witter](http://www.ntnu.edu/employees/witter)

Prof. Witter has over 170 publications in international peer reviewed journals.



**Mr. Ulrik Ditlev Eriksen**, Chief Science Officer & Co-founder of Brain+ ApS. An entrepreneur in the field of cognitive training & rehabilitation, with 17 years of experience in building companies from ground up, and extensive leadership experience in start-ups as well as corporate giants. His specialty is analysing customer needs, user-driven concept development and product specification, management of product development, product launch. He brings from working with more than 20 high-tech companies within biotech, medtech, energy, information & communication tech, media and engineering. He has been responsible for bringing several new products from the idea stage to fruitful commercialization in healthcare and high-tech telecom.

He has worked for over a decade bridging the gap from the sciences and academia to bring new knowledge to fruitful application in industry. This makes him especially well-suited for the role of managing the product development and coordinating the scientific activities and the constant interactions between the scientific and academic partners, with the knowledge generated in the project, ensuring that it is successfully integrated into a commercial product solution with high functionality and appeal to the target users.

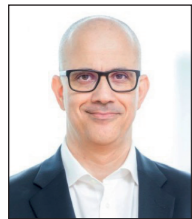
@Ulrik\_Eriksen  
@TheBrainPlus



**Hugh Marston** PhD, FRSB is a senior research fellow leading the Translational Neuroscience Group at Lilly's Erl Wood research site in Surrey supporting all of Lilly's active neuroscience programmes. Erl Wood's research focus covers novel approaches designed to modify neurodegeneration, chronic pain and effective neurosymptomatic intervention. Having originally trained as a psychopharma-



colologist at Cambridge, he has now had nearly 30 years' experience in various forms of drug discovery research. Most recently as head of pharmacology at IOM-et Pharma (pka TPP GD) a virtual pharma company acquired by Merck in 2016. Prior to that he has lead neuropharmacology teams at Merck, Schering-Plough and Organon working on projects principally in the psychiatry area from discovery through to launch. As such he has had a long-standing interest in transforming our ability to translate science to and from the clinic across the neuroscience disciplines. As part of his role at Lilly he is Project Leader of the IMI2 PRISM initiative an industry/academe EU funded consortium that is seeking to find translatable, quantitative biological phenotypes in CNS disorders. He maintains an active interest in academic research through collaboration and an honorary professorship at the University of St Andrews with 70+ peer reviewed publications and five granted patents.



**Danny Bar-Zohar** holds a Bachelor in Medical Sciences, as well as a Medical Doctor Degree from the Sackler Faculty of Medicine, Tel-Aviv University (Israel), specialized in general surgery, focusing on trauma and transplantation.

Danny joined Novartis in 2013, as the Global Program Head for Gilenya and assumed responsibility for the development and in-licensing of additional assets for multiple sclerosis. In this position, he secured all life-cycle initiatives for Gilenya, accurate understanding of the benefit-risk profile of the drug and significant label changes. In 2015 he relocated to Italy, serving as the Chief Scientific Officer, heading the Italian Novartis medical affairs and clinical development department for the entire pharmaceuticals business in neuroscience, respiratory, ophthalmology, cardiometabolic and Immunology & dermatology disease areas. Since April 2017, Danny has returned to Global Drug Development as the Neuroscience Development Unit Head, in charge of the MS pipeline and mid-late stage assets in migraine, neuropathic pain, Alzheimer's disease and neuromuscular diseases.

Prior to joining Novartis, Danny had worked in Teva Pharmaceutical Industries, Global Branded Products, Innovative R&D Division as the global clinical lead for a variety of mid and late stage assets, e.g. Copaxone, Azilect and Laquinimod. While managing global, cross-functional teams in the development unit, Danny also maintains strong collaboration with the Novartis Institute of Biomedical Research teams to allow seamless handover of high-value projects from early to late stage development.

@Novartis

## Interactive session



**Donna Walsh** became the Executive Director of the European Federation of Neurological Associations (EFNA) in June 2012. Donna's training is in Journalism, but she has worked with patient organisations in the neurological sector – in various roles – since leaving university. This included work with the European Migraine and Headache Alliance [EMHA] and the Migraine Association of Ireland [MAI], as well as being a representative to the Neurological Alliance of Ireland.

## Session 2: Engaging Patients in Their Care



**Hilikka Kärkkäinen**, President of the Global Alliance of Mental Illness Advocacy Networks (GAMIAN) - Europe, is a social worker by profession and expert by experience. Suffered reactive depression in 2002. Has worked both for the City of Helsinki and the City of Espoo in Child Welfare for many years. Worked as a Senior Social Worker in Probation and After Care Association in Helsinki for several years. Was Executive Director of Finnish Central Association for Mental Health and has been President and Vice President of Mieli Maasta, which is a patient association for those suffering from depression. Worked for the City of Järvenpää as a Planner of Regional Mental Health Care. Retired from her job as Social Ombudsman in Sosiaalitalo in 2014. Was President of GAMIAN-Europe once before in 1999.

@HilikkaKrkkinen2

@GamianE



**Prof. Silvana Galderisi**, MD, PhD, is full professor of Psychiatry, Chair of the Department of Mental and Physical Health and Preventive Medicine of the University of Campania Luigi Vanvitelli.

She is President of the European Psychiatric Association (EPA), Chairperson of the EPA Schizophrenia Section, of the European College of NeuroPsychopharmacology (ECNP) Schizophrenia Network, and of the World Psychiatric Association (WPA) Neuroimaging Section. She is founding member and member of the Board of Directors of the European Group for Research in Schizophrenia; board member of the Schizophrenia International Research Society (SIRS). She is Honorary Member of the World Psychiatric Association-WPA, International Distinguished Fellow of the American Psychiatric Association-APA, International Advisor of the Japanese Society of Psychiatry and Neurology (JSPN), and Honorary Fellow of the European Society of Social Psychiatry (ESSP).

Her research activity focuses on Schizophrenia pathophysiology, treatment and outcome, with particular reference to the domains of negative symptoms and cognition and their impact on psychosocial outcome. She is author/coauthor of more than 200 publications, in national and international journals and books, and member of the Editorial Boards of several international psychiatric journals.

@Euro\_Psychiatry



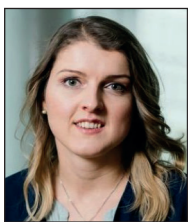
**Stefan Pype** is the Neuroscience Medical Affairs Lead at Janssen Benelux. He holds a PhD in Biochemistry from the University of Antwerp and did his Postdoc at the NIH (USA) and the University of Leuven (BE). Stefan has experience in Neuroscience Drug Discovery, Early Development, Clinical trials and Program Management and currently leads a team of 6 Medical Advisors and Medical Science Liaisons (MSLs), all active in the Psychiatry Therapeutic Area, working in close collaboration with the Sales and Marketing team. His team's current focus is on the treatment of schizophrenia and preparing the launch of new treatments for severe depression.



**David Yeandle**, OBE, was diagnosed with relapsing remitting MS in 2010, having experienced symptoms up to 3 years prior to this. While many people find an MS diagnosis a difficult and confusing time due to a lack of general awareness around the disease, David was unfortunately all too familiar with MS, having seen his sister diagnosed with the disease almost 30 years previously. Using his existing knowledge and experience of MS, David decided to approach his diagnosis with a positive attitude and the motto 'I will manage my MS rather than allow it to manage me'; while his illness did eventually force him to take early retirement from his demanding job as Head of Employment for an organisation representing the UK's manufacturing industry, he has since flourished as a part time consultant performing a variety of roles, including serving as the President of the United Nations' Staff-Management Committee. David joined the MS in the 21st Century Steering Group in July 2017, has presented the initiative to a number of national and international audiences, and as a result of his own experiences and expertise is a passionate advocate of helping MS patients to stay in employment.



**Pieter Van Galen** was diagnosed with MS in 2005 and is an active member of the European Multiple Sclerosis Platform (EMSP). In addition to his extensive work with EMSP, he is a self-employed freelance trainer and consultant, with broad professional experience as a speaker. Pieter feels that MS is sometimes misunderstood as, often, on the outside, there are no physical symptoms, but mobility and fatigue can play a large role in day-to-day life. Through his advocacy work, he hopes to help raise awareness of MS and improve patients' experiences. Pieter has been an active member of the MS in the 21st Century Steering Group since 2016. He is an author on the most recent group manuscript and presented at the first MS in the 21<sup>st</sup> Century symposium at the 2017 World Congress on Controversies in Neurology (CONy) in Athens.



**Vanessa Pott** is Director of Patient Advocacy & Strategic Partnerships, Global Healthcare Government & Public Affairs at Merck. In her role, Vanessa oversees Merck's partnerships and collaborations with the MS community in Europe.

Vanessa enjoys creating one-of-a-kind partnerships with the patient and carer community to support Merck's vision of becoming the most patient-directed healthcare company. She enjoys working with colleagues across Europe and is particularly proud of her work on the 2017 Report on the Socioeconomic Impact of MS on Women in Europe, and the 2018 'Living with Multiple Sclerosis: The Carer's Perspective' Report which is being launched at ECTRIMS this year.

Besides her professional experience, Vanessa also brings a high level of personal commitment to advancing patient care as the legal guardian and carer to a brother living with a rare genetic disorder.

@PottVanessa

## Closing Speaker



**Monica Di Luca**, EBC President, is Professor of Pharmacology, Director of NeuroNest (Center of Neuroscience) 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).

## POSTER SESSION ON DISEASE AWARENESS INITIATIVES

### Shift.ms: Awareness and Understanding of Pediatric MS

George Pepper, Co-Founder and CEO, Shift.ms

Pediatric MS is not well understood or recognized, posing challenges of delayed diagnosis and disease-related stigma for patients and their families. There is also a lack of exchange on optimal disease-management practices, including tailored support for children and teenagers living with MS.

A collaboration between Shift.ms and Novartis raises awareness for the experience and needs of people living with and treating pediatric MS. Shift.ms utilizes the pioneering patient-led video interview format, called 'MS Reporters', where people living with MS (MSers), trained as citizen reporters, interview professional or MSer experts on questions centered around unmet needs and interests. This series of interviews directly addresses questions MSers have around living with pediatric MS and delivers the perspectives and thoughts of a specialist pediatric MS nurse, pediatric MS neurologist and an expert MSer (someone diagnosed with MS as a teenager). These video interviews have received almost 100k views (true as of submission date), highlighting the interest in this content from the MS community.

@gpeps

@shiftms

### Lundbeck's medical education platforms provide a deep dive into the science of Schizophrenia, Depression, Parkinson's and Alzheimer's disease to increase disease knowledge, understanding and awareness

Audrey Dufour, Brian Lawrence Odlaug, Danilo Pagano and Christoph von der Goltz, Lundbeck

Lundbeck has 2 platforms, the Lundbeck Institute Campus and Progress in Mind Resource Center, which are fully dedicated to medical education for health care professionals (HCPs). Its mission is to raise disease awareness, but also to engage with and support HCPs working towards

the international agenda and goals for better and broader acceptance of patients and their diagnoses – reducing stigma and helping increase the opportunities for better patient care and treatment.

### **Speeding up access to new treatments in Parkinson's Disease: A PPP collaboration seen from an industry participant perspective**

**Daniele Bravi, Tiia Maria Metiäinen and Anders Blædel Lassen, Lundbeck**

Lundbeck is a company specialized in the research and development of new treatments for brain disorders, including a focus on psychiatric and neurologic diseases.

As the scientific understanding of many neurologic disorders have improved, new opportunities for medicines development has emerged. In parallel, tools and methodologies for collecting, analyzing and interpreting data is becoming available, leading to new opportunities and challenges for medicines development and regulatory decision making.

Public Private Partnerships have evolved accordingly, and many are now focused on collaboration in the development of new treatments to address unmet needs in areas where there is new technology, new ways of working with data, a focus on previously untreated patient populations and therefore substantial regulatory uncertainty.

One such partnership is the Critical Path Institute (C-Path), a US-based, nonprofit, public-private partnership with the Food and Drug Administration (FDA) created under the auspices of the FDA's Critical Path Initiative program.

In the area of Parkinson's Disease (PD), the Critical Path for Parkinson's (CPP) is together with Parkinson's UK, leading a collaboration that aims to achieve global regulatory endorsement of novel translational biomarkers and drug disease trial models for use in clinical medicines development trials. Lundbeck has been a member since 2014.

The CPP is representing a partnership approach to effective medicines development with a focus on ensuring regulatory acceptance of novel methodologies, including:

- Validation of imaging biomarker for clinical trials
- Integrated data platform for clinical trial enrichment
- Collaborative assessment of additional work streams to support faster access to new treatments, e.g. utilization of digital technologies in trials

From a societal perspective, the CPP is adding value by joining forces to develop a better understanding of the disease which can be translated into better more targeted development plans.

From a patient perspective, the collaboration adds traction to the hope of conceivably improving the therapeutic management of symptoms (both motor and non-motor) in the near future. The development of therapies aimed at slowing down or halt the progression of the disease requires both scientific, digital and regulatory efforts due to the novelty of such domain.

From a company perspective, the benefit of pooling experience, data, ideas and learnings in a non-competitive environment is unique. The CPP collaboration is already leading to an increased awareness about the need for new outcome measures, scales and diagnostic tools

by regulators, patients, healthcare professionals and industry, and is an excellent example of how PPPs can help address these needs by putting them on the public health agenda and facilitate a supportive regulatory path for future treatments.

Thank you to **Diane Stephenson, CPP** and **Jill Gallagher**, Parkinson's UK for review and support.

### **Silent MRI**

**Nikou Damestani, Emil Ljungberg, Tobias Wood, Fernando Zelaya, David Lythgoe, Florian Wiesinger, Gareth J. Barker, Steven Williams**, Institute of Psychiatry, Psychology and Neuroscience, King's College London, London, UK

**Ana Beatriz Solana Sánchez, Florian Wiesinger**, GE Healthcare, Munich, Germany

Magnetic resonance imaging (MRI) produces acoustic noise comparable to the sound levels of a passing underground train. This can make studies of brain structure and function of some populations very difficult, such as neonates or persons suffering noise-triggered migraines. Recent innovation of MRI hardware and software has led to the development of silent MRI techniques, reducing the acoustic noise to the level of conversation. Silent MRI has the potential to revolutionize our understanding of the brain in health and disease, alongside how the brain processes sound.

In this work we present novel silent imaging techniques that have been developed in collaboration with General Electric Healthcare. This includes quantitative imaging techniques, sensitive to features of brain tissue microstructure such as myelin and water content, and a functional imaging technique, with demonstrated sensitivity to neural activity. These techniques are currently in the process of optimization for use in clinical populations.

### **Mapping Brain Myelin**

**Tobias C Wood, Emil Ljungberg, Diana Cash, Camilla Simmons**, Institute of Psychiatry, Psychology and Neuroscience, King's College London, London, UK

**Ana Beatriz Solana Sánchez, Florian Wiesinger, Steve Williams**, GE Healthcare, Munich, Germany

Myelin is responsible for fine-tuning the conduction speed of neurons and is hence an essential part of a healthy mature nervous system. De- or dysmyelination is implicated in multiple neurological and psychiatric disorders such as Multiple Sclerosis, Autism and Schizophrenia. Myelin fortuitously displays multiple physical properties that can be probed with Magnetic Resonance Imaging techniques such as Myelin Water Imaging, Magnetization Transfer Imaging and Diffusion Imaging. However, myelin is a highly complex structure and such methods tend to probe only one of its aspects while ignoring the others.

In this work we give an overview of existing myelin-sensitive MR methods and discuss how they can be validated against histology. We also present a new state-of-the-art myelin-specific silent MR technique that exploits dipolar-coupled Magnetization Transfer combined with a zero echo-time radial readout, which has been developed in collaboration with General Electric Healthcare.

## MS Inside Out experiential disease awareness

**Vanessa Pott**, Director, Patient Advocacy & Strategic Partnerships Global Healthcare Government & Public Affairs, Merck

For more than 20 years, Merck has been relentlessly focused on understanding the journey people living with MS face in order to create a meaningful, positive experience for them and the broader MS community. The MS Inside Out experiential disease awareness tools consist of a virtual reality activity and a modular installation comprising a home, a workspace and a public transport element (the “MS House”) that allow the user to experience “a day in the life” of someone with MS. These interactive tools were developed based on patient insights with the aim to create greater awareness and deeper understanding of how patients feel: to actively change perception of MS in the real world.

## Embracing Carers – Living with Multiple Sclerosis: The Carer’s Perspective

**Vanessa Pott**, Director, Patient Advocacy & Strategic Partnerships Global Healthcare Government & Public Affairs, Merck

Embracing Carers is a global Merck initiative that aims to elevate the often-overlooked needs of carers across all therapeutic areas. Advised by eight caregiver organizations from around the world, Embracing Carers is committed to identifying and implementing tangible resources and support for carers. Aiming to explore more specifically how the relapsing and episodic nature of multiple sclerosis (MS) impacts those close to the patient, the ‘Living with Multiple Sclerosis: The Carer’s Perspective’ report was developed in 2018, in collaboration with the International Alliance of Carer Organizations (IACO) and Eurocarers and examined the experiences of 1,050 MS carers across seven countries (US, Canada, UK, France, Germany, Italy and Spain).

## CDNF – A neuroregenerative therapeutic to address motor and non-motor symptoms in Parkinson’s disease

**Dr. Henri J. Huttunen**, CSO, Herantis Pharma Plc.

There is a significant unmet medical need in Parkinson’s disease (PD) and other neurodegenerative diseases for disease-modifying therapies. Cerebral Dopamine Neurotrophic Factor (CDNF) is a novel neuroprotective factor that promotes survival and functionality of midbrain dopaminergic neurons and improves both motor and non-motor symptoms in several animal models of PD including non-human primates. Intracerebrally administered CDNF is currently in a randomized, placebo-controlled, first-in-human clinical trial in patients with PD at three centres in Finland and Sweden. Herantis Pharma, a spin-off company of University of Helsinki, is developing CDNF in close collaboration with a network of academic and industrial partners. A cutting-edge approach based on leading science to develop a disease-modifying therapy for PD has been made possible by the agility of a small biotech company. Continued academic collaboration has recently also led to early development of a non-invasive next generation CDNF (ngCDNF).

## Models of Patient Engagement in Alzheimer’s Disease (MOPEAD) IMI Project

**Mercè Boada**, Project Coordinator, **Annette Dumas**, Project Communications Lead, and **Laura Campo**, Eli Lilly

More than 34 million people worldwide have Alzheimer’s Disease (AD). Current clinical paradigm does not support or emphasize the need for early detection, diagnosis and urgency for action, as soon as symptoms of AD first begin. Focus is still on later clinical stages of the disease. This creates a barrier to access available treatments and support services, as well as enrolment in Clinical trials. We need to better understand the obstacles to engagement for early diagnosis and treatment, and successful strategies to overcome them. The MOPEAD project (Models of Patient Engagement for Alzheimer’s Disease), is designed to assess different Patient Engagement models across Europe, to identify efficient approaches of earlier identification of mild AD dementia and prodromal AD patients. MOPEAD has the potential to contribute to move the AD Environment towards earlier diagnosis to improve identification of appropriate patients for disease modifying therapies.

MOPEAD is a multi-national project funded by IMI, a public-private partnership involving the European Commission and the European Federation of Pharmaceutical Industries and Associations (EFPIA). MOPEAD will be carried out by a multi-disciplinary consortium of 14 members, including academic institutions, pharmaceutical companies, technology companies and relevant stakeholders such as patient associations.

@MopeadEU

## Brain Mind and Pain (BMP) Patient-Centred Innovation Grant

**Anca Pop**, **Joop van Griensven**, Pain Alliance Europe and **Gudula Petersen**, Grünenthal

Established in 2017, the Brain Mind and Pain Patient-Centred Innovation Grant is a biennial grant which encourages patient-centred, innovative solutions to improve the living conditions of patients with brain, mind, and pain disorders.

The novelty of the Brain Mind and Pain Patient-Centred Innovation Grant lies in its patient-driven and patient-centric character. The rewarded projects are developed for the patients and with the patients – as patient involvement is ensured at every level of the grant project and also as a main criterion for candidate selection.

Three patient-empowering solutions are currently being developed by the winners of the inaugural 2017-2018 edition of the Brain Mind and Pain Grant. The Brain, Mind, and Pain Patient-Centred Innovation Grant is a joint project run by Pain Alliance Europe and financially supported by the Grünenthal Group, with partner support from the European Pain Federation (EFIC), the European Academy of Neurology (EAN), and the European Federation of Neurological Associations (EFNA).

@bmp\_grant

## Burden for Parents of Patients with Schizophrenia: A Nationwide Comparative Study of Parents of Offspring With Rheumatoid Arthritis, Multiple Sclerosis, Epilepsy, and Healthy Controls

Annabelle Godet, Market Access EMEA Manager, Janssen

This multi-stakeholder innovative project aims at improving disease awareness. This study is based on nationwide registers (linkage of several Swedish registers), with a long observation period (from 5 years' pre-diagnosis to 7 years after diagnosis), covering a large number of parents of patients with schizophrenia, as well as parents of MS, RA, epilepsy, and healthy controls and giving the possibility to take the disease severity of schizophrenia into account. The analysis showed that Parents of patients with schizophrenia have considerably higher rates of psychiatric health care and social welfare dependence than other parents and that the burden measured as psychiatric health care use worsens over time and with increasing disease severity of the offspring with schizophrenia.

## Patient, Investigator, Nurse, Carer Questionnaire (PINC-Q): exploring the impact of less frequent medication administration in the maintenance treatment of schizophrenia

Katalin Pungor, EMEA Medical Affairs Director - Schizophrenia/Long acting therapies, Janssen

Co-authors: Margaret Walker, The European Federation of Families of People with Mental Illness (EUFAMI), Nigel Olisa, Global Alliance of Mental Illness Advocacy Networks (GAMIAN)-Europe, Vadim Strulev, Janssen and Annette Wooller, Janssen

PINC-Q (Patient, Investigator, Nurse, Carer Questionnaire) is a multi-country, cross-sectional, retrospective, non-interventional study designed to explore the impact of less frequent administration of antipsychotic medication in the maintenance treatment of schizophrenia, incorporating the perspective of multiple critical stakeholders involved in the treatment of people living with schizophrenia. Representatives from patient and carer advocacy groups (GAMIAN and EUFAMI respectively), and also psychiatrists and nurses collaborated with Janssen on the study concept including the different questionnaires to be answered by the respective stakeholders. All stakeholders will also be involved in the outcome analysis and the development of the communication plan [Q3'19].

The results are anticipated to provide important insights into the value of less frequent administration of medication and on the communication from the perspective of the person living with schizophrenia and their carer, physician, nurse. Such insight will empower patients and their carers to be active participants in their care.

## Co-creation of Psychosis Information Brochure for Patients and Family/Caregivers

Dr. Stefan Pype, Neuroscience Medical Affairs Lead, Janssen

Schizophrenia is a complex disorder that is poorly understood, and often misunderstood, by the public at large. Hence, it is very important that people who are confronted with the disorder, be it as patient, family or friend, have access to information that is relevant, comprehensible and trustworthy. A Psychosis Information Brochure for patients and caregivers was co-created by Similes (Flemish association for family members of patients with a psychotic vulnerability <https://nl.similes.be/>), psychiatrists, a professional creative agency (Bones), and Janssen as sponsor and coordinator. The objective of the brochure, the co-creation process, the highlights of the brochure, and the collaborative distribution strategy to multiple stakeholders will be explained during the presentation.

## Harnessing the voice of the mental health community on social media

Cristiana Maria, Therapeutic Area Communication & Public Affairs Manager EMEA, Janssen

To help stimulate discussion amongst the online community around mental health, and schizophrenia specifically, Janssen EMEA created a social media disease awareness campaign. Three moments in time were used to amplify online conversations around mental health:

- #TalkSchizophrenia - on World Mental Health Day 2017, a tweetchat was hosted in partnership with TalkHealth, discussing the stigma around schizophrenia.
- #SeasonsTweetings - throughout December, a social media 'advent calendar' was created, highlighting the mental health challenges that can occur during the festive season, providing links to useful information and resources.
- #LoveMeFirst - working with patient groups across Europe, patient stories were transformed into love letters showcasing their journeys to recovery. These were compiled into an ebook shared on social media.

The campaign resulted in over 3.15 million social media impressions and almost 30,000 engagements.

@JanssenEMEA



## ACKNOWLEDGMENTS



With kind contribution from:



This event was supported by:



## NOTES

Series of horizontal dotted lines for taking notes.





## European Brain Council Brussels Office

---

Rue d'Egmont, 11  
BE-1000 Brussels  
Tel: + 32 (0) 2 513 27 57

[info@braincouncil.eu](mailto:info@braincouncil.eu)

 [@EU\\_Brain](https://twitter.com/EU_Brain)

[#PublicPrivate](#)

[#TherapeuticInnovation](#)

[#PatientNeeds](#)

[#IndustryDay](#)

[#ILoveMyBrain](#)

[www.braincouncil.eu](http://www.braincouncil.eu)