



Expanding Brain Research in Europe

Shaping FP9 and Delivering Innovation
to the Benefit of Patients

23rd & 24th April 2018

**University Foundation
Rue d'Egmont, 11- 1000 Brussels, Belgium**

**#BrainResearch
#BrainMissionFP9**



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■ 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 are living 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

■ INTRODUCTION

Investments into research and innovation have delivered unprecedented results for patients across Europe. Publicly and privately funded innovation schemes in the EU empowered researchers to accelerate scientific discovery, increase the understanding of non-communicable diseases and improve healthcare services. Yet, despite the progress that was achieved in recent decades, there is currently no effective treatment to cure a wide range of mental and neurological conditions. What is more, the complexity of many brain disorders hinders researchers in their efforts to develop innovative healthcare interventions.

In 2018, the European Commission is expected to submit proposals for a mission-oriented and impact-focused 9th Framework Programme. In view of the preparations for the forthcoming EU research scheme, the European Brain Council (EBC) aims to bring attention to issues that affect therapeutic innovation and facilitate an exchange of views on how the post-2020 Framework Programme can make a real difference for patients living with brain disorders.

The event, which consists of three individual sessions, will allow leading healthcare stakeholders and policymakers to address key questions in the domain of research, such as: how can the 9th Framework Programme accelerate brain research across Europe? What measures can be taken in order to stimulate the development of new central nervous system drugs for treating brain disorders? What can be done to address the concerns of patients?

■ AGENDA - Missions and FP9 23rd April

The upcoming EU Framework Programmes have the potential to provide tangible solutions for patients living with brain disorders. In view of the upcoming FP9 proposal, a wide range of independent experts provided recommendations on mission-oriented research and how to gain the most out of EU-funded innovation programmes. The "Lab - Fab - App" report, written under the leadership of Pascal Lamy, recommended to double the budget of the next Framework Programme. Increasing the budget was subsequently recommended amongst others by the European Parliament, Commission President Jean-Claude Juncker and European Commissioner for Budget Günther Oettinger. Additionally, Prof. Mariana Mazzucato provided guidance on how research and innovation can address global challenges in the recently released report "Mission-Oriented Research & Innovation in the European Union". In light of these recommendations, the session "Missions and FP9" aims to facilitate dialogue amongst experts on the mission-oriented approach of the European Commission and how the next Framework Programme can boost therapeutic innovation.

16:00 – 16:10 **Introduction**

16:10 – 16:30 **Keynote:**

Prof. Andrea Renda, Member of the Expert Group on the Economic and Societal Impact of Research and Innovation (ESIR)

16:30 – 17:00

Brain related missions:

Prof. Monica di Luca, President, European Brain Council

17:00 – 17:20

The Commission's Perspective:

Jean-Eric Paquet, Director-General, Directorate-General for Research and Innovation, European Commission

17:20 – 17:50

The Parliament's Perspective:

Lieve Wierinck, ALDE

17:50 – 18:20

Discussion with the audience

18:20 – 18:30

Concluding remarks

18:30

Walking dinner

■ AGENDA - The Value of Innovation 24TH April

Developing effective treatments to improve the lives of those affected by brain disorders is extremely challenging. Despite decades of publicly and privately funded brain research, there is currently no treatment available to cure a wide range of mental and neurological conditions. What is more, research efforts do not always translate into tangible results for patients. In view of this, and in the light of the high burden that brain disorders impose on European society, the session "The Value of Innovation" aims to empower healthcare experts and stakeholders to present their views on issues that hinder therapeutic innovation and discuss potential solutions.

- 09:30 – 09:45** **Welcome and introduction:**
Joke Jaarsma, Treasurer, European Brain Council
- 09:45 – 10:15** **Patient perspective:**
Hilkka Kärkkäinen, President, GAMIAN-Europe
Jacobo Santamarta Barral, Young Person's Network at the European Multiple Sclerosis Platform
- 10:15 – 10:45** **Research perspective:**
Prof. dr. Guus Smit, Department of Molecular and Cellular Neurobiology, VU Amsterdam - Prof. Sebastian Brandner, Professor and Chair of Neuropathology Division of Neuropathology and Dept. of Neurodegenerative Disease, UCL Institute of Neurology
- 10:45 – 11:00** **Regulatory perspective:**
Dr. Marisa Papaluca, Senior Scientific Advisor, European Medicines Agency (EMA)
- 11:00 – 11:15** **Industry perspective - challenges in clinical trials:**
Dr. Christoph von der Goltz, Senior Director, Head of HEOR, RWE & Lu Institute, Lundbeck
- 11:15 – 12:15** **Panel discussion and Q&A:**
Menno Aarnout, Executive Director, Association Internationale de la Mutualité - Matthias Wismar, Senior Health Policy Analyst, European Observatory on Health Systems and Policies - Nathalie Moll, Director General, European Federation of Pharmaceutical Industries and Associations (EFPIA) - Prof. Colm O'Morain, Past President, Alliance for Biomedical Research in Europe - Jaroslaw Waligora, Policy Officer, Directorate-General for Health and Food Safety, European Commission
- 12:15 – 12:45** **Conclusions drawn by the moderators:**
Margaret Walker, Executive Director, European Federation of Families of People with Mental Illness (EUFAMI) - Alexander Schubert, Executive Director, European College of Neuropsychopharmacology (ECNP)
- 12:45 – 14:00** **Lunch**

■ AGENDA - European Brain Research: Shifting Gears and Going Global 24TH April

Many initiatives aimed at supporting brain research and improving the allocation of research funds were launched at global level in recent years. These efforts have the potential to significantly strengthen collaboration across disciplines and can therefore make a lasting difference for patients and scientists. The session "European Brain Research: Shifting Gears and Going Global" aims to provide an overview of the current global brain research initiatives and allows experts to present their perspectives on how to further enhance cooperation at global level.

Moderated by Prof. Patrice Boyer, Vice-President, European Brain Council

- 14:00 – 14:30** **Introduction on the global initiatives launched with the support of the European Commission:**
Dr. Karim Berkouk, Acting Head of Unit, Non-communicable diseases and the challenge of healthy ageing, Directorate-General for Research and Innovation, European Commission
- 14:30 – 15:00** **Examples of existing and potential collaboration:**
Dr. Ari Ercole, CENTER-TBI and the International Initiative for Traumatic Brain Injury Research (InTBIR)
Prof. Philippe Ryvlin, Co-Chair, Joint Task Force for Epilepsy Advocacy Europe, International League Against Epilepsy (ILAE)
Dr. Helena Ledmyr, Head of Development & Communications, International Neuroinformatics Coordinating Facility (INCF)
- 15:00 – 15:30** **Global networks, organization's perspective:**
Prof. Philippe Amouyel, Chair, EU Joint Programme - Neurodegenerative Disease Research (JPND)
Chris Ebell, Executive Director, Human Brain Project
Dr. Hella Lichtenberg, Senior Scientific Officer, ERA-NET Neuron
- 15:30 – 16:00** **Concluding remarks:**
Prof. Wolfgang Oertel, Vice-President, European Brain Council
- 16:00 – onwards** **Cocktail reception**



■ SPEAKERS BIOGRAPHIES

“Missions and FP9” Session



Prof. Andrea Renda, is a Senior Research Fellow and Head of Regulatory Policy at CEPS. He holds the Chair for Digital innovation at the College of Europe in Bruges and is non-resident Senior Fellow at Duke University’s Kenan Institute for Ethics. He specializes in regulatory governance, cyberpolicy and the ethics, law and economics of emerging technologies. He also specialized in EU law and policy. Over the past two decades, he provided academic advice to several institutions, including the European Commission, the European Parliament, the OECD, the World Bank and several national governments around the world. He holds a Ph.D. degree in Law and Economics awarded by the Erasmus University of Rotterdam.

@profAndreaRenda



Prof. Monica Di Luca is the President of the European Brain Council and Professor of Pharmacology, Vice – Rector for International Strategies, 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 a council member of several national and international scientific organizations including Federation of European Neuroscience Societies (FENS, Past President), the International Brain Research Organization (IBRO) and the European Dana Alliance for the Brain (EDAB).

@EU_Brain



Lieve Wierinck has been a Belgian Member of the European Parliament (MEP) since 2016. She is part of the Group of the Alliance of Liberals and Democrats for Europe (ALDE) and sits in the Committee on Industry, Research and Energy (ITRE). Ms. Wierinck has a background in Pharmacy and worked as a Pharmacist for almost 30 years before becoming an MEP.

@LieveWierinck



Jean-Eric Paquet, is the newly appointed Director-General of the Directorate-General for Research and Innovation of the European Commission. With 23 years of experience in the European Commission, and as one of the three Deputy Secretaries-General of the Juncker Commission since November 2015, Mr Paquet has most recently helped in shaping the European Commission’s proposals for deepening the Economic and Monetary Union and for an Industrial Policy Strategy.

He previously served as the Deputy Head of Cabinet of former Commissioner for Research, Philippe Busquin, as well as having strengthened the European Semester process in his previous role as Deputy Secretary-General of the European Commission.

@EUScienceInnov

“The Value of Innovation” Session



Joke Jaarsma is the Treasurer of the European Brain Council. Joke is past president of the European Alliance for Restless Legs Syndrome (EARLS), and has broadened her outlook to advocacy for all neurological illnesses. Joke Jaarsma is President of the European Alliance for Restless Legs Syndrome, Vice-President of the Dutch Restless Legs Patient Group and Member at Large of EFNA. She has suffered from severe Restless Legs for many years. In her working life, Joke was Publisher of scientific books and journals.

@joke_jaarsma



Hilikka Kärkkäinen is the President of GAMIAN-Europe. Hilikka has been both the expert and the patient in regard to mental health work. Suffering from reactive depression herself, she has worked both for the City of Helsinki and the City of Espoo in Child Welfare, as a Senior Social Worker in Probation and After Care Association in Helsinki, was Executive Director of Finnish Central Association for Mental Health (which is the biggest Mental Health Patients’ organization in Europe with about 18,000 individual members) and President and Vice President of Mieli Maasta, a patient association for those suffering from depression.

GAMIAN-Europe (Global Alliance of Mental Illness Advocacy Networks-Europe) is a patient-driven pan-European organization, representing the interests of persons affected by mental illness and advocates for their rights. Its main objectives are: advocacy, information and education, anti-stigma and discrimination, patients’ rights, co-operation, partnerships and capacity building.

@HilikkaKrkkinen2

@GamianE



Jacobo Santamarta Barral, a representative of the Young Person’s Network at the European Multiple Sclerosis Platform is 32 years old and was diagnosed with relapsing-remitting multiple sclerosis (RRMS) in September 2007. He studied law, specialising in IP and worked in an Oil & Gas company for about five years. Currently he is working on his PhD on pharmaceutical products related to IP law, a field in which he would like to keep working. Jacobo writes weekly blog posts on IP law, recently joined a theater group and advocates for people with MS whenever and everywhere he can.

The European Multiple Sclerosis Platform (EMSP) is committed to an ultimate vision of a world without multiple sclerosis (MS), working to ensure that people with MS have a real voice through advocacy and awareness-raising, collecting and sharing knowledge and expertise, encouraging research and data collection. Their Young Person’s Network brings together groups of young people with MS wanting to make a difference and have their voices heard.

@jacobosantamar1



Prof. dr. Guus Smit is Director of the Center for Neurogenomics and Cognitive research at the Neuroscience Campus of the VU University in Amsterdam, Chairman of the Neuroscience Graduate School Amsterdam and of the Dutch Neurofederation.

He currently heads a group of 40 researchers in the field of molecular and cellular mechanisms of neuronal synaptic plasticity. This work is centred around the understanding of synaptic (dys)functions in animal models and the human post-mortem brain, in relation to neurological and psychiatric disease. His group uses an integrated set of novel quantitative proteomics technologies, high-content cellular assays, automated behavioural screening, and optogenetics approaches. In particular, synaptic proteomics approaches have been instrumental in definition of the synaptic proteome and interactome and the functional annotation of synaptic proteins. was trained as molecular biologist and obtained his PhD (1990) on insulin signalling in the brain.

Apart from his activities in research, he coordinated EU-SYNSYS, and EU-Neurocypres, large-scale projects on synaptic function and receptor structure



Prof. Sebastian Brandner, MD FRCPath is Professor, Chair of Neuropathology and Head of the Division of Neuropathology at Queen Square, UCL Institute of Neurology, one of the largest academic neuropathology departments in the United Kingdom. His work involves modelling intrinsic brain tumours, oncogenic signalling in neural stem cells and working on the mechanisms of how mutations in genes that control cell division and migration of stem cells can cause brain tumours.

@Seb_Brandner
@uclneuro



Dr. Marisa Papaluca is Senior Scientific Advisor in the Research and Development Division at the European Medicines Agency. In her role as co-chair of the EU Innovation Offices Network Dr. Papaluca focuses on strengthening the overall EU regulatory support to innovation and the establishment of the EMA Regulatory Science Observatory. Dr. Papaluca is also responsible for a number of projects in collaboration with European and international partners and stakeholders at the forefront of Next Gen Medicines and Patient Centred Medicine innovation for the benefit of patients and society as a whole.

@EMA_News



Dr. Christoph von der Goltz is Senior Director and Head of HEOR & RWE with global strategic responsibility of health economics and real-world evidence at Lundbeck. He joined H. Lundbeck A/S in 2012 as Head of Department, Corporate Medical Affairs, with global responsibility for leading and managing all medical activities for the launch of the opioid antagonist nalmefene. He carried on as Scientific Lead and Senior Director of the Lundbeck Institute with global strategic responsibility for disease state education programs and medical information, and since June 2016 additionally took over global responsibility for Medical Affairs Neurology with focus on Alzheimer's and Parkinson's in early and late stage projects.

Furthermore, he is a specialist in Psychiatry with 10 years of clinical experience in neurology and psychiatry in Germany and Sweden.

@Lundbeck



Menno Aarnout is the Executive Director of the the International Association of Mutual Benefit Societies (AIM). He is in charge of representing AIM and coordinating transversally the AIM secretariat; coordinator of the working group on pharmaceuticals and medical devices. The International Association of Mutual Benefit Societies (AIM) is an international umbrella organisation of federations of health mutuals and health insurance bodies counting with 64 members from 31 countries around Europe, Latin America and Africa and the Middle East.

@AIM_Healthcare



Dr. Matthias Wismar is Senior Health Policy Analyst with the European Observatory on Health Systems and Policies. In this capacity, he works as knowledge broker supporting evidence informed policy making for health and health systems.

He has covered in his professional career a large range of policy and health system related topics. In recent years he has focused his activities on Health in All Policies (HiAP), health impact assessment (HIA), Health for All (HFA), health targets, inter-sectoral governance, health system governance, the European Union and health services, the European Union and health research, cross-border health care and human resources for health. The geographical focus of his work is the WHO European Region comprising 53 Member States.

The European Observatory on Health Systems and Policies supports and promotes evidence-based health policy-making through comprehensive and rigorous analysis of the dynamics of health care systems in Europe.

@ matthiaswismar



Nathalie Moll is the Director General of the European Federation of Pharmaceutical Industries and Associations (EFPIA). Nathalie previously worked as the Secretary General of EuropaBio. After graduating with Honours in Biochemistry and Biotechnology from St Andrews University, Scotland, and a traineeship at the European Commission, Nathalie has spent 20 years working for the biotech industry at EU and national level in associations and corporate positions.

EFPIA represents the pharmaceutical industry operating in Europe. Through its direct membership of 33 national associations and 40 leading pharmaceutical companies, EFPIA is the voice on the EU scene of 1,900 companies committed to researching, developing and bringing new medicines to patients.

@ NathalieMoll
@EFPIA



Prof. Colm O'Morain is the immediate past President of the BioMedical Alliance for Health Research in Europe and continues to be a board member of the organisation that represents 28 major European Scientific societies which sever the interests of 400,000 European Translational Scientists. He graduated from University College Dublin and received his post-graduate training in Dublin, Nice, London and New York. He was the foundation Professor of Medicine at Tallaght Hospital, Trinity College Dublin, elected Dean of the Faculty of Health Sciences at Trinity College from 2007 – 2012 and has held many positions of authority in National, European and World. He has published over 300 scientific papers and his research interests are in Helicobacter pylori, Inflammatory Bowel Disease and Colorectal Cancer Screening.

@Biomedalliance



Dr. Jarosław Waligóra MD PhD is a policy officer on rare diseases in the Directorate General for Health and Food Safety, European Commission. Dr. Waligóra joined the Commission in 2006 and he has worked on several health policies: cancer, nutrition and physical activity. Currently he is responsible for rare diseases policy developments in the Commission. Graduate of the Medical University of Warsaw, he worked the next 10 years at the University's 2nd Department of Paediatrics. Jaroslaw is a specialist in clinical genetics and paediatrics; in 2002 he obtained his PhD in human genetics.

@JarekWaligora
@EU_Health



Margaret Walker joined EUFAMI as Executive Director in January 2018. A committed public affairs and association management professional, Margaret has more than 15 years' experience in the field and has worked with both scientific and patient umbrella associations, at European and international level. Margaret has a Post-graduate Certificate in Humanities, a BA (Hons) in Humanities, as well as a Diploma in Gender and Development. She is a member of the UK's Royal Society for Public Health. At EUFAMI Margaret oversees the day to day operation of the network and works to ensure its mission, to represent all family members of persons affected by severe mental ill health at European level so that their rights and interests are recognised and protected, is fulfilled. EUFAMI, the European Federation of Associations of Families of People with Mental Illness, is an organisation with ongoing commitment to improving care and welfare for people affected by mental illness.

@MargAnneWalker
@EUFAMI



A New Zealander, **Dr. Alexander Schubert** studied at the University of Auckland before starting graduate studies at Cornell University in the United States. After completing his PhD in history at Cornell in 2000, he joined Deloitte, serving in a variety of business development and marketplace strategy roles, first in New York City, and later in London and Paris. In 2008 he moved to the Netherlands, becoming a lecturer at the strategy centre of Nyenrode Business University before taking up his current position as Executive Director for the European College of Neuropsychopharmacology (ECNP) in 2009.

@ECNPtweets

"European Brain Research: Shifting Gears and Going Global" Session



Dr. Karim Berkouk, is the Acting Head of Unit for Non-Communicable Diseases and the Challenge of Healthy Ageing at the Directorate-General for Research and Innovation of the European Commission.

He develops and implements research policies on brain, cancer, cardiovascular, diabetes and obesity, ageing, and other chronic diseases. Previously, he was Head of Sector for the EC Marie Curie Actions.

Prior joining the EC, he held various research positions on prosthesis specific to patients, improvement of nuclear brain images and brain connectivity, respectively in Exeter (UK), the French National Institute of Health and Medical Research (INSERM, FR) and Cambridge (UK). He graduated in fluid mechanics from the University of Paul Sabatier (Toulouse, FR) and holds a PhD in bio-fluid mechanics from the University of Warwick (UK), where he developed a new mathematical model for the understanding of the pathogenesis of Syringomyelia, a rare disease of the spinal cord.

@EUScienceInnov



Dr. Ari Ercole is a research-active intensive care physician holding a substantive consultant post in neurosciences intensive care medicine at Cambridge University Hospitals NHS Foundation Trust (CUHFT). His clinical interests focus on the physiological measurement, support and resuscitation the critically ill patients, in particular patients that have sustained severe neurotrauma. He is also an experienced prehospital helicopter emergency physician providing life-support at the scene of major trauma including traumatic brain injury. Prior to his medical training, Dr Ercole completed a PhD in physics at the University of Cambridge. As such, he also has an extensive background in mathematical modelling and computing.

Dr. Ercole is a named participant in the CENTER-TBI project, a large European research project that aims to improve the care for patients with Traumatic Brain Injury (TBI), where he plays a leading role in data curation and portal design for this complex dataset of more than 2,000 clinical entities. Within InTBIR, a collaborative effort of the European Commission (EC), the Canadian Institutes of Health Research (CIHR) and the National Institutes of Health (NIH) to coordinate and leverage clinical research activities on traumatic brain injury (TBI) research, he is actively engaged in developing and improving data curation standards for large observational studies such as in traumatic brain injury with a view to improving data quality, accessibility, interoperability and sharing in the future.

@CenterTBI



Prof. Philippe Ryvlin is professor of neurology at Lyon University, France, where he obtained his MD and PhD in neurosciences. He is the Chair of the Research Advocacy Task Force, Co-Chair of the Joint Task Force for Epilepsy Advocacy Europe and a member of the Commission on European Affairs of the International League Against Epilepsy. The International League Against Epilepsy (ILAE) is an organisation of more than 100 national chapters, with the mission to advance and disseminate knowledge about epilepsy, promote research, education and training and to improve services and care for patients, especially by prevention, diagnosis and treatment.

@IlaeWeb



Dr. Helena Ledmyr has a PhD in genetics and cardiovascular disease from the Karolinska Institute in Stockholm, Sweden. After a post-doc project on gene therapy, she left academia for the Royal Swedish Academy of Sciences where she worked with science communication and administration for 3 years. Helena is currently the Head of Development and Communications at INCF (incf.org), a global organization that supports the development and implementation of neuroinformatics. She is also the vice chair for the Swedish Network for Research Communication (forskomp.org), and one of the moderators for Real Scientists (realscientists.org), a science communication project on Twitter with 64k followers.

@Helena_LB
@INCForg



Prof. Philippe Amouyel is Professor of Epidemiology and Public Health at the University Hospital of Lille. He leads a large academic research unit working on public health and the molecular epidemiology of ageing diseases both vascular and neurodegenerative. He is the Chair of the EU Joint Programme on Neurodegenerative Disease Research (JPND), a 30-country initiative whose mission is to tackle the challenge of neurodegenerative diseases in particular Alzheimer's disease. In addition, Professor Amouyel is the General Director of the Fondation Plan Alzheimer, a French non-profit dedicated to supporting innovative, cutting-edge Alzheimer's research.

@P_Amouyel
@JPNDEurope



Chris Ebell is the Executive Director at the Human Brain Project, where he heads the management unit of this large and ambitious European Flagship project. Prior to this position, he served as the Science and Technology Counselor at the Swiss Embassy in Washington, D.C. During his diplomatic posting, he connected Switzerland and the United States in the fields of science, technology, innovation, higher education, as well as professional education. Before his posting in the United States, Chris worked at the Department of Economic Affairs in Bern, Switzerland, where he headed the international cooperation section for innovation, education and international organizations. Specializing in innovation policy issues, he was a delegate at the OECD Committee for Science and Technology Policy, UN commissions, and a member of several expert working groups, including the expert panel on the OECD Innovation Strategy. Prior to that, Chris built up extensive experience with R&D-related EU institutions and multilateral cooperation mechanisms both on a European and global level with an emphasis on advanced manufacturing. He began his career at the Swiss Commission for Technology and Innovation, Switzerland's innovation funding agency. Before his career in the government services, Chris studied Physics and Humanities, did research in American and International studies and culture, in Switzerland and at Harvard University. He received Masters degrees from the University of Bern and from the University of Illinois at Chicago and taught at the University of Basel.

@ HBPExecDir
@HumanBrainProj



Priv.-Doz. **Dr. Hella Lichtenberg**, is a geneticist with a habilitation in microbiology. Her scientific contributions have been reported in 43 full papers published in internationally reviewed journals. Since 2007 she is responsible for NEURON's, and since 2015 also for ERA-CVD's (Cardiovascular Diseases) coordination office and involved in other DLR-PT international cooperations like CORBEL and ESFRI (Infrafrontier, Elixier, BBMRI) measures. This work necessitates all areas of conceptualizing and executing research funding programmes. Within a secondment to the Federal Ministry of Education and Research (BMBF, 2010 – 2012) she benefitted by the acquisition of public relation expertise. She is, as senior programme manager at DLR-PT for both, national and international governmental funding measures, recognized for strategic organizational competence. Her national focal areas of research funding are Mental Health and Multiple Sclerosis.

■ ACKNOWLEDGEMENT

This event was supported by:





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