



Dear Colleagues,

We are pleased to share with you a detailed overview of our activities throughout the first half of 2021, a year still heavily impacted by the "new normal" of the ongoing COVID-19 pandemic. In these unprecedented times, EBC continues to adapt in order to take on the activities planned by the Board for 2021. Despite events and meetings being forced to shift online, we are pleased to update you on the immense amount of work that has continued regardless. Below you will find an overview of all that is current and all that has been achieved so far this year, with plenty more still to come. We hope you will appreciate the recap and we look forward to continued collaboration for the remainder of 2021.

Sincerely,

On behalf of the EBC Executive Committee

Monica Di Luca

Half-Year Highlights



Brain Innovation Days: Digital Journey

The EBC-led Brain Innovation Days, launched in October 2020, were faced with a challenge when the planned in-person event had to be postponed due to the pandemic. Rather than cancel, the Brain Innovation Days were reshaped into one full year of brain innovation activities, with a series of digital events and the release of podcasts, articles and more.

[Read more](#)

Launch of Policy Roadmap "Brain Health in Europe: Fostering Innovation, Improving Outcomes"

The European Brain Council was pleased to release its Policy Roadmap 'Brain Health in Europe: Fostering Innovation, Improving Outcomes' on the occasion of Brain Awareness Week 2021, calling for the establishment of an EU-wide and public health combined Brain Plan.

[Read more](#)



Work continues within the EBC-led European Brain Research Area project

Launched on 1 November 2018, the European Brain Council (EBC)-coordinated EU project The European Brain Research Area (EBRA), was designed to respond to a Horizon 2020 call calling for coordinating European brain research and developing global initiatives. Three years in, the EBRA project continues and has been extended due to the COVID-19 pandemic. The final EBRA Clusters were announced in January 2021 and the work towards a Shared European Brain Agenda is currently underway, with a workshop held in November 2020.

[Read more](#)

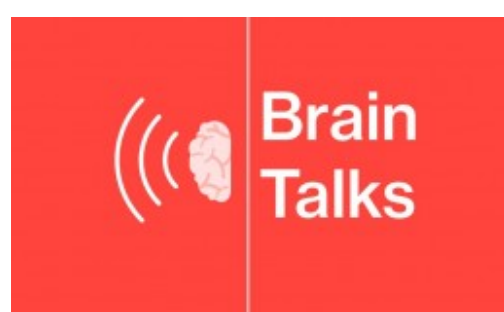


Brain Awareness Week Event on “Patient Engagement in EU-Funded Brain Research Projects”

On 16 March 2021, EBC, in partnership with the European Federation of Neurological Associations & GAMIAN-Europe, held its annual Brain Awareness Week event on **Patient Engagement in EU-Funded Brain Research Projects**.

The event aimed to shed light on the current state of patient engagement in EU-funded brain research projects, exploring how patients have been involved to date, their experiences in this involvement, the challenges continued to be faced, examples of patient-involved projects and initiatives and looking at what can be done to improve engagement.

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Take a listen to the EBC/Brain Innovation Days podcast series

In late 2020, EBC launched the Brain Talks podcast series as part of the Brain Innovation Days digital journey. The series features a number of prominent guests in the brain innovation space, exploring topics such as creating a successful medtech start-up, telemedicine, disease-specific mobile applications and the role of health innovation in Europe - to name a few. New episodes are released regularly!

[Listen now](#)



Policy Roundtable on Brain Health in Europe: Fostering Innovation, Improving Outcomes

On 20 April 2021, EBC held a virtual Roundtable to formally launch its **Policy Roadmap ‘Brain Health in Europe: Fostering Innovation, Improving Outcomes’**, co-hosted by MEPs Maria da Graça Carvalho (EPP, Portugal) and Tomislav Sokol (EPP, Croatia).

The roundtable was an opportunity to formally launch the Policy Roadmap to policymakers, bringing together key stakeholders to discuss the Roadmap's recommendations and next steps for better outcomes for people living with mental and neurological disorders. This roundtable was a first step in laying the groundwork for the development of an EU-wide research and public health Brain Plan.

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RETHINKING MS IN TIMES OF COVID-19

Policy Report

“RETHINKING MS in times of COVID-19” launched on World Multiple Sclerosis Day

On the occasion of World Multiple Sclerosis Day (30 May 2021), EBC released its new policy paper, “**RETHINKING MS in times of COVID-19**”. This new paper is part of the main report “RETHINKING MS in Europe”, a research-driven project offering tangible policy changes to improve the lives of people living with MS across Europe, building on the 2017 Value of Treatment report from the European Brain Council.

[Read more](#)



LIVING WITH MS DURING COVID-19

A case for rethinking MS in the EU

Virtual Exhibition

"Living with MS during COVID-19: A case for rethinking MS care in the EU" Virtual Exhibition

Alongside the launch of the "RETHINKING MS in times of COVID-19" policy paper, EBC also launched its first-ever virtual exhibition ‘**Living with MS during COVID-19: A case for rethinking MS care in the EU**’, featuring people living with MS, clinicians, care givers, policymakers and industry representatives who want to make a difference in how MS care and treatment are delivered in Europe. The exhibition will remain open and be updated throughout the year.

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The Value of Treatment for Brain Disorders: Case Studies on Rare Diseases & Mental Disorders preliminary findings presented at Synthesis Meeting

In 2019, in order for the research to dig deeper into the current unmet needs in health care using a value-based approach, a second round (VOT2) on new therapeutic areas was launched; focusing on **The Value of Early Coordinated Care for Rare Diseases** and **The Value of Early Intervention and Continuity of Care for Mental Disorders**.

On 8 June 2021, EBC hosted a virtual **Synthesis Meeting for the Value of Treatment 2** case study working groups to present their preliminary findings.

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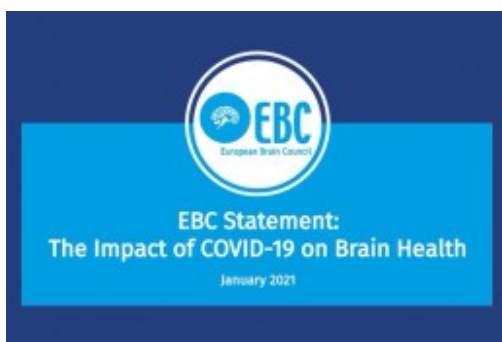


New Value of Treatment stream on Transversal Topics currently underway

Kicked off in December 2020, a third stream of the Value of Treatment project on Transversal Topics is officially underway over a three-year period from 2021 to 2023.

A case study on chronic pain has begun and soon a case study on sleep and wake disorders is to follow, potentially among others.

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Statement on the impact of COVID-19 on brain health

The impact of Covid-19 on brain health during the last months has been a major and dramatic one with severe mental and neurological consequences. In January 2021, EBC released a statement on **The Impact of COVID-19 on Brain Health**, summarising the latest findings on COVID-19 and its impact on the brain and why it should be considered as a brain disease, with increased mental and neurological disorders, which has to be taken into consideration when choosing the most appropriate and effective way to support research linked to the epidemic.

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Brain Innovation Days: From Innovative Ideas to Creative Brain Interventions

The second Brain Innovation Days digital session, "From Innovative Ideas to Creative Brain Interventions", took place on 26 January 2021. The session hosted the first-ever Brain Innovation Days Pitch Competition, where a number of start-ups went head-to-head to pitch their business for the chance to win Best Pitch, awarded by a jury of esteemed experts in related fields and the Public Prize for Best Pitch. Furthermore, a panel discussed the challenges faced by innovators in Europe – from idea to business – and the support structures that exist to alleviate and guide the process.

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EBC joins the OneNeurology initiative

In March 2021, EBC joined the newly launched OneNeurology Initiative, which aims to unite and strengthen neurology-related groups to stimulate collaborative advocacy, action and accountability for the prevention, treatment and management of neurological disorders worldwide.

The European Federation of Neurological Associations, together with the European Academy of Neurology, founded this patient-driven initiative, which includes a multi-stakeholder global partnership.

[Read more](#)



EBC attends EPA Congress 2021

EBC attended the EPA Congress held virtually on 10-13 April 2021. As every year, EBC was present in the Exhibition Hall with a stand filled with information on activities related to mental health, including the Value of Treatment 2 case studies on mental disorders and the EBRA project.

A dedicated EBRA symposium was also held, entitled "A Catalysing Initiative for Brain Research Stakeholders to Streamline Brain Research across Europe".

[Read more](#)



7th Academy Meeting of National Brain Councils

The 7th Academy Meeting of National Brain Councils was held virtually on 15th April 2021.

Prof. Monica Di Luca, President of the European Brain Council, started the meeting with words of welcome to the participants, followed by an Opening Address by MEP Tomislav Sokol (HR, EPP) on the perspective of a European Health Union. Pierre Delsaux, Deputy Director-General of the Directorate-General for Health and Food Safety, delivered his keynote speech and replied to the questions from the audience, focusing on the key role of Member States in developing and establishing a European brain health agenda.

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Training workshop for early-stage researchers to become a voice for neuroscience

In the context of the Marie Skłodowska-Curie actions on Innovative Training Networks funded by the Horizon 2020 programme, EBC organised a workshop on the role of science in the European policy-making process. The workshop addressed to a group of early-stage researchers aimed to empower them with ways to become a voice for neuroscience research throughout their careers.

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Brain Innovation Days: Fast-tracking brain innovation in times of COVID-19

The third Brain Innovation Days digital session, "Fast-tracking brain innovation in times of COVID-19", took place on 26 January 2021.

The event explored the positive direct and indirect results of COVID-19 pandemic response and research on the brain innovation ecosystem, what lessons have been learned, what advancements have been made and what threats lie ahead – particularly when and if the world returns to the pre-COVID status quo. The session featured testimonials from key opinions leaders, patients, representatives from the EU and WHO level and the industries that were forced to adapt to this rapid change of pace in innovation.

[Read more](#)



GOLUP Roundtable on Patient safety and informed consent: The importance of good off-label use practices

In 2016, the Declaration for Good Off-Label Use Practice was launched, recommending that off-label use of medicinal products should only occur if certain criteria, drawn together by independent experts, are met.

The GOLUP roundtable held on 17 June 2021 allowed for exchange of ideas and experience among stakeholders and local actors, to understand which paths to take in individual Member States and to allow a continuous exchange of ideas and information on the off-label use of medicines.

[Read more](#)



EBC attends EAN Congress 2021

EBC was in attendance at the EAN Congress held virtually on 19-22 June 2021. As every year, EBC was present in the Exhibition Hall with a stand filled with information on activities related to neurology, including the Value of Treatment 2 case studies on rare neurological disorders, EBRA, MULTI-ACT and various communications activities, including the Science & Society videos.

A dedicated EBRA Special Session was also held, featuring project coordinators and a few representatives from the EBRA Clusters.

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Brain conditions, mental and neurological alike – Open Access Government

EBC President, Prof Monica Di Luca, was featured in the January 2021 edition of Open Access Government, a digital publication that provides an in-depth perspective on key public policy areas from all around the world, including research and innovation and health.

This article shed light on the existing burdens of brain conditions, as well as the need for increased funding, coordinated action, stronger policy and political response and the need for an increased sense of urgency in tackling this burden.

[Read more](#)



EBC and MEPs call for EU to take lead in tackling brain disorders and Policy Roadmap featured in Parliament Magazine

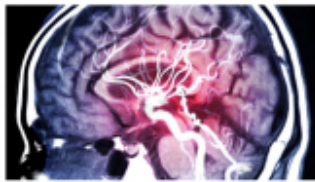
EBC was featured in a March edition of Parliament Magazine with a **Thought Leader by EBC President, Prof. Monica Di Luca**, outlining why the establishment of a European brain health strategy is critical to fostering research and innovation, and improving patient care.

This was accompanied by a call to foster innovation and research for brain health in Europe and coordinate efforts with all stakeholders by **MEPs Tomislav Sokol (HR, EPP)** and **Maria da Graça Carvalho (PT, EPP)**. The MEPs highlighted the importance of prioritising brain research in Europe exploiting the strong response from international and European institutions provided by the attempt to tackle the current COVID-19 pandemic.

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The importance of prioritising brain health

10 October 2021



© European Brain Council

The importance of prioritising brain health – Health Europa

EBC was featured in discussion with **Health Europa**, addressing the need for collaboration, research and increased support for brain health, in the article entitled “The importance of prioritising brain health”.

The article introduced the role and main objectives of EBC in the European brain health sector and the key challenges currently facing the management and treatment of brain conditions, both mental and neurological alike.

[Read more](#)



Aging Brain

Journal homepage: www.elsevier.com/locate/agingbrain



Invited Opinion

Future of the aging brain: Bridging the gap between research and policy

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1. Introduction

The complexity of the brain defies our attempts to fully understand its physiology, how it coordinates the body's functions, knowledge that is fundamental in the search for cures of its dysfunction. Indeed, this complexity has long hindered the analysis, diagnosis and treatment of brain disorders, as reflected by the heavy burden they represent on health systems and the increasing share associated with the aging of the world population. Contrasted

global burden of MDS. It resulted in adding mental and neurological health to the “5th MDG”, complementing global efforts to combat cancer, cardiovascular disease (CVD), diabetes and chronic respiratory diseases. This has been reinforced in the recent 2019 UN Declaration on the Universal Health Coverage (UHC), where “mental disorders and other mental health conditions as well as neurological disorders” have been identified as an essential component of UHC. Additionally, the World Health Organization (WHO) is also now building a new Brain Health team to

Future of the aging brain: Bridging the gap between research and policy – Aging Brain Journal

EBC contributed to the inaugural issue of **Aging Brain** with a publication on the “**Future of the aging brain: Bridging the gap between research and policy**”, examining the current state of brain research and looking ahead at our vision for research and policy on the ageing brain in the next decades.

The publication highlighted the need for continued and coordinated support to achieve real solutions as well as the need for relentless prioritization efforts to make sure that brain disorders remain high on the health policy agenda at EU and global level.

[Read more](#)



Multiple Sclerosis and Related Disorders

Volume 54, September 2021, 103107



NAverting multiple sclerosis long-term societal and healthcare costs: The Value of Treatment (VoT) project

Michela Tinelli^a, Maura Pugliatti^{b,1}, Andreea Antonovici^c, Bettina Hausmann^c, Kerstin Hellwig^d, Vinciane Quoidbach^e, Per Soelberg Sørensen^f

VOT multiple sclerosis economic analysis published in Elsevier

The findings from the VOT multiple sclerosis working group have been published in Elsevier. The publication covers the work of the first Value of Treatment report, highlighting the need for early diagnosis-intervention, integrated, seamless care underpinning timely care pathways and access to best treatments. The VOT multiple-sclerosis (MS) economic case study analysis aimed to estimate the effectiveness/cost-effectiveness of both early treatment and reducing MS risk factors.

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Ongoing Projects



European Brain Research Area (EBRA)

The European Brain Research Area project — EBRA — was created as a catalysing initiative for brain research stakeholders to streamline and better co-ordinate brain research across Europe while fostering global initiatives.

EBRA now has 4 clusters aiming to promote cooperation and exchange between brain research projects and to enable or enhance international collaboration, with a final call for clusters currently open until September.

The brain research landscape analysis was finalized recently and the work within the Shared European Brain Research Agenda has begun.

[Read more](#)



EBC RESEARCH PROJECT
THE **VALUE OF TREATMENT** FOR BRAIN DISORDERS

Value of Treatment II

In the continuity of the Value of Treatment (VoT) research activities, new case studies are currently underway in new therapeutic areas.

On 2018, EBC launched a second round of case studies related to Rare Neurological Disorders (RNDs) focusing upon Ataxia, Dystonia and Phenylketonuria. In 2019, a second round of case studies on mental disorders followed, focusing on Eating Disorders (ED), Major Depressive Disorder (MDD) and Autism Spectrum Disorder (ASD).

The study is looking at value, early intervention and exploring the potential benefits and consequences of seamless, coordinated care through the examination of health services, patient outcomes and patterns of multidisciplinary care.

[Read more](#)



Value of Treatment - Transversal Topics

A third stream of the Value of Treatment project is currently underway, focused on Transversal Topics, to span a three-year period from 2021 to 2023.

Currently there is one case study on chronic pain, potentially to be followed soon with a case study on sleep and wake disorders.

The objectives of the chronic pain case study are to explore the patient pathway of adults of working age in three selected diseases: fibromyalgia, painful diabetic neuropathy and non-specific low-back pain; and to compare Interdisciplinary Multimodal Chronic Pain Management with current care.

[Read more](#)



MULTI-ACT

The EU-funded **MULTI-ACT** project entered its final months in 2021, with EBC heavily involved in a number of work packages.

The project aims to increase the impact of health research on people with brain diseases and will create and implement a new model allowing for the effective cooperation of all relevant stakeholders. The MULTI-ACT project works with patients and patient organizations, academics, private and public stakeholders to develop brand new tools to assess the value of research.

Alongside communications and dissemination, EBC currently also leads work packages on the strategic research agenda and funding model and the transferability (WP4) and test of the MULTI-ACT framework (WP7).

MULTI-ACT came to an end in April 2021 and EBC was tasked with the organisation of its final conference, which took place on 23 March 2021.

[Read more](#)



AD Detect-Prevent

The EU-funded **AD Detect-Prevent project**, which is led by the Danish company Brain+, kicked-off in late 2018 with the aim of developing a digital tool to improve early detection of Alzheimer's disease (AD) and combining this with lifestyle programs for reducing life style risk related to Alzheimer's dementia. To achieve this, the project brings together a diverse group of partners with strong expertise in brain health, dementia, clinical neuroscience and patient advocacy.

Work within the Consortium has carried on in 2020 and a public webinar was held in June on the subject of 'Enhancing the early detection of Alzheimer's disease through digital technologies'.

[Read more](#)



PRIME

The EU-funded **PRIME (Prevention and Remediation of Insulin Multi-morbidity in Europe)** project was launched in January 2020 and will last 5 years.

The multidisciplinary PRIME consortium aims to better understand this body-brain co-morbidity and will bring this acquired knowledge to society (e.g., medication, lifestyle interventions, medical guidelines and policy). Furthermore, educational approaches to inform clinicians, patients, and general public will be developed.

EBC is involved in work surrounding communication and dissemination.

[Read more](#)



Brainteaser

EU-Funded BRAINTEASER aims to integrate societal, environmental and health data to develop patient stratification and disease progression models for Amyotrophic Lateral Sclerosis (ALS) and Multiple Sclerosis (MS). ALS and MS are two very complex degenerative neurological diseases, but with very different clinical picture, evolution, prognosis and therapies.

BRAINTEASER will integrate large clinical datasets with novel patient-generated and environmental data collected using low-cost sensors and apps. The collected data will allow the development of Artificial Intelligence (AI) tools able to address the current needs of precision medicine, enabling early risk prediction of disease fast progression and adverse events. Technical solutions developed within the project will follow agile and user-centered approaches, accounting for the technical, medical, psychological and societal needs of the specific users.

[Read more](#)



ASCTN-Training

ASCTN-Training is a four-year project, funded by the European Union Horizon 2020 Programme (H2020-MSCA-ITN-2018) under the Marie Skłodowska-Curie Initial Training Network and Grant Agreement No. 813851.

ASCTN-Training is addressing existing gaps within Human Stem Cell-based Neuronal disorders (NDs) Modelling (NDM) for research to develop new medicines for the treatment of neurological disorders (e.g. Parkinson's (PD), Huntington's (HD) and Demyelination's (DM) diseases), which occur as a result of acute or progressive loss of cells, glial or neuronal, and structures and function in the brain.

EBC led the organisation of a workshop training early-stage researchers to become a voice for neuroscience research throughout their careers, introducing them to the European policy-making environment and EU funding mechanisms.

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