

EBC ANNUAL REPORT 2020



IMPROVING BRAIN KNOWLEDGE AND ADVOCACY
(no matter what!)

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EBC IN TIMES OF COVID-19

*Letter from EBC President
& Executive Director*



Dear Colleagues,

We are pleased to present to you the EBC Annual Report for 2020.

In spite of a very challenging year, we are extremely proud that we were able to carry on our activities and continue to deliver upon the agenda and objectives that were defined for the organisation.

COVID-19 naturally had a major impact on many areas over 2020. The entire brain community, i.e., patients, clinicians, researchers, carers, and society as a whole needed to adapt to unprecedented circumstances. At the level of EBC, we were forced to adapt the way in which we organised and carried out activities and projects, and, in doing so, have demonstrated a clear commitment as well as capacity for adaptation.

Overall, 2020 enabled us to conclude on a number of key achievements which we invite you to discover in this current edition.

With kind regards,



Prof. Monica Di Luca
President

A handwritten signature in black ink, appearing to read 'Monica Di Luca'.

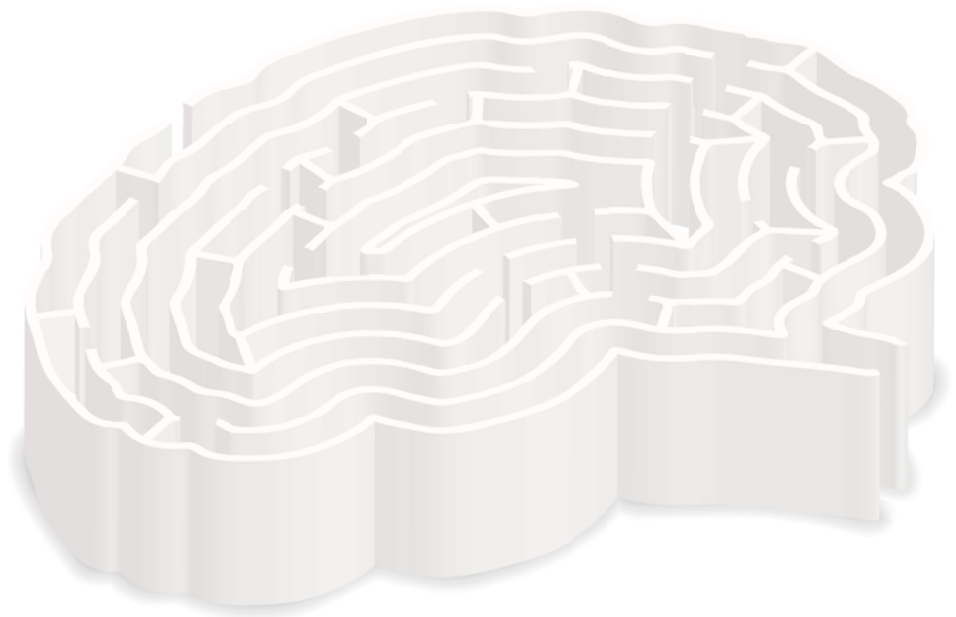


Frédéric Destrebecq
Executive Director

A handwritten signature in black ink, appearing to be a stylized 'F' followed by 'Destrebecq'.

THE SITUATION HAS CHANGED

Not the mission





MISSION & VISION

The European Brain Council (EBC) is a network of key players in the “Brain Area”, with a membership encompassing scientific societies, patient organisations, professional societies and industry partners.

EBC strives for a world where:

- The brain is recognised as our most valuable asset
- No stigma is associated with brain diseases
- Prevention, early diagnosis and treatment of brain diseases and research of the brain is prioritised by society

EBC realises this through:

- Policy and advocacy work alongside awareness raising
- Encouraging prevention & treatment
- Stimulating innovation

A non-profit organisation based in Brussels, our main mission – by bringing together science & society – is to promote brain research with the ultimate goal of improving the lives of the estimated 179 million Europeans living with brain conditions, mental and neurological alike.

WORKING IN A NEW NORMAL

The year of teleworking



EBC

HIGHLIGHTS

Brain Innovation Days

In 2020, EBC was excited to launch the Brain Innovation Days, which started as an idea for an annual, two-day event but due to COVID-19 was transformed into a full year of activities around brain innovation and community engagement.

Partnered with Belgian reference accelerator, beLean.net, who specialise in the field of health biotechnology and medical technologies, the Brain Innovation Days were virtually launched on 13 October, 2020 in a two-hour digital session around the overarching theme, "Disrupt and rewire: How brain innovation is changing Europe".

The event was opened by Monica Di Luca, EBC President and Jean-Eric Paquet, Director-General of the Directorate-General for Research and Innovation at the European Commission. Furthermore, the session brought together representatives from the European Commission, the European Medicines Agency, the Innovative Medicines Initiative and the European Parliament alongside key opinion leaders, researchers, start-ups, clinicians and more to explore and answer the question: why is brain innovation important and how is it changing Europe and the world?



Despite the prevalence of brain disorders in Europe, there is currently no disease modifying treatment available to cure a wide range of mental and neurological conditions. Yet, compared to other disease areas, the pace of innovation in this field has traditionally been hindered by multiple factors, including the complexity of the brain itself. As a result, brain treatments remain insufficient and research is disproportionately underfunded compared to other disease areas. Enhanced multi-stakeholder engagement in the brain ecosystem is needed to foster dialogue, exchange knowledge, accelerate investment in research and innovation, facilitate business development and showcase on-going work, which led to the launch of the Brain Innovation Days initiative.



Brain Innovation Days
 @BrainDays

📢 @EU_Brain and beLean.net are pleased to launch the first ever #Brain #Innovation Days, set to take place on 13-14 October 2020 – physically in #Brussels as well as virtually all over Europe & the world. Learn more about the #BIDays 🧠: braininnovationdays.eu

Brain Innovation Days
 13-14 October
 Brussels, Belgium



The series of digital sessions will continue in 2021, including a start-up Pitch Competition.

Launch of Rethinking MS Country Profiles: Denmark, Italy, Romania and Spain



The European Brain Council and the Health Policy Partnership collaborated in 2018-2019 with experts from across Europe to build an interdisciplinary consensus around practical and sustainable policy responses to MS management at the European level. This project, calling for change in how MS care and support is organised, formed the basis of the core report, **RETHINKING MS in Europe: Prioritising timely integrated services for people with multiple sclerosis**, which was launched on the occasion of Brain Awareness Week 2020.

Multiple Sclerosis (MS) is a progressive neurological disease that can lead to severe disability. It is one of the most prevalent causes of disability in young adults in the world. According to the new MS Barometer (2020), over 1,000,000 people are affected across Europe.

RETHINKING MS, released during the Brain Awareness Week in March 2020, featured a sequence of research which led to a main report accompanied by a suite of four country profiles — Rethinking MS in Denmark, Italy, Romania and Spain — which took an in-depth look at the different MS-related policy and regulations, health services delivery. A series of clinical and patient-oriented benchmarks along the care process were developed, focusing on multidisciplinary, integrated care as a key area which has been identified amongst the priorities for policy action to meet the needs of people living with MS.

The priorities identified in Denmark, Italy, Romania and Spain stem from experts' consensus within those countries; however, they are also likely to be relevant to other regions in Europe. The RETHINKING MS in Europe report highlights that European and national policymakers should focus their efforts around these priorities and take specific actions. Similarly, the COVID-19 pandemic brings opportunities to re-think integrated care models across Europe and the work towards an additional report, Rethinking MS in times of COVID-19, is to be released in 2021.



Publication:

Rethinking MS in Europe: Prioritising Timely, Integrated Care for People with Multiple Sclerosis (Di Luca M, et al. J Clin Neurol Neurosurg, Volume 3:3, 2020)

See full report:

www.braincouncil.eu/wp-content/uploads/2020/01/RETHINKING_MS_Europe_EBC_pp_31012020.pdf



PROJECTS & INITIATIVES

EBC Projects

VOT 2nd Round

Update on ongoing work in 2020

The Value of Treatment for brain disorders (VOT) is a health economics and outcomes research project coordinated by the European Brain Council (EBC). Brain disorders - both neurological and mental alike - constitute a major factor, alongside cancers and cardiovascular diseases, driving the overall burden of diseases in Europe. Neurological and psychiatric disorders across all lifespans are the leading cause of poor health and disability in Europe. The conclusions of the VOT research project first round released in 2017 (which included case studies on schizophrenia, Alzheimer's disease, epilepsy, headache, normal pressure hydrocephalus, Parkinson's disease, multiple sclerosis, restless legs syndrome and stroke) highlighted the need for more research, early, if possible prodromal, diagnosis and intervention, seamless care and access to the best treatments available. 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 rare brain disorders (ataxia, dystonia and phenylketonuria) and mental disorders (anorexia nervosa, autism spectrum disorder and major depressive disorder).

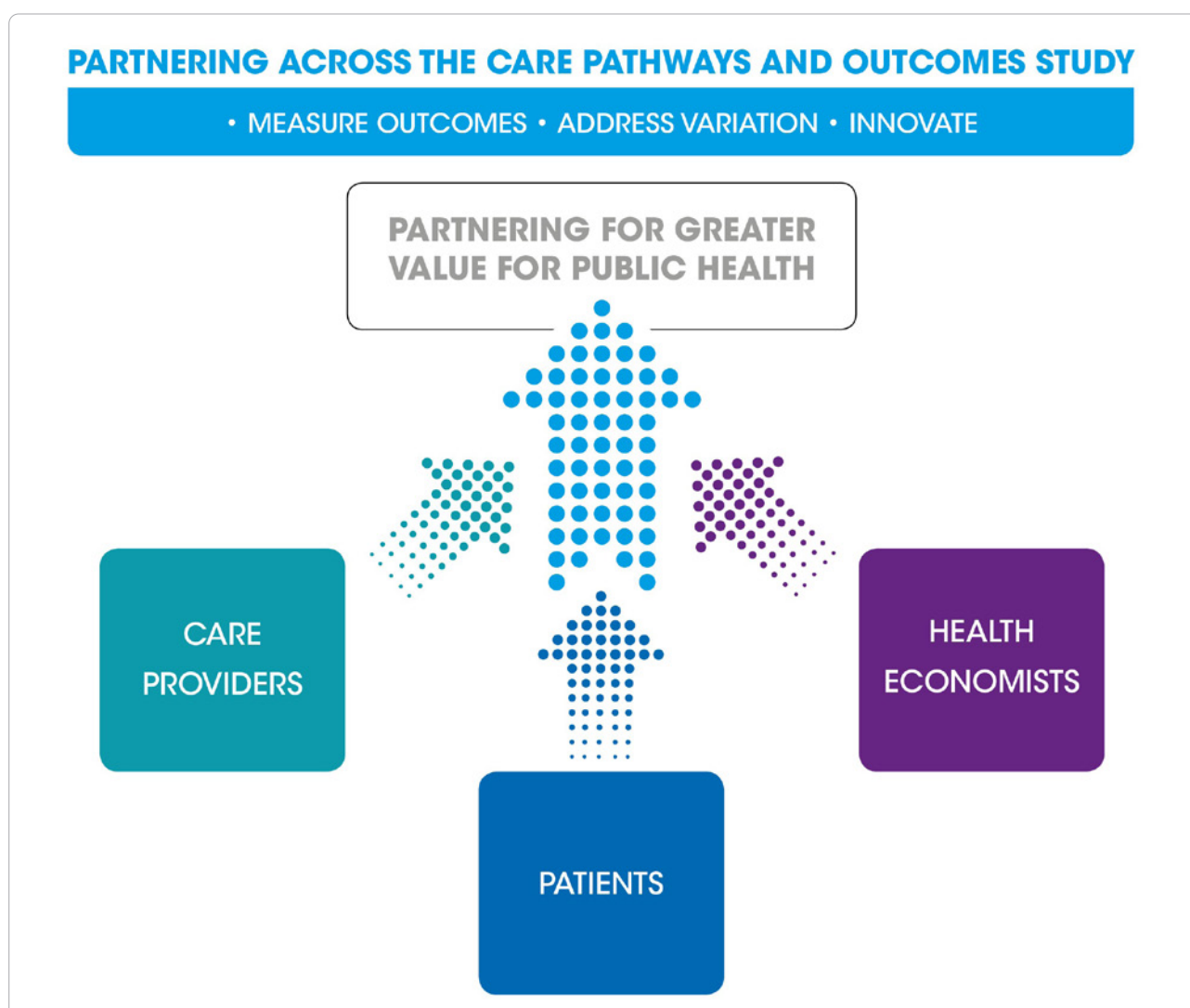
The study objective is to examine health gains resulting from optimised healthcare interventions in comparison with current care or inadequate treatment, and converge data evidence to policy recommendations on how to improve the care pathway(s). In particular,

- The EBC Study on ataxia, dystonia and phenylketonuria (PKU) aims to assess the benefits of early coordinated care and treatment, multidisciplinary care patterns (also addressing comorbidity) and health care providers education on outcomes to patients and costs.
- The EBC Study on anorexia nervosa (AN), anorexia nervosa (ASD) and major depressive disorder (MDD) aims to assess the benefits of early continuity of care and treatment, and collaborative care patterns (also addressing mental health problems with comorbid medical conditions) on outcomes to patients and costs.

Overall, the VOT research highlights the importance of harmonising outcome metrics (outcomes measurement to patients and costs) to allow for meaningful comparisons and interpretation of research findings.

Throughout 2020, joint working sessions aimed to exchange and build synergy between the research-work and the DG SANTE Rare Diseases European Reference Networks (ERNs) programme as well as the EU H2020 PECUNIA project on mental health services. A VOT2 mid-term review took place on 18 May 2020 followed by two meetings to reach consensus on the method which respectively took place on 6 October 2021 and 11 December 2021. Results will be presented on 8 June 2021 followed by scientific publications to be released end 2021, early 2022. Beyond the research design and considering current context, the impact of COVID-19 on treatment and healthcare transformation will be also explored.

Furthermore, a new case study under the VOT research framework was initiated in 2020. A working group was established on the topic of chronic pain disorders. The working group is chaired by a representative of the European Pain Federation (EFIC) and includes members of the European Academy of Neurology (EAN), the European Psychiatric Association (EPA) and Patient Alliance Europe (PAE). The kick-off meeting of this 2-year project took place in early December with preliminary discussions on the scope of the study.



EU-Funded Projects



The MULTI-ACT project **A Collective Research Impact Framework and multi-variate model to foster the true engagement of actors and stakeholders in Health Research and Innovation**, aims to increase the impact of Multi-stakeholder Health Research Initiatives.

The 3-year project which started on the 1st of May 2018 received funding from the EU Horizon 2020 Research and Innovation Programme.

It created a new framework allowing for the effective cooperation of all relevant stakeholders by aligning results to the mission and agenda of research initiatives. The framework addressed to Health Research Funding and Performing Organisations (RFPOs) is easily accessible in an online toolbox that includes tools and guidelines for governance, stakeholder engagement and impact assessment of multi-stakeholder research initiatives. In particular, guidelines are provided on how to maximise and evaluate the impact of Research & Innovation (R&I) on the outcomes that matter to patients in order to enable transformational missions that any health R&I process should aspire to.

EBC is a partner of the MULTI-ACT consortium with responsibility for testing the framework on a multiple sclerosis (MS) case study and its transferability to other brain disease areas.

In 2020, collaboration was initiated with the epilepsy research community through the EPICLUSTER established as part of another EU-funded project coordinated by EBC, the European Brain Research Area (EBRA). A self-sustainability plan was designed for the continued use of the framework among end users after the end of the project. The plan includes further actions with the EBRA EPICLUSTER and other brain diseases in which key players have been grouped in EBRA clusters as well as action in the brain research community as a whole.

The plan seeks to promote the use of all tools and guidelines deployed by the MULTI-ACT consortium to support brain research consortiums in the development of multi-stakeholder managerial models in which each stakeholder has its return on investment aligned with the common goals of improving health and providing effective care for patients.

In addition, EBC continued to deliver on its responsibilities regarding the dissemination & communication activities including the production of videos, newsletters, blogposts, factsheets, social media posts and website updates.

@MULTIACTProj • #MULTIACT

www.linkedin.com/in/multi-act

www.multiact.eu

EU-Funded Projects



The European Brain Research Area project — EBRA — was created in 2018 as a catalysing platform for brain research stakeholders to streamline and better co-ordinate brain research across Europe while fostering global initiatives. EBRA aims to harmonise the different brain research and funding initiatives in Europe and brings key players around the same table— the European Brain Council, the Network of European funding for Neuroscience research (NEURON), the Joint Program – Neurodegenerative Disease Research (JPND) and the Human Brain Project (HBP)— to reduce fragmentation in both funding and research, as well as to identify where the gaps in knowledge are and how we can facilitate translation. In 2020, EBRA released its project video to introduce the project as a whole – at both the operational and strategic levels – as well as the main activities ongoing and still to come.

Watch here: www.youtube.com/watch?v=MCcgbRcNhHI

In 2020, the following EBRA activities took place:

- A landscape of brain research in Europe was finalised
- Expert surveys and a workshop to develop the Shared European Brain Research Agenda (SEBRA) were organised
- 2 new brain research clusters were selected
- 3 cluster activities were performed
- EBRA was presented at several international events

Mapping of the European brain research landscape

The aim of the mapping was to provide an overview of brain research activities funded in the EU framework programmes (FP7/H2020) and the funding initiatives of JPND, NEURON and HBP. The mapping was performed through the searching of relevant projects in the existing repositories made available by the European Commission (i.e., eCORDIS), JPND, NEURON and HBP. A list of 21 brain research topics has been created and 1 or more topics were then assigned to each project. The number of projects per topic, the budget and other relevant parameters were analysed. The mapping report will be shared with the brain research community in 2021.

Development of the Shared European Brain Research Agenda (SEBRA)

The aim of SEBRA is to identify research opportunities and research and innovation gaps to be addressed in the field and to provide recommendations on future areas for excellent, innovative and translational brain research in Europe. SEBRA covers all brain research fields and brain disorders, including both psychiatric and neurological disorders and will serve as a framework to guide future brain research investments in Europe.

Such a framework allows to:

- Increase the impact of brain research
- Advance basic, translational and clinical brain research
- Improve the lives of persons with brain disorders
- Enable brain innovation
- Address societal and economic challenges in Europe and globally

SEBRA integrates pre-existing documents, such as the Strategic Research Agendas of the different initiatives participating in EBRA. It also includes input from brain research experts, including basic, translational and clinical neuroscientists, psychiatrists and neurologists and expert patients/patient representatives. All experts were consulted through 2 surveys in which they were asked to identify priority areas and gaps in brain research, as well as to list potential enabling actions to address those. On the 25th of November 2020, the experts came together in a dedicated virtual SEBRA workshop. The aim of this workshop was to further build on the results of the surveys and to build consensus on the most pressing priorities, gaps and enabling actions needing to be addressed at the European level. On the 26th of November 2020, the main outcomes of the first day's discussion and consensus were presented to a broader group of experts and to the EBRA partners.



EBRA Booth & Poster Presentation at the Human Brain Project Open Day & Summit 2020

EBRA's clusters¹



In order to promote co-operation and exchange between European brain research projects and networks, EBRA supports brain research communities to:

- Consolidate and expand further the research community
- Build consensus on various issues (research priorities, research roadmap, data sharing, etc.)
- Promote links with existing research infrastructures
- Increase the visibility of the research community

Cluster Selection

In 2020, 2 new EBRA clusters have been selected: the TRISOMY21 cluster and the BRAINFOOD cluster.

The Trisomy 21 cluster is led by Prof. M. Dierssen and Dr. MC. Potier and aims to establish a collaborative framework for the coordinated actions of Down syndrome research in Europe. More info: www.ebra.eu/trisomy21

The BRAINFOOD cluster is led by Prof. R. Adan and Prof. S. Dickson and their overarching objective is to ultimately positively impact on brain health by improving nutrition of European citizens based upon fundamental insights in the bidirectional links between brain health and nutrition. More info: www.ebra.eu/brainfood

Cluster Activities

In total, 3 cluster activities were organised in 2020.

On June 17th, the leadership of EPICLUSTER held their first meeting. The aim was to bring together the leadership, hear from them about the organisations (including the International League against Epilepsy - ILAE, International Bureau for Epilepsy - IBE, Epilepsy Alliance Europe - EAE and Lancet Comm) and projects (i.e., EpimRNA, DESIRE, EPI-STOP, EPI-TARGET, EPI-PGX, EpiXchange, EpiCARE) and discuss the originally planned actions and priorities. EPICLUSTER also engaged with external stakeholders including relevant EU-projects (Epi25, Solve-RD, EuroEPINOMICS, EpiEpiNet, ECMED), data and ethics (QUEST center), research infrastructures (HBP/EBRAINS), the patients and carers perspective and industry (UCB). Together, they co-created the priorities in the epilepsy field. Each participant was enthusiastic to partner with EPICLUSTER and contribute to success.

On November 12th, TRISOMY21- CLUSTER held the first meeting. The focus of the meeting was to bring together the leadership of the TRISOMY21-cluster and a number of relevant stakeholders, from funding agencies to patient organisations and industry, to discuss priorities and opportunities for Down syndrome research and liaise with industry partners and patient representatives. During the meeting, consensus was built on research needs in the short and long term, and main objectives and priorities for action.

¹ A cluster is understood as an association of research projects or research community that can be directed towards basic research, clinical research and/or methodological approaches under a common topic and disease area.

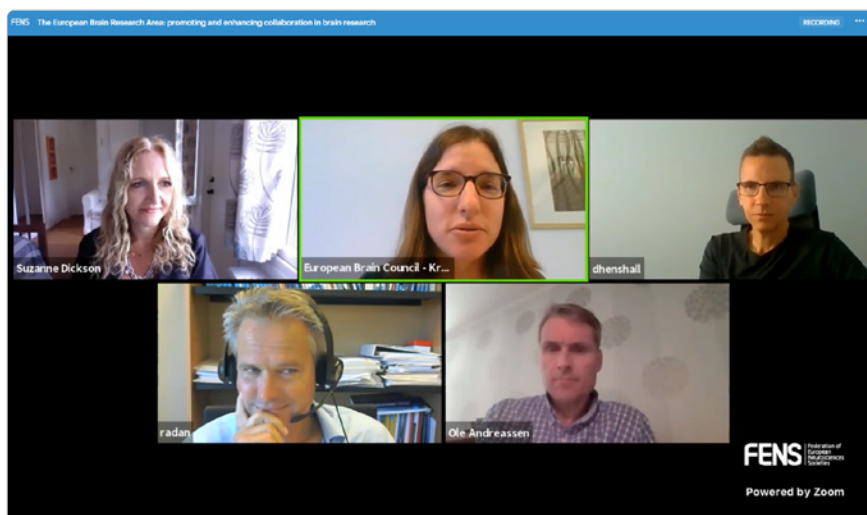
On December 1st and 2nd, EPICLUSTER's second activity took place. On the first day, the EPICLUSTER leadership and wider stakeholder group met for a workshop on funding. On the second day, EPICLUSTER organised and ran EpiXchange II, a community-building meeting based on the format of EpiXchange I (2018). The meeting brought together various FP7 and Horizon 2020 epilepsy projects with stakeholders to review progress and future directions in key research areas including genetics, biomarkers, therapeutics, co-morbidities and biobanks/resources.

More info: www.ebra.eu/existing-clusters

EBRA goes global

EBRA participated in several international events and conferences. EBRA was featured in July 2020 during a Special Interest Session at the FENS Forum on Global Brain Research Collaboration, organised by the European Brain Council, and in September 2020 during a "Science Digital @ UNGA75" side session on Global Collaboration in Science. In October 2020, EBRA was presented to the International Brain Initiative and continues to be active in its communications and in the establishment of international ties. EBRA was presented as a poster and/or oral presentation during the HBP Summit in February 2020, the EAN congress in May 2020 and the ECNP Congress in September 2020. Furthermore, EBRA was also showcased via the European Brain Council exhibition stands at the following congresses: HBP Summit, EPA Congress, EAN Congress, FENS Forum and ECNP Congress 2020.

More info: www.ebra.eu/news-events



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www.EBRA.eu

EU-Funded Projects



The “AD Detect and Prevent” (ADDP) project is pursuing the ambitious aim of developing a digital tool to improve the detection of Alzheimer’s disease (AD) prior to the possible onset of AD dementia. This novel digital tool will subsequently provide personalised intervention programmes aimed at addressing lifestyle-related risk factors connected to AD dementia. The consortium consists of Brain+, University of Oxford, Aarhus University, University of Nottingham, Alzheimer Europe and EBC.

The AD Detect and Prevent tool is designed to be user-friendly and easily accessible and will be delivered on various types of devices such as tablets and smartphones. This digital solution will be initially launched in Denmark and the United Kingdom but the consortium hopes to expand the tool to other European countries.

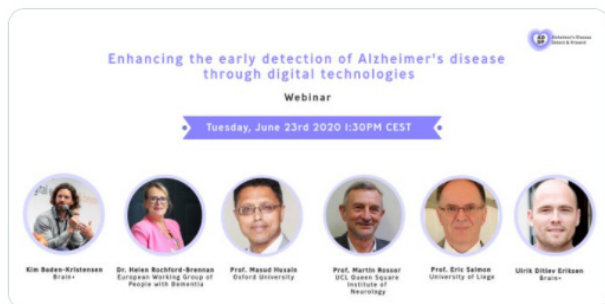
EBC is closely involved in Work Package 5, “Market launch in DK & UK, secure Key Opinion Leader (KOL) endorsement and disseminate results”, supporting the outreach and dissemination activities launched within the framework of the project.



Alzheimer's Disease Detect and Prevent
@addp_eu

ADDP held its first webinar in June, focused on “Enhancing the early detection of #Alzheimers through digital #technologies”, with leading experts discussed opportunities & challenges of #digital solutions.

The full webinar report is available now bit.ly/3krKZFE



@addp_eu



www.linkedin.com/company/addp-eu



www.addp.eu

EU-Funded Projects



In January 2020, EBC joined the EU-funded project: Prevention and Remediation of Insulin Multimorbidity in Europe (PRIME). PRIME is a European consortium of research institutes, medical centres, companies and societal stakeholders. From 2020 – 2024, PRIME will aim to unravel the insulin-dependent mechanisms that underly both somatic conditions (i.e., type 2 diabetes, obesity, metabolic syndrome) and brain disorders (i.e., Alzheimer's disease, obsessive-compulsive disorder, autism spectrum disorders). EBC is involved in carrying out dissemination activities to enhance awareness of insulin-related multimorbidity amongst the legislative, medical, scientific and patient communities.



 @PRIME_H2020

 PRIME Horizon2020

 www.prime-study.eu

REINVENTING THE WHEEL

Digitalisation of Advocacy & Awareness



ADVOCACY & OUTREACH

COVID-19

COVID-19 brought unprecedented changes to everyone across the world, including EBC. Alongside being forced to change our day-to-day functioning, the brain community was also affected in multiple ways, directly and indirectly.

What was clear from the start of the pandemic in March 2020 was the importance of robust health systems and well-funded research and innovation. European health systems were caught off-guard by the pandemic, with hospitals struggling to accommodate vital ICU admissions, Member States grappling for supplies and all non-COVID services brought to a standstill.

Chronic illnesses faced deprioritisation in the face of this emergency, with potential repercussions that could impact the longer term running of hospitals and treatment for patients. Priorities were shifted, particularly within hospitals, to be able to accommodate the sudden increase of patients and many hospital departments – both neurological and psychiatric – saw massive cuts in the ability to see patients, with treatment such as non-emergency surgeries, chemotherapy, diabetes treatment and more interrupted and deemed non-priorities.

If COVID-19 has taught us anything, it is that, as a society, we are not yet fully prepared nor capable to tackle the majority of health epidemics we are currently facing or will potentially face in the coming future. [EBC published a lessons-learned piece by President, Prof. Monica Di Luca, in April 2020.](#)

Furthermore, EBC also led [a call](#) with its Member Organisations to the European Commission's Directorate-General for Research and Innovation requesting to postpone the current deadline of all open Horizon 2020 calls by at least 2 months due to the pandemic. This call was echoed by many other research groups across the EU and was inevitably [granted by the European Commission](#).

As the year went on and more information was released about COVID-19 as well as its impact on the brain community, EBC made sure to keep an updated [resource for all brain-related information](#), which included informative resources and surveys/consultations from EBC Members and the wider community.



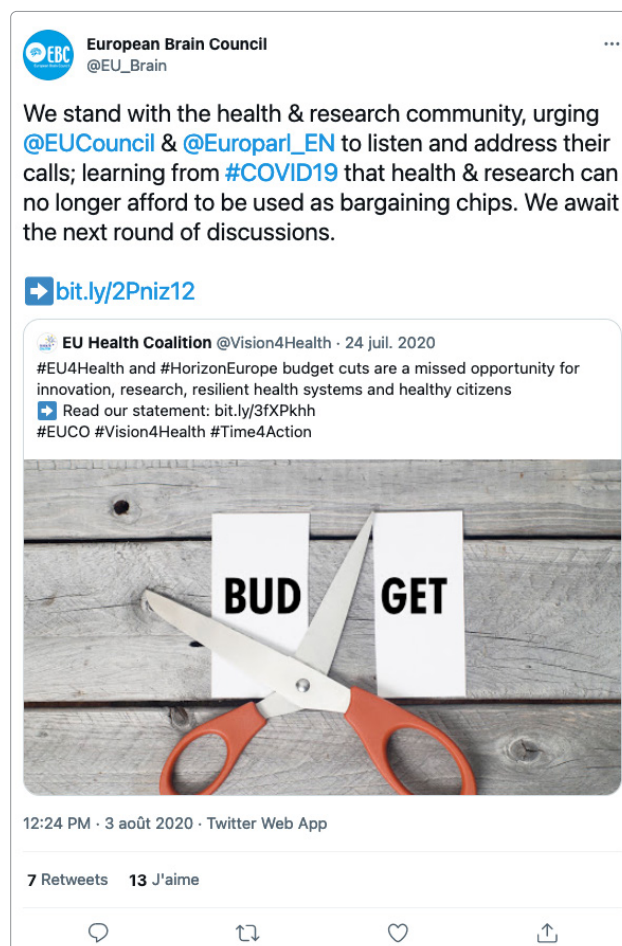
Brain-related COVID-19
surveys and resources

EU Budget & Horizon Europe

EBC's engagement and advocacy work around the European Commission's 2021-2027 funding programme for research and innovation, Horizon Europe, continued in its final stages of planning and establishment.

In August 2020, EBC provided [feedback](#) and input to the European Commission on the draft of the "First Horizon Europe Work Programme 2021-2022 of the Health Cluster". An overarching first response to the draft Work Programme was composed, representing the views of the brain research community as a whole.

Furthermore, throughout 2020, EBC continued to follow the ongoing discussions on the EU Budget 2021-2027, particularly around its impact on health and research funding. The year brought many ups and downs in the discussion as health, in particular, saw increases and decreases in funding across the negotiation process due, in part, to the lessons learned from the ongoing COVID-19 pandemic.



75th United Nations General Assembly

In September 2020, EBC was invited to host two side sessions at sciencedigital@UNGA75, a series of virtual side events within the context of the 75th United Nations General Assembly (UNGA75). The central theme of these activities was fostering awareness of the role and contribution of science and digital technologies to the attainment of the United Nations Sustainable Development Goals (SDGs).

Science infrastructures and digital research capacity building are crucial to enable scientists to collaborate at global level to create opportunities for wide-ranging initiatives that can produce innovations to address challenges in the area of health, climate, environment, energy, agriculture and food, amongst a range of other objectives.

EBC was pleased to host the following sessions:

The Potentials of Increased Collaboration in Science: examples from the brain community

Enhancing global collaboration in the domain of research and innovation is key for effectively addressing today's societal challenges and improving the health and well-being of citizens. This is particularly true for brain disorders, including both neurological and mental conditions, which are widespread and highly disabling diseases that are often difficult to treat. This session explored how global research collaboration can support brain research in a meaningful way, to the benefit of patients across the globe, and gathered voices from across the world to showcase their international partnerships and the importance of building and fostering international connections in science, with insight from the European Union, North America, Asia, Oceania, Africa as well as international organisations.

Do the SDGs address the global burden of disease? A focus on regional health and research policies

This session was co-organised with the European Federation of Neurological Associations (EFNA). Brain disorders, neurological and mental alike, have the highest disease burden. Neurological disorders alone are the leading cause of disability-adjusted life years (DALYs) and second leading cause of deaths worldwide, affecting one in three people. The leading cause of DALYs by 2030 is projected to be unipolar depressive disorders. Thus, global momentum to address the threat posed by brain disorders is increasing. In 2018 mental and neurological disorders were added by world leaders to the list of priority non-communicable diseases. In 2019, WHO established a "Brain Health" team. In 2020 WHO Member States requested a resolution on Epilepsy and other neurological disorders that can lead to a global action plan. However, the existing high-level commitments, such as Sustainable Development Goals and Universal Health Coverage, have not afforded brain conditions the political priority that they require and fall short on tangible global commitments to reduce their burden. Strategic linkages to these high-level commitments therefore need to be built, laying out a strong foundation for an integrated and all-encompassing approach to brain health. This session featured neurological experts/clinicians, patient representatives and representatives from the WHO.

Read [full event report](#).

Follow live coverage on [Session 1](#) and [Session 2](#).

Visibility

Awareness raising days

Every year a number of awareness-raising days take place across the world, many concentrated in the brain area, neurological and mental alike. These days were created with the intention of dedicating one full day or week to a certain topic, such as a specific disease, in order to reach as many stakeholders as possible with information and calls for action. EBC ensures to join in the support of as many brain-related awareness days as possible through its social media channels, always addressing the major days by sharing information (and resources) on the topic and any relevant EBC work. These are a number of days/weeks EBC highlighted last year:

World Autism Awareness Day

We joined in raising awareness on autism spectrum disorder (ASD), a complex neuro-developmental condition affecting brain development and behaviour, on the occasion of [World Autism Awareness Day](#) on **2 April 2020**. ASD is one of the [Value of Treatment 2](#) case studies focused on mental disorders (MDs).

World Parkinson's Day

For [World Parkinson's Day](#) on **11 April 2020**, the Parkinson's community came together to share their experiences. Approximately 1.25 million people are affected in Europe and the figure is expected to double within the next 20 years. EBC is deeply committed to the prioritisation of research for Parkinson's Disease (PD) and created its first Science & Society video to highlight that. Furthermore, PD was also part of the [1st round of the Value of Treatment project](#).

Huntington's Disease

EBC joined a social media initiative #LetsTalkAboutHD during [Huntington's Disease Awareness Month](#) in **May** to raise awareness about this rare, hereditary, degenerative disorder of the brain that was first described by George Huntington in 1872.

World Schizophrenia Day

[World Schizophrenia Day](#) is commemorated on **24 May** to increase awareness about the disorder and educate people about the challenges faced by people living with schizophrenia, affecting around 20 million worldwide.

World Multiple Sclerosis Day

[World Multiple Sclerosis \(MS\) Day](#) takes place on **30 May** every year. The 2020-2022 World MS Day theme is 'connections'. MS Connections is all about building community connection, self-connection and connections to quality care. EBC joined the world MS community by raising awareness for this chronic condition on social media and challenging social barriers that leave people affected by MS feeling lonely and socially isolated.

International Phenylketonuria Day

EBC celebrated [International Phenylketonuria \(PKU\) Day](#) on **28 June 2020**. This inherited metabolic disorder affecting about 1 in every 10,000 children born in Europe was one of the case studies of [the second round of the Value of Treatment project](#).

World Brain Day

The brain is not only the engine of our bodies but a great contributor to history, through inventions and great ideas. Taking care of our brain means living in a better body and in a better world. EBC and the [Brain Innovation Days community](#) celebrated our most amazing organ on [World Brain Day](#), which takes place every year on **22 July**.

International Ataxia Awareness Day

Ataxia is a rare disease with symptoms that worsen over time, affecting a person's ability to walk, talk, and use fine motor skills. On the occasion of [International Ataxia Awareness Day](#) on **25 September**, we joined the coordinated effort from individuals and ataxia organisations around the world to help shed light on this rare disease. Ataxia was part of the case studies on Rare Neurological Disorders (RNDs) conducted in the framework on [the second round of the Value of Treatment project](#).

World Mental Health Day

The goal of the [World Mental Health Day](#) campaign on **10 October 2020**, was to encourage increased investment in mental health. Supporting mental health programmes at the national and international levels is now more important than ever. We joined the global mental health community in raising awareness for this cause.

International Stress Awareness Week

[International Stress Awareness Week](#) (**2-6 November 2020**) was created in 2018 to raise awareness about stress prevention, following the establishment of Stress Awareness Day in 1998. EBC joined the community by raising awareness of stress and mental health problems which have never been more important than in the wake of the COVID-19 pandemic.

Awareness Week on Alcohol Related Harm

EBC is one of the official partners of the [Awareness Week on Alcohol Related Harm](#), initiated in 2013 by a group of like-minded organisations following three roundtable meetings on an integrated approach to alcohol-related harm. The 8th edition was held on **16-20 November 2020** under the theme "Alcohol & Cancer". The aim of the week was to raise awareness among EU policymakers of the harms caused by alcohol, to increase awareness of the need to address alcohol-related harm in Europe and highlight the need to address it through an integrated approach to alcohol policy.



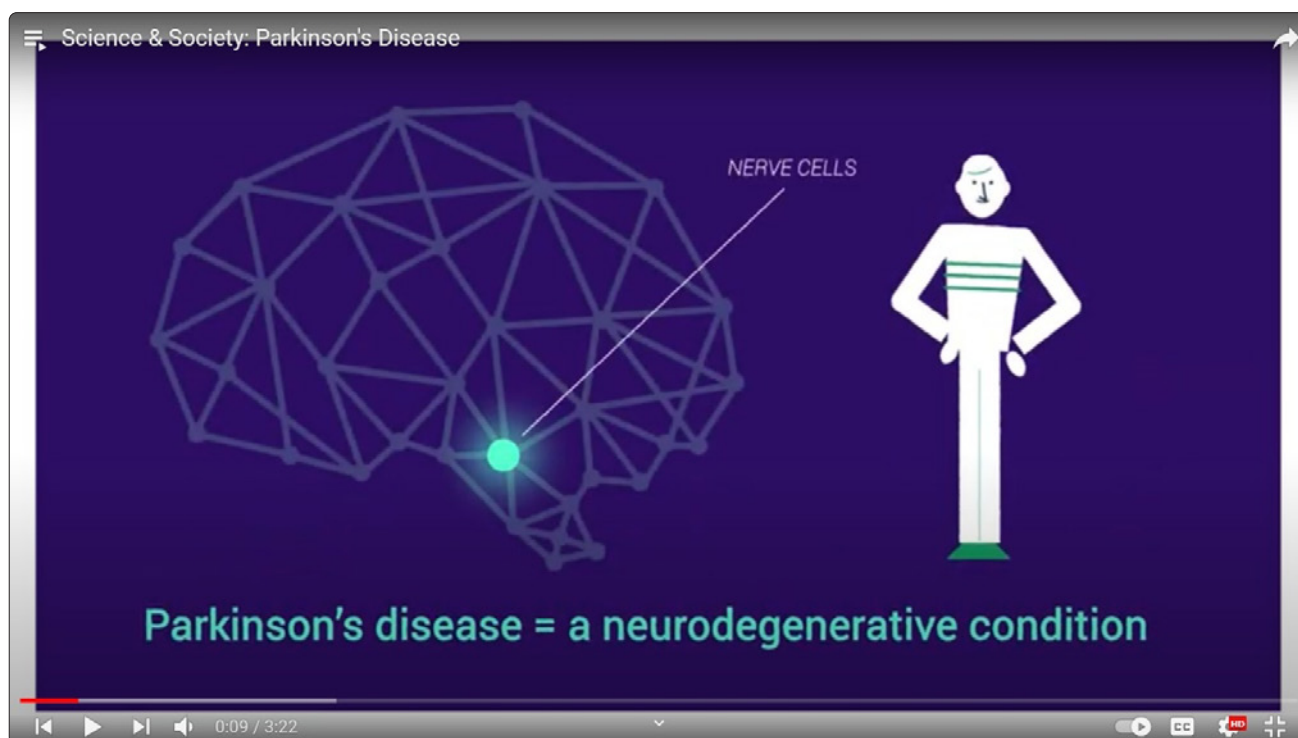
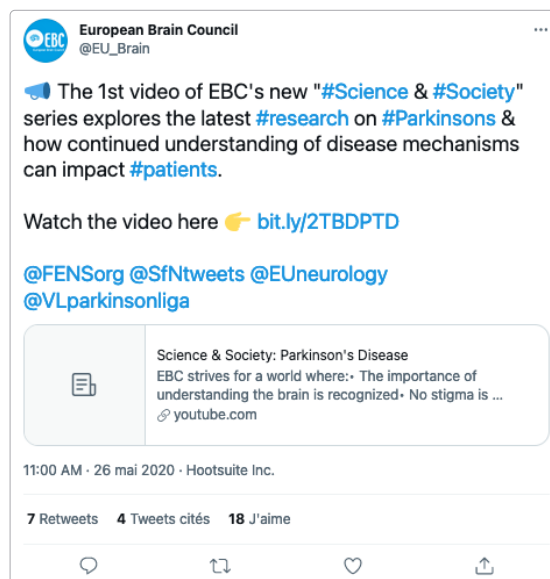
Science & Society videos

Disease awareness and understanding of not only what it is but what people are living with is a lacking knowledge to the majority of society. With a large existence of health conditions and growing prevalence of most, knowledge is easily diluted.

In this regard, EBC launched a new video series, "Science and Society", to raise awareness of brain disorders and for those living with these conditions. Furthermore, the videos aim to build a stronger voice for basic neuroscience and the research that goes on "behind the scenes" to learn more about the underlying causes for different brain disorders and their treatments, as well as the research that is conducted to gain insight on the mechanisms behind the disease.

The "Science and Society" videos are supported by experts and patients in the chosen field, the Federation of European Neuroscience Societies (FENS) and the Society for Neuroscience (SfN).

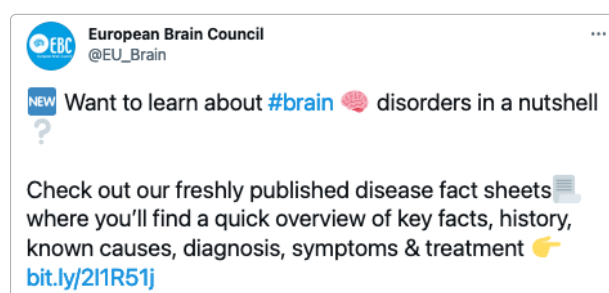
This first video in the series explores [Parkinson's disease](#), which is estimated to affect around 10 million people worldwide.



Disease factsheets

EBC was very pleased to announce the launch of updated [disease fact sheets](#), providing a quick overview of key facts, history, known causes, diagnosis, symptoms and treatment of brain disorders – neurological and mental alike.

Information contained in these fact sheets, developed with the help of experts for specific brain conditions, is intended for a wider general audience in search of useful information about brain conditions. These fact sheets fall under the #ILoveMyBrain campaign, which was created by EBC to promote and communicate brain health and ongoing efforts to prevent and treat brain disorders in Europe. The ultimate goal of the campaign is to gain more attention for brain disorders from EU policymakers and the general public, and ensure that more resources are channelled towards research on the brain and for patients of brain disorders.



Collaboration

Scientific Congresses

EAN Congress

EBC was present at the 6th Congress of the **European Academy of Neurology**. The Congress was held online and EBC was pleased to be able to participate with a virtual booth as well in the Scientific Theatre and the Special Session.

In the [Scientific Theatre](#) EBC was able to coordinate the presentation of two of its current major projects, EBRA and RETHINKING MS.

As project coordinators, EBC [presented](#) EBRA providing a general introduction of the project and discussing how fragmentation in both funding and research can be reduced. RETHINKING MS was presented by Vinciane Quoidbach, EBC Research Project Manager.

Lastly, EBC was invited to speak at the Special Session on "[Severely affected patients in neurology and psychiatry: Detecting – Managing – Refining](#)". The session was chaired by Ms. Joke Jaarsma, President of the European Federation of Neurological Associations (EFNA) and Treasurer of EBC. Speakers included David B. Vodusek, European Academy of Neurology, Philip Gorwood, European Psychiatric Association, and Bruno Dubois, Salpêtrière University Hospital.

Room Seville
08:00 - 09:30

European Brain Council: Severe patients in neurology and psychiatry: Detecting - Managing - Refining



Bruno Dubois
An integrated approach for managing severe patients living with brain disorders

ean congress virtual 2020

Room Seville
08:00 - 09:30

European Brain Council: Severe patients in neurology and psychiatry: Detecting - Managing - Refining

Engagement EU institutions



Joke Jaarsma
Introduction

David B. Vodusek
The Perspective of Neurology

Philip Gorwood
Similarities in Psychiatry

Bruno Dubois
An integrated approach for managing severe patients living with...

Frédéric Destrebecq
Open discussion

Joke Jaarsma
Wrap-up

ean congress virtual 2020

EPA Congress

During the **28th European Congress of Psychiatry**, held online by EPA (European Psychiatric Association) on 4-7 July 2020, EBC together with EPA and GAMIAN-Europe held a [workshop](#) on «The Value of Treatment for Eating Disorders: A Joint EPA & EBC Project» chaired by Professors Janet Treasure and Palmiero Monteleone. EBC was pleased to welcome Eva Bonin, London School of Economics, Umberto Volpe, Marche Polytechnic University, Fernando Fernandez-Aranda, University Hospital Bellvitge-IDIBELL and CIBERObn, Philip A. Gorwood, Sainte-Anne Hospital, Miia Männikkö EUFAMI as speakers of the workshop.

The EPA meeting was adapted to a fully virtual congress, offering the mental health community the possibility for educational exchanges, scientific news and best practice updates.

The EBC virtual booth displayed an EBRA and EBC brochure, as well as the Value of Treatment reports.



FENS Forum

The bi-annual **Federation of European Neuroscience Society** (FENS) Forum, the largest international neuroscience meeting in Europe, was held on 11-15 July 2020. EBC virtual booth hosted links and digital content (like video, digital brochures, etc.) for EBRA and EBC.

Due to the COVID-19 outbreak, the FENS Forum was held entirely virtually, making it accessible from all over the world and giving access to all sessions, lectures, events and the exhibition hall up to three months afterwards. In this context, EBC organised a series of activities within the Forum, particularly on the topic of Global Brain Research Collaboration on 13 July, highlighting the importance of creating partnerships within research, with a focus on brain research.



EBC held a Special Interest Event on “[Global Brain Research Collaboration](#)”, featuring the global perspective as well as EU, USA and China - with presentations from Prof. Tracy Bale, IBRO, and Prof. Mhamed Hassan, President of World Academy of Sciences. Representatives from all over the world shared their ways to enable international collaboration in research. EBC widely communicated about the session, including [live tweeting](#) during the event. In this context, Carlos Morais Pires, Cabinet Member of Commissioner Mariya Gabriel, shared his [message](#) on the future of brain research in Europe.

The Special Interest Event on “[Neuroscience Research Funding in Europe Post-COVID-19](#)” communicated insights and experience on advocacy activities for neuroscience policy and funding in Europe.

SiE15 at FENS Virtual Forum

Research Funding in Europe post COVID-19

- Monica Di Luca, Chair of European Brain Council & University of Milan
- Camilla Bellone, Society for Neuroscience (SfN) Policy and Advocacy & University of Geneva
- Karim Berkouk, DG Research & Innovation, European Commission
- Mark Ferguson, European Innovation Council & Science Foundation Ireland
- Moderator: Tomás Ryan, FENS-Kavli Network & Trinity College Dublin

www.fens.org/2020

15 JULY 2020 9:30-10:30 AM BST

Finally, EBC held an EBRA dedicated session on “The European Brain Research Area: Promoting and enhancing collaboration in brain research” to share more information on the work and developments of the clusters.

ECNP Congress

EBC was present at the **33rd ECNP Virtual Congress** with its virtual booth for the entire duration of the event. EBC showcased the EBRA and the Value of Treatments projects and was able to present an e-poster on the EBRA project.

Joint statement on making cancer-related complications and comorbidities an EU health priority

EBC joined like-minded European health organisations in signing a joint statement calling for making cancer-related complications and comorbidities an EU health priority.

Cancer-related complications and comorbidities – many neurological or psychiatric – are a highly significant, and in many cases fatal burden on patients across Europe but are all too often neglected in policy and research.

Cancer has become a top health priority for the next five years in the EU. The statement called for increased attention for cancer patients' long-term well-being and quality of life, addressing the often-debilitating comorbidities and complications of cancer, both in terms of the disease itself and its treatments.

Read the full statement [here](#).

Brain Health as a Global Priority – time for the EU to act now

The global momentum to deliver a more coordinated response to the threat posed by neurological disorders is increasing. At the global stage it also became clear that there is a push for bringing mental health and neurology under one umbrella of brain health. To capitalise on this global prioritisation, EFNA, the European Academy of Neurology and EBC organised a meeting at the European Parliament on February 18th. The meeting was entitled: "Brain Health as a Global Priority – time for the EU to act now".

The meeting heard the latest statistics from the Global Burden of Disease Study, highlighting how neurological disorders are the leading cause of disability worldwide, and the second leading cause of death. Other presenters highlighted the global trends mentioned above, and how these could be leveraged at EU level. Some concrete examples from the field were also discussed; including successful global advocacy work on epilepsy and national efforts to create a Norwegian Brain Plan.

The event made for a clear and strong signal to EU policy makers that our efforts need to be urgently stepped up. The event's co-patron and Vice-President of the Parliament Ms. Ewa Kopacz said "We need to act fast and we need to act together!" High-level representatives from the European Parliament, European Commission and EU Presidencies also reiterated opportunities for this international activity to be reflected in EU initiatives.

Read the full event report [here](#).

Position statement on the issue of triage of patients in the context of access to intensive care services during the COVID-19 pandemic

EBC endorsed Alzheimer Europe's calling for caution and sound ethical principles in the current triage guidelines, which would exclude people with dementia from life-saving access to ventilators during the COVID-19 pandemic.

Alzheimer Europe emphasised its commitment to a human rights based approach to dementia and its firm belief that after diagnosis, people with dementia can live many years of meaningful existence with a high quality of life. A diagnosis of dementia on its own should therefore never be a reason to refuse people access to treatment, care and support.

Read the full statement [here](#).

Call for support for Medical Societies during COVID-19 pandemic

EBC supported a BioMed Alliance statement and a letter to Commission President Ursula von der Leyen calling for support for medical and research societies to ensure continued guidance for healthcare professionals during the COVID-19 pandemic.

Read the full letter and statement [here](#).



Biomedical Alliance in Europe

Calls for increased support for medical & research societies to ensure continued guidance for healthcare professionals, now and in the future



Societies support health professionals and researchers during the current COVID19 Crisis, e.g. by issuing guidelines and releasing relevant clinical evidence.



As they cancel medical congresses and other activities, their mission and source of income are threatened. Urgent support is necessary to allow them to continue fulfilling their purpose.

Call for increased prioritisation of neurological health

EBC gave its support to a letter penned by EFNA, together with the European Academy of Neurology (EAN) and neurology advocacy groups from across Europe, calling on the European Commission to acknowledge the full burden of neurological disorders and to take concrete steps to fully integrate neurological health into its main priority areas in the field of noncommunicable diseases (NCDs).

Read the full letter [here](#).



COVID-19 and Brexit – Protecting patients across Europe from pandemics

EBC was part of a group of stakeholders endorsing a statement on “COVID-19 and Brexit – Protecting patients across Europe from pandemics” which highlights the importance of addressing health issues as part of the agreement on the future relationship between the EU and the UK.

The COVID-19 pandemic has demonstrated that cross-border health threats need effective coordination and brought to the forefront issues such as shortages and unequal access to medicines and personal protective equipment (PPE), the importance of global supply chains and the negative effects of export bans, stockpiling requirements and other restrictions.

The full statement can be read [here](#).

EBC echoes EU Health Coalition statement on budget negotiations

EBC, as part of the EU Health Coalition, joined in expressing regret on the initial outcome of the European Council, where health, research and innovation were sacrificed in the overall budget negotiations.

The statement urged the Council to listen to the calls from the community and the European Parliament to address these cuts, learning from the current COVID-19 pandemic that health and research can no longer afford to be used as bargaining chips.

Read the full statement [here](#).

Joint event on Neurological diseases: Lessons learnt from COVID and the future of neuroscience

EBC was pleased to co-organise with EFNA and EFPIA a virtual event “Neurological diseases: Lessons learnt from COVID and the future of neuroscience” on 28 September 2020.

The discussion was centred around access to care, treatments and trustworthy information, which were very difficult during the first wave of the COVID-19 pandemic. It posed important questions such as: how has this impacted the community of patients with neurological diseases? What can we learn from their experience? How can industry and patient organisations work better together to find solutions and in the longer run: how will the future of neuroscience look like?

More information [here](#).

The future of brain health innovation in Europe

EBC was pleased to be invited to speak at an Incisive Health Breakfast Club, where Executive Director Frédéric Destrebecq spoke on the future of brain health innovation in Europe.

Follow the discussion [here](#).

The future of brain health in Europe

with Frédéric Destrebecq, European Brain Council

Virtual meeting

• Thursday 17 September 2020, 8:30 – 9:30am CET •

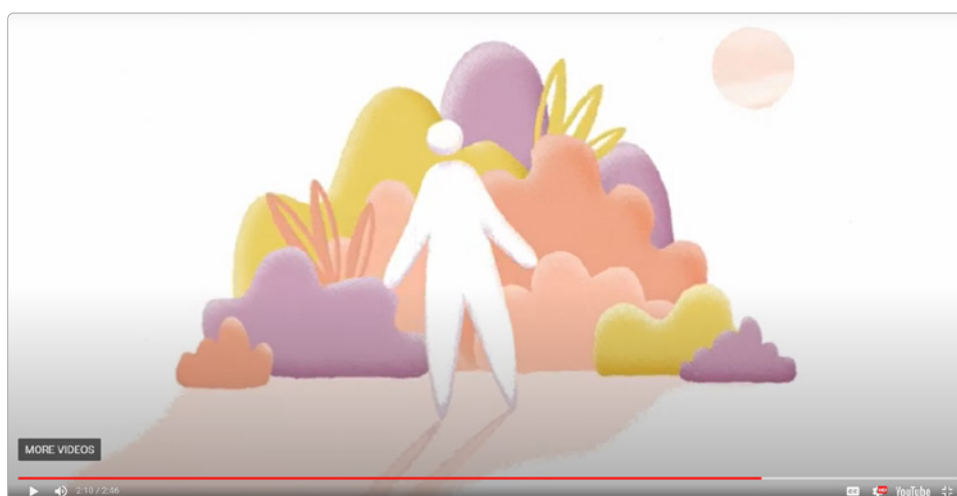


Launch of 'Words to Action' video on depression

The Words to Actions initiative began in 2018, when nine organisations working in mental health across Europe – including EBC – came together to develop and publish a policy report, [A sustainable approach to depression: moving from words to actions](#).

In 2020, the [@WTA_initiative](#) Twitter account was launched to promote the initiative on social media. Words to Actions released an animated video alongside a series of digital posters and a Twitter campaign highlighting four overarching themes related to managing depression. The content was based on the original policy report.

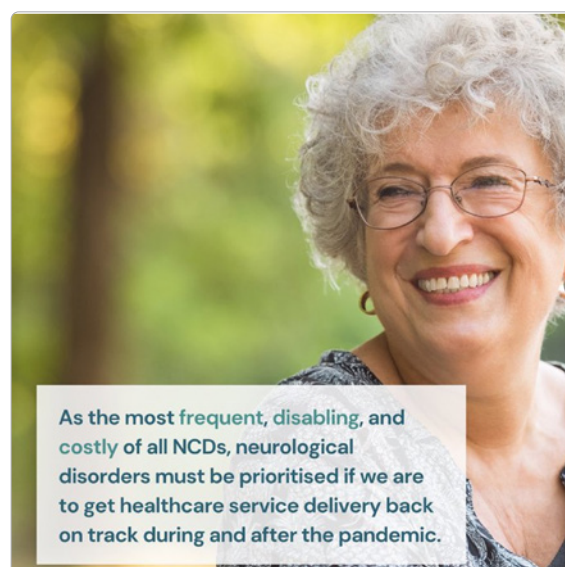
View the animated video [here](#).



World Health Assembly campaign led by EFNA

EBC joined EFNA in its efforts to campaign to promote the cause of neurology, raise the visibility of neurological issues and call for support of neurology within Resolution 68.20 on Global Action on Epilepsy and Its Synergies with Other Neurological Disorders at the World Health Assembly, the decision-making body of WHO.

The online campaign – which included infographics and videos – informed that neurological disorders have the highest prevalence, biggest disability and greatest cost among NCDs; but decision-makers have traditionally been looking away. With the continued rapid growth of these numbers, clearly the investment in care and research does not match the soaring burden. It reminded that we need to work together to help prioritise neurological health and develop neurological action-plans to future-proof our healthcare systems and bring hope and solutions to people with neurological disorders across the world.



WORKING TOGETHER

(through Zoom, Teams et al)



EBC MEMBERS & PARTNERS

Full Members

The **European Federation of Neurological Associations** (EFNA) brings together European umbrella organisations neurological patient advocacy groups, to work with other associations in the field of neurology and advocate for better quality of life for people in Europe living with a neurological disorder.



👁 www.efna.net 🐦 @EUneurology

GAMIAN-Europe represents a coalition of patient organisations, placing the patient at the centre of all issues of the EU healthcare debate. The organisation aims to bring together and support the development and policy influencing capacity of local, regional and national organisations active in the field of mental health.



👁 www.gamian.eu 🐦 @GamianE

The **Pan European Regional Committee** (PERC) of the **International Brain Research Organization** (IBRO) is a global organization resulting from the union of neuroscience organizations with the aim to promote and support neuroscience training and collaborative research around the world. The IBRO-PERC is a Pan European Regional Committee supporting the IBRO mission and helping to plan and implement IBRO activities in Europe. In the last few years, IBRO-PERC has established collaborations with European organizations to promote neuroscience in Europe at all levels, including the training of the next generation of European neuroscientists as well as stimulation of using scientific knowledge to develop and improve treatments of disease.



👁 www.ibro.org 🐦 @ibroSecretariat

Full Members

FENS, the **Federation of European Neuroscience Societies**, is the main voice of European neuroscience, representing close to 23,000 European neuroscientists from over 30 European countries. FENS promotes excellence in neuroscience research and neuroscience research to policy-makers, funding bodies and the general public, both regionally and internationally, and facilitates the exchange between neuroscientists within the European Research Area and beyond.



👁 www.fens.org 🐦 @FENSorg

EPA, the **European Psychiatric Association**, deals with psychiatry and its related disciplines with a focus on the improvement of care for the mentally ill as well as on the development of professional excellence. Representing over 78,000 European psychiatrists, EPA is the main association representing psychiatry in Europe.



EUROPEAN PSYCHIATRIC ASSOCIATION

👁 www.europsy.net 🐦 @Euro_Psychiatry

The **European College of Neuropharmacology** was established at the instigation of European scientists to encourage research and facilitate exchange in the convergent disciplines of neuropsychopharmacology. ECNP is committed to ensuring that advances in the understanding of brain function and human behaviour are translated into better treatments and enhanced public health.



👁 www.ecnp.eu 🐦 @ECNPtweets

The **European Academy of Neurology** (EAN) is a non-profit organisation that unites and supports neurologists across the whole of Europe. EAN is a society of national neurological societies and at the same time a society of individual members. The purpose of EAN is to promote "Excellence in Neurology in Europe". Currently, 45 European national neurological societies as well as 800 individuals are registered members of the EAN. Thus, the EAN represents more than 20,000 European neurologists.



👁 www.ean.org 🐦 @EANeurology

Full Members

The **European Association of Neurosurgical Societies** (EANS) is an independent, supranational association of national European neurosurgical societies and individual members. The EANS network has 40 National Member Societies from the European regions, as well as over 2000 Individual Members around the globe. The society's main aim is to enable its members to enhance the care they deliver to their patients by facilitating the exchange of scientific information at the highest level.

👁 www.eans.org 🐦 @eansonline



THE EUROPEAN ASSOCIATION
OF NEUROSURGICAL SOCIETIES

The **European Paediatric Neurology Society** (EPNS)* is a society for physicians with a research or clinical interest in Paediatric Neurology. With more than 1,500 members, the EPNS is a thriving and growing society which continues to play an important role in and beyond Europe by promoting training, clinical care and scientific research in the field of Paediatric Neurology.

👁 www.epns.info 🐦 @EPNSnews



**Joined as Full Member in 2021*

Associate Members

The **European Chapter** is one out of five chapters of the **International Federation of Clinical Neurophysiology**. It encompasses at present 35 European and African member societies. The Chapter is represented by an Executive Board and the delegates of each Member Society.

👁 www.ifcn.info 🐦 @IntFedCNP



The **European Federation of Associations of Families of People with Mental Illness** (EUFAMI) has an ongoing commitment to improve care and welfare for people affected by mental illness. EUFAMI has a number of programmes supporting people affected by severe mental illness and the organisations representing them across Europe.

👁 www.eufami.org 🐦 @EUFAMI



The **European Stroke Organisation** (ESO) is a pan-European society of stroke researchers and physicians, national and regional stroke societies and lay organisations that was founded in December 2007. Their aim is to reduce the incidence and impact of stroke by changing the ways that stroke is viewed and treated.

👁 www.eso-stroke.org 🐦 @ESOstroke



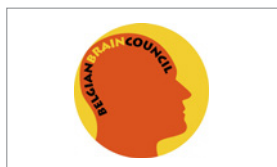
The **European Sleep Research Society** (ESRS)* is an international scientific non-profit organisation that promotes research on sleep and related areas, to improve the care for patients with sleep disorders and to facilitate the dissemination of information regarding sleep research and sleep medicine.

👁 www.esrs.eu 🐦 @ESRS_Sleep



**EBC Member as of 1 January 2020*

National Brain Councils



Belgium



Bulgaria



Croatia



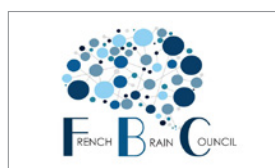
Czech Republic



The Netherlands



Finland



France



Germany



Hungary



Ireland



Luxembourg



Norway



Poland



Portugal



Serbia



Slovenia



Spain

Industry Partners



MEMBERS' HIGHLIGHTS

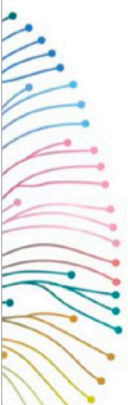
6th NBCs Academy (Event Report)

On the 29th September 2020, the National Brain Councils active in the “Share4Brain” EU project (Erasmus+) organised a virtual session for the [6th National Brain Councils](#) with the auspices of the European Brain Council.

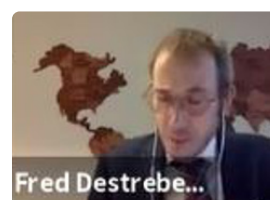
Monica Di Luca, EBC President, talked about the challenges that the EU will face to combat the rapid expansion of brain diseases. Frédéric Destrebecq, EBC Executive Director, had the opportunity to emphasise the importance of acting also at national level to involve stakeholders in the creation and adoption of national brain plans. The webinar saw the launch of the new Hellenic Brain Council presented by Christina Dalla from the National and Kapodistrian University of Athens, Greece.



Benefits & Challenges



- Strengthening synergies between EBC and the NBCs
 - *Bottom-up vs Top down*
- Creating impact at national level
 - *Adopting & Implementing National Brain Plans*
- Limited organizational capabilities and/or resources (human & financial)
- Need for support to advocacy



European Federation of Neurological Associations (EFNA)

A new direction

In the early part of 2020, governance and strategy took a front seat for EFNA, with work underway on an updated Constitution to ensure full compliance with new Belgian legislation. This coincided with the creation of EFNA's new [Strategic Plan 2020-2025](#), which was approved by a virtual meeting of our General Assembly in May.

EFNA organised [two webinars on the topic of COVID-19](#), the first exploring the impact of COVID on the neurology community and the second focusing on how we can advocate to ensure the challenges and opportunities faced by our members are addressed. These high-level webinars included representatives from the World Health Organisation, European Commission and well-known advocacy groups. EFNA is the only patient organisation represented at the global Neuro-COVID Forum of the World Health Organisation and is actively participating in the working group on the continuation of essential services. We have also been working with our colleagues at the European Academy of Neurology to capture the views of our members of the impact of COVID-19 via surveys.

Raising awareness

Our [#BrainLifeGoals awareness campaign](#) continued this year. The focus in 2020 has been 'Stigma' and during Brain Awareness Week in March we [launched a major survey](#) to identify how and when the neurology patient community experiences stigma. With over 1,300 responses, this eye-opening survey will inform our work on this topic in the years to come. Following on from the survey results, we launched a call to collect examples of best practice in 'Action on Stigma'. Selected projects will receive the EFNA Advocacy Award in 2021!

As part of the campaign, EFNA's [#BrainLifeGoals grants scheme](#) saw 10 projects receive funds of €3,000 each to support their work on the topic of 'access'.

We announced the [winners of our Photo Competition](#) in January and, to finish the year, launched an [Art Competition](#) on the #BrainLifeGoals theme.

Making Neurological Health a Global Priority

Building on meetings with the World Health Organisation in 2019, this year EFNA really stepped up efforts to push for neurological health to become a global priority.

This started with [a meeting at the European Parliament in February](#), which had the patronage of influential MEPs from across the political spectrum. We also enjoyed high level participation in a full plenary room – including a presentation from the Director of WHO's Department on Mental Health, Substance Use and Neurological Disorders.

Following this event, a multi-stakeholder workshop was convened to discuss how we can advance neurology as a public health priority. The outcome was a call for coordinated action. So, throughout the summer, with the help of a Communications Consultant and a Policy Specialist, we worked hard on our advocacy messaging and strategy. A two-year strategy, along with an associated advocacy toolbox, was then launched at a virtual working conference on November 27th.

MEP Interest Group on Brain, Mind and Pain

Unfortunately, the [MEP Interest Group on Brain, Mind and Pain](#) was unable to meet in 2020. However, we took this opportunity to review our approach. A steering committee, with support from Weber Shandwick, performed a landscape analysis to assess policy challenges and opportunities in the public health sphere – which has changed due to the pandemic. The group approved a two-year Roadmap to Action which was launched at [a virtual meeting of the Interest Group](#) on November 10th.

Training Initiatives for Neurology Advocates

Unable to host our planned face-to-face workshops, EFNA built a series of e-learning modules that were launched in November 2020 and focused on 'effective advocacy in a virtual world'. Our planned workshop at 'The Power of the Patient-Physician Partnership' became a virtual session during our General Assembly and the outputs will now be taken forward as part of a joint EFNA-EAN Taskforce on Patient Involvement.

Publications

In 2020, EFNA published two position papers spinning out of our Training Initiatives for Neurology Advocates workshops in 2019.

These focused on:

- Optimising patient involvement in neuroscience research
- Advocating for access to treatment, services and support



European Academy of Neurology (EAN)

In 2020, EAN contributed to the EBC “**Value of Treatment -VOT/cost of non-treatment II - Rare Neurological Diseases**” project that aims at bridging the gaps and achieving seamless, coordinated care. Three of the six diseases studies and analysed are neurology related disorders – Ataxia, Dystonia and Phenylketonuria (2018 – 2020). Prof. M. de Visser and Prof. A. Federico acted as external experts to the VoT study.

The study looked at the value of treatment and early intervention. It will explore the potential benefits and consequences of coordinated care through the examination of health services, patient outcomes and patterns of multidisciplinary care. Case studies were conducted in collaboration with experts and with the support of Academic Partners (University College London and University of Zagreb Medical School), applying empirical evidence from different European countries. The study will hold its summary meeting in June 2021.

EAN is third party in the EU funded project **EBRA – European Brain Research Area** that wants to be a catalysing initiative for brain research stakeholders (researchers, clinicians, patients, governments, funders and public institutions) to streamline and better co-ordinate brain research across Europe while fostering global initiatives. EAN is actively involved also in the SEBRA work package.

A successful **virtual 6th EAN Congress** took place in 2020. The overarching theme of the congress was “Predict, Prevent, Repair”. The congress addressed the three fundamental challenges in dealing with neurological diseases. Preclinical detection of diseases, developing disease-modifying treatments that will provide neuro-protection, and interventional approaches to repair or compensate for neurological alterations are currently hot and challenging topics. Novel therapeutic interventions, designed to predict, prevent and repair across the spectrum of neurodegenerative diseases, neuro-inflammation, stroke, epilepsy, sleep disorders, neuromuscular disorders and genetic disorders were in the focus of many sessions. More than 45.000 neurologists attended the virtual Congress.

2020 saw the publication the Lancet Public Health of the study conducted by Prof. G. Deuschl “**European Burden of Neurological Diseases**”. The study, conducted in cooperation with the GBD – Global burden of Disease study (2016) is an important source of information for European Neurology.

The study showed neurological disorders are the third most common cause of disability and premature death in the EU28 and will increase with the progressive ageing of the European population. It highlighted the need for greater attention to neurological diseases by health authorities for prevention and care. The data suggest different priorities for health service development and resource allocation in different countries.

EAN joined the **ECDA – European Chronic Disease Alliance** and Prof. R. Soffietti sits on its Steering Committee.

EAN was very active in the EBC **Brain Innovation Days** – BID, project and interviews with Prof. G. Deuschl, C. Bassetti are available on the BID website. Prof. D.B. Vodusek sits on the BID programme committee and Prof. E. Moro and M. Leonardi were speakers at BID events.

Prof. G. Waldemar, a prominent EAN member, is President-Elect to the **Biomedical Alliance**, a lobby group for basic and clinical biomedical science of an important number of medical societies in Europe. Prof. D.B. Vodusek chairs the CME Experts Permanent Committee while Prof. P. Van den Bergh is member of the TF Regulatory Affairs and Medical Devices. Prof. Van den Bergh also sits on the Task Force that looks into Academic Clinical Trials. Prof. T. Berger takes part in the BiomedScape working group and Prof. D. Leys is active in the working group looking into Plan S.

EAN partners with EFNA for the **#ONENeurology** Campaign 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 first task was to comment on the draft of the Global action Plan on epilepsy and other neurological disorders (GAP), developed by the WHO Brain Health Unit. The document is to be adopted by the World Health Assembly in May 2022. The GAP represents a unique opportunity worldwide to build, with all relevant stakeholders, an integrated response to neurology across the life course and within healthcare systems to improve lives of people living with neurological disorders. Prof. D.B. Vodusek sits on the project's Steering Committee and internal working group.

European Psychiatric Association (EPA)

In 2020, the European Psychiatric Association (EPA) successfully held its annual European Congress of Psychiatry virtually for the first time. The virtual Congress welcomed over 2,900 participants from across Europe and beyond. In an effort to continue providing high-quality, accessible training to mental health professionals everywhere, the EPA enriched its education offer and launched a new online course on the topic of Major Depressive Disorder during its 2020 Congress.

In the context of the COVID-19 health emergency, the EPA committed to further advocating and raising awareness on the importance of mental health care for healthcare workers, mentally ill people, and the global population overall. In these challenging times, the EPA highlighted the importance of collaboration and prevention by conveying key messages on the occasion of World Suicide Prevention Day (10 September) and World Mental Health Day (10 October). With the aim of supporting healthcare professionals and the general public with easy access to relevant COVID-19 information related to mental health, the EPA created a "COVID-19 Resource Centre", compiling key sources in several European languages from its partner associations. The EPA also took part in the EU Health Policy Platform Network on "COVID-19 Mental Health Support" and contributed in psychiatry-related matters.

In the frame of furthering exchange on the impact of the COVID-19 pandemic on mental health care, the EPA centred its annual Forum around the importance of collaboration among mental health workforces during the COVID-19 outbreak.

Held on 4 July and preceding the opening of the 2020 congress, the 2020 Forum also featured an exceptional keynote message from EU Commissioner for Health and Food Safety, Stella Kyriakides.

Throughout the year, the EPA initiated and strengthened strategic collaborations and alliances with relevant associations active in the field of health and mental health, including collaborating with GAMIAN-Europe in launching the Expert group of mental health workforces, where representatives of EU-level organisations discussed about cross-cutting topics in the field. To further raise awareness on care in 2020, the EPA joined other associations to promote the importance of self-care in people's daily life and set up a social media campaign on the occasion of the "Self-Care Week Europe 2020".

In addition to that, the EPA continued contributing in relevant projects such as Recover-E (led by the Trimbos Institute), and key projects initiated by the EBC such as EBRA and Value of Treatment – Phase 2, where the EPA leads a working group on Anorexia Nervosa. The two-year EPA-GAMIAN project on "Developing Trust and Effective Care for People with Depression" ended in 2020 and the outcomes were published in a report.



Federation of European Neuroscience Societies (FENS)

The 12th edition of the FENS Forum of neuroscience took place virtually in July 2020, bringing together over 5,000 European and international neuroscientists from 88 countries.

With a comprehensive scientific programme of 132 scientific sessions, 20 plenary and special lectures, 56 symposia and nearly 150 live Q&A sessions, the FENS 2020 Virtual Forum united the international neuroscience community at a critical time. The Forum's special interest events addressed topics such as gender bias in neuroscience, animal research, alternative careers for neuroscientists, funding opportunities in Europe, science communication and much more.

The first Brain Debate also took place on this occasion, focusing on "What brains do we study and why do we study them?" A panel of high-level scientists discussed the merits of focused and comparative approaches and reflected on neuroscientists' scientific mission and their vision for the field.

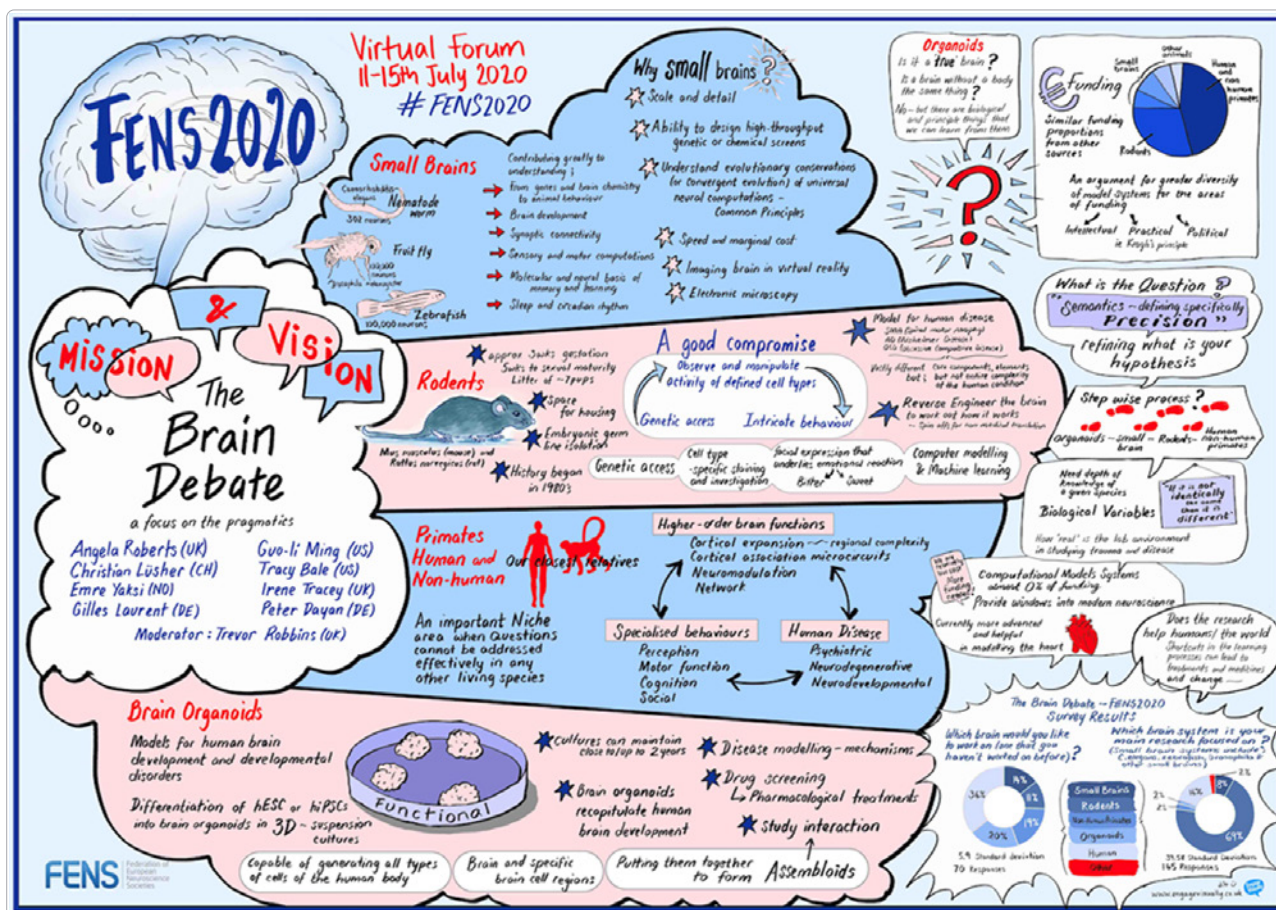


Figure 1 – The Brain Debate, graphic recording by Engage Visually

Looking forward, the [FENS Forum 2022](#) will take place on 9-13 July 2022 in Paris, France.

Chaired by Professor Angela Roberts (UK), the Programme Committee will establish the scientific programme on the basis of proposals from scientists from all over the world and all areas of neuroscience research. The call for symposium and technical workshop proposals is open until 20 May 2021.



Figure 2 – [FENS Forum 2022](#): join us in Paris on 9-13 July 2022!

European Paediatric Neurology Society (EPNS)

The EPNS became an associate member of the EBC in 2019, and in 2021 was honoured to be accepted as a full member. During 2020 the EPNS developed its understanding of how the EBC operates and started to become part in its activities, advocating to improve the lives of children with neurological problems.

2020 of course was a year like no other in our professional and personal lives with the COVID-19 pandemic presenting unprecedented challenges. Children have not suffered the severe medical consequences of COVID-19 infection in the same way as older adults, but the long-term impact on their health should not be underestimated. The psychological impact of illness and bereavement in the family, parental unemployment with reduced family income, disruption of education and isolation from peers are just some of the factors which will have long term consequences. Access to medical services has been significantly impacted in most European countries for the majority of 2020 with clinics, procedures and investigations cancelled or delayed. It has been inspiring to see how child neurologists throughout the world have innovated and redesigned services to maintain the best possible care for children with neurological disorders.

Within the EPNS it was necessary in 2020 for educational and scientific activities to be postponed or moved to a virtual platform; this includes the EPNS biennial congress which was postponed from 2020 and will now take place as a hybrid event on 28 April – 2 May 2022 in Glasgow UK, and virtually. The EPNS has adapted in the way services are delivered and these changes will remain beyond 2020. The virtual platform enables the EPNS to reach out to more child neurologists and colleagues in related fields, and as an environmentally conscious organisation, contributes towards reducing the carbon footprint of the Society.

Now more than ever it has been important for the EPNS to strengthen partnerships and build new connections at a European level. In 2020 the EPNS was invited to nominate representatives on all the relevant European Academy of Neurology (EAN) scientific panels and the collaboration with the EAN grows in strength. The EPNS has developed closer links with the European Reference Networks (ERNs), including ERN-RND, and EpicCare. Patient representative and advocacy groups have a vital role to play in articulating the important issues for children with neurological disorders. Within 2020 the EPNS reached out to the European Federation of Neurological Associations (EFNA) and EURORDIS, European level neurology patient groups and looks forward to developing these relationships further.

Through our membership of the EBC, the EPNS has the stage to lobby for high quality patient management to prevent and treat childhood onset neurological disorders at the European level. During 2020, the EPNS attended virtual EBC board meetings and general workshops/project update meetings. With representatives on the Government Affairs – Advocacy – Communication, Value of Treatment (VoT), European Brain Research Area (EBRA), Digital Health Working Groups, the EPNS has started to foster partnerships and raise the voice of child neurology.

The foundations were laid in 2020, and in 2021 as a full member the EPNS is looking forward to making a significant contribution to the EBC. Child neurological disorders are important from an individual and public health perspective, disorders are treatable, rehabilitation is possible and treatment in childhood has a lifetime's benefit for the individual and society.

International Brain Research Organization (IBRO)

The COVID-19 pandemic impacted all activities of IBRO in 2020. It was an exceptional year due to the quick and unexpected global spread of the coronavirus. Although many meetings and education and training activities had to be cancelled or postponed, IBRO's leadership and community members were able to accomplish valuable work.

At the beginning of the year, the new IBRO officers and secretariat had a kickoff meeting to define new goals and evaluate IBRO's impact. The objective was to make IBRO more transparent by improving communication and accountability. This led to IBRO's first ever External Review that took place during the summer. Invaluable feedback was received from a committee comprised of neuroscience leadership from around the world. Significant deliverables of this process included formalized core organizational values and the development of the organization's first 5-year Strategic Plan. This established a future focus for IBRO with goals and metrics to ensure transparency and accountability of all operations and activities moving forward. This was officially approved by IBRO's Governing Council at the end of the year.

Although more than half of all IBRO-funded events in 2020 were postponed, grants were still awarded to ensure support would be available once safe conditions could be re-established. Overall, IBRO was able to support 203 awardees with 21 different grants. Also, 218 students were accepted to participate in 9 IBRO schools that were able to take place. There were 10 Return Home Fellows who received €20,000 each to set up laboratories in their countries of origin and 15 young Principal Investigators who received €5,000 each to support their research with Early Career Awards. Due to COVID-19 and travel restrictions, many conferences and congresses were also postponed or went virtual. Adapting to the situation, more than 50 researchers obtained grants to attend online meetings. Most of the activities supported by Global Engagement and IBRO/Dana Brain Awareness Week grants were postponed to 2021, but 11 were successfully organized and helped to increase understanding and interest in brain research.

In many ways, the COVID-related lockdowns brought the IBRO community closer together. Increased communication, engagement and understanding occurred intentionally between IBRO leadership, regional and other standing committees, Young IBRO and Governing Council members. Most notably, regular online meetings were initiated between the officers and Regional Committees to ensure transparency and collaboration at all levels and across all regions. In addition, the online Governing Council meeting attracted the most participants in IBRO's recent history with more than two-thirds of its 95-member constituency in attendance.

The IBRO community met the challenges of 2020 and adapted with flexible and innovative solutions to reinforce its leadership, governance and operations. Difficult conditions provided many constructive opportunities and time for self-reflection and improvement which had not been available previously under normal circumstances. IBRO in fact concluded 2020 with a much stronger vision that could better respond to the unique and specific needs of its members as well as help the organization fulfill its potential in the coming years. As it moves into 2021, IBRO will continue to engage closely with its community members and increase its partnerships to secure its future and advance equitable and inclusive neuroscience around the world.

GAMIAN-Europe

Quality of Life project

In 2020, GAMIAN-Europe expanded its realm of activities to the topic of quality of life, an issue identified as highly important to our members. The first part of the project consisted in producing a mini-documentary entitled: '[Beyond a Mental Health Diagnosis: What is Quality of Life?](#)'.



The video put forward the stories of individuals with a mental health condition and their advice on how one can improve one's quality of life. The video was launched on World Mental Health Day. We conducted a very successful promotional campaign on social media platforms, with the teaser video receiving over 90 000 views on Twitter. The documentary was also mentioned in the Politico Pro Playbook, a widely read newspaper. Several 2-hour roundtable discussions were convened with individuals with lived experience of a mental health condition. The information gathered from the workshops will be used to produce a guide for patients entitled: «Top Tips for Managing Quality of Life». The guide will feature patients' perspectives on the issue and will be complemented with an overview of the latest research on the topic.

Developing Trust and Effective Care project: Patients and Psychiatrists working in partnership

There has been little systematic exploration of the mutual experiences of patients and clinicians and how these interact throughout the care process. Yet, mental health care can only be effective if patients and mental health workers can develop mutual trust that will reduce fear and enable the establishment of a therapeutic relationship.



In this context, GAMIAN-Europe, in partnership with the European Psychiatric Association (EPA), set out to explore the care experience of patients, complemented by the narrative of mental health care professionals. The two experiences were brought [together in a dialogue, leading to conclusions about desirable actions.](#)

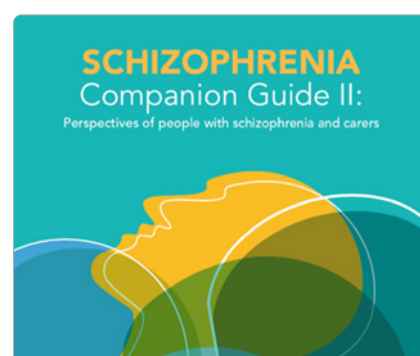
COVID-19 survey for patients

We have all been affected by the current COVID-19 pandemic - and mental health has been so much in the spotlight. This situation has presented an opportunity to underline the importance of mental health and to ensure an appropriate understanding of the needs of patients, now as well as post COVID-19. For this reason, GAMIAN-Europe took the initiative to carry out a survey, focusing on the patient experience during the crisis and patient needs. The survey was translated into 13 languages and gathered over 500 respondents across Europe. The findings of the survey have been presented in [a report](#), together with lessons learned from the crisis and recommendations to services and governments.



Schizophrenia Companion Guide

2020 also saw the development of the [Schizophrenia Companion Guide II](#), designed to provide practical advice to people with schizophrenia, and their caregivers, friends and family. The information used for this companion guide is based entirely on first hand experiences of people diagnosed with schizophrenia, along with carers, relatives and friends and it describes how they have learned to manage and live with this condition.



Campaigning for a European Year for Mental Health

The MEP Alliance for Mental Health, which GAMIAN-Europe coordinates, held [a meeting in November 2020](#) in which representatives of mental health-related organisations and MEPs underlined the need and voiced their support for a dedicated European Year for Mental Health, to be instigated in the short term. Maria Walsh MEP, co-chair of the MEP Alliance for Mental Health had already referred to the need for such a Year in October 2019. Discussions took place on the actions which should be taken to best advocate to ensure that such a Year will become a reality as well as the potential roles of the various participating organisations can play in this campaign.



Following this initial meeting, [a larger stakeholder meeting](#) was held, in which the aims, themes and content of the European Year for Mental Health were discussed. Over 120 stakeholders from the mental health field and beyond, as well as 40 MEPs, voiced their support for such a Year in [a statement](#) addressed to the European Commission. The MEP Alliance co-chairs also co-authored [an article in Parliament Magazine](#) highlighting the urgent need for a European Year for Mental Health.

European Association of Neurosurgical Societies (EANS)

EANS Webinars

The Individual Members Committee, together with the EANS Webinar Working Group and the EANS Office Team was proud to present the EANS Webinar Series in 2020.

This initiative started in September 2020 and continues until today, aiming to fill in the educational gap that the pandemic imposed without any physical meeting or educational activity taking place through 2020.

11 webinars were prepared and launched from September to December 2020.



https://www.eans.org/page/EANS_Webinars

eEANS 2020 – What a congress!

eEANS 2020 Beyond Borders Virtual Congress took place from 19 to 21 October 2020... and it was an absolute success!

Under the theme "Highlights of European Neurosurgery" and a free of charge registration, eEANS 2020 truly took European Neurosurgery Beyond Borders.



The numbers tell their own tale:

- 2.527 participants from...
- 111 countries!
- 16 Sponsors & Supporters in a Virtual Exhibition
- 67 Outstanding Lectures
- 1.000.000 thank yous to our participants!

Brain & Spine: EANS and Eurospine launch a new journal together!

EANS was very excited to launch of their entirely new journal: Brain & Spine! This will act as the new medium for future EANS representation and visibility in the scientific world.

As opposed to Acta Neurochirurgica, which is still owned as a title by the publishing company Springer, the new Journal will be owned by the EANS and its partner organisation, Eurospine, providing more liberty and leverage when it comes to publication policy, strategy and management.

The two co-editors – Wilco Peul for the EANS and Frank Kandziora for Eurospine – stand for the best scientific quality. The first Open Access edition will be ready in the first quarter of 2021.



Call for Submissions

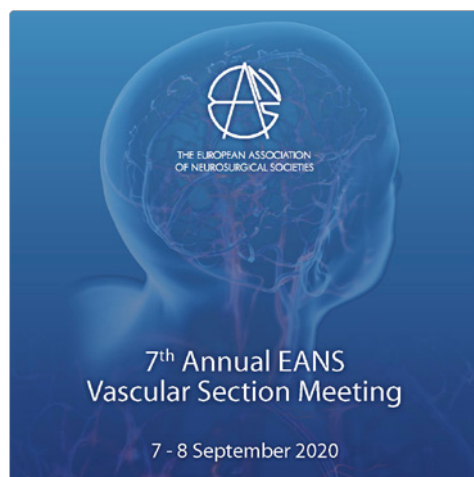
Brain and Spine

The official journal of the Spine Society of Europe (EUROSPINE) & the European Association of Neurosurgical Societies (EANS)

**Learn More &
Submit your Research Today!**



7th Annual EANS Vascular Section Meeting



EANS held its 7th Annual EANS Vascular Section Virtual Meeting on 7-8 September 2020.

Although physical presence was dearly missed, the Meeting exceeded expectations, reaching **1200** live connections in total during its **2** days with **8** Sessions, more than **70** Speakers and **4** Sponsors!

EANS 2020 Research Fund Grants

Diseases of the brain and spine in Europe are of major importance to patients, their families and society. There are 165 million Europeans with brain disorders, causing a global cost (direct and indirect) exceeding 800 billion euros for National Health budgets.

European Association of Neurosurgical Societies focuses is on neurosurgical conditions which include brain injuries, brain tumours, stroke, epilepsy, hydrocephalus and disorders of the spine. While advances have been made in the treatment of these conditions there remain many unanswered questions and major opportunities to improve treatment and outcome for patients.

Its mission is to achieve this through comprehensive research strategies including both basic science laboratory research and clinical studies including trials. Access to research funding from large grant funding bodies, for example, the European Union and national government agencies and charities is highly competitive and usually requires initial pilot research data. EANS have therefore established a research fund to pump prime projects to enable the acquisition of the pilot data necessary to apply for more substantial funding, achieved through the award of €10000 seed grants for neurosurgical research projects.



THE EUROPEAN ASSOCIATION
OF NEUROSURGICAL SOCIETIES

EANS Research Fund Grant Winners!

Congratulations to all **[2020 Winners!](#)**

<https://www.eans.org/page/Research-fund>

The EANS Diversity Task Force (DTF)

The DTF was initiated during the 2019 EANS Annual Congress (AC) with the goal to tackle disparity (of any kind) within our professional field. Neurosurgical patients are found all over the world. Nevertheless, the density of neurosurgical care is different. Since neurosurgery is global, neurosurgery affects different cultures, expectations, interests, genders, skin colours, role models, restrictions and challenges. Neurosurgery is with all these aspects of diversity in a European and global exchange.

Now more than ever, we know that acceptance and embracement of diversity is of utmost importance for a successful future. The DTF currently consists of 10 EANS members and calls for more members are open.

https://www.eans.org/page/Diversity_Task_Force

🐦 @EANS_Diversity



European Neurosurgical Societies

European Association of Neurosurgical Societies (EANS)

Board of Officers



Scientific Section Chairs



EANS Member Countries and National Societies' Boards



COVID-19 in Neurosurgery

During 2020, EANS developed a dedicated COVID-19 website to provide resources and references to the neurosurgical community.



Covid-19 in Neurosurgery News, Guidelines and Discussion Forum

<https://www.eans.org/page/covid-19>

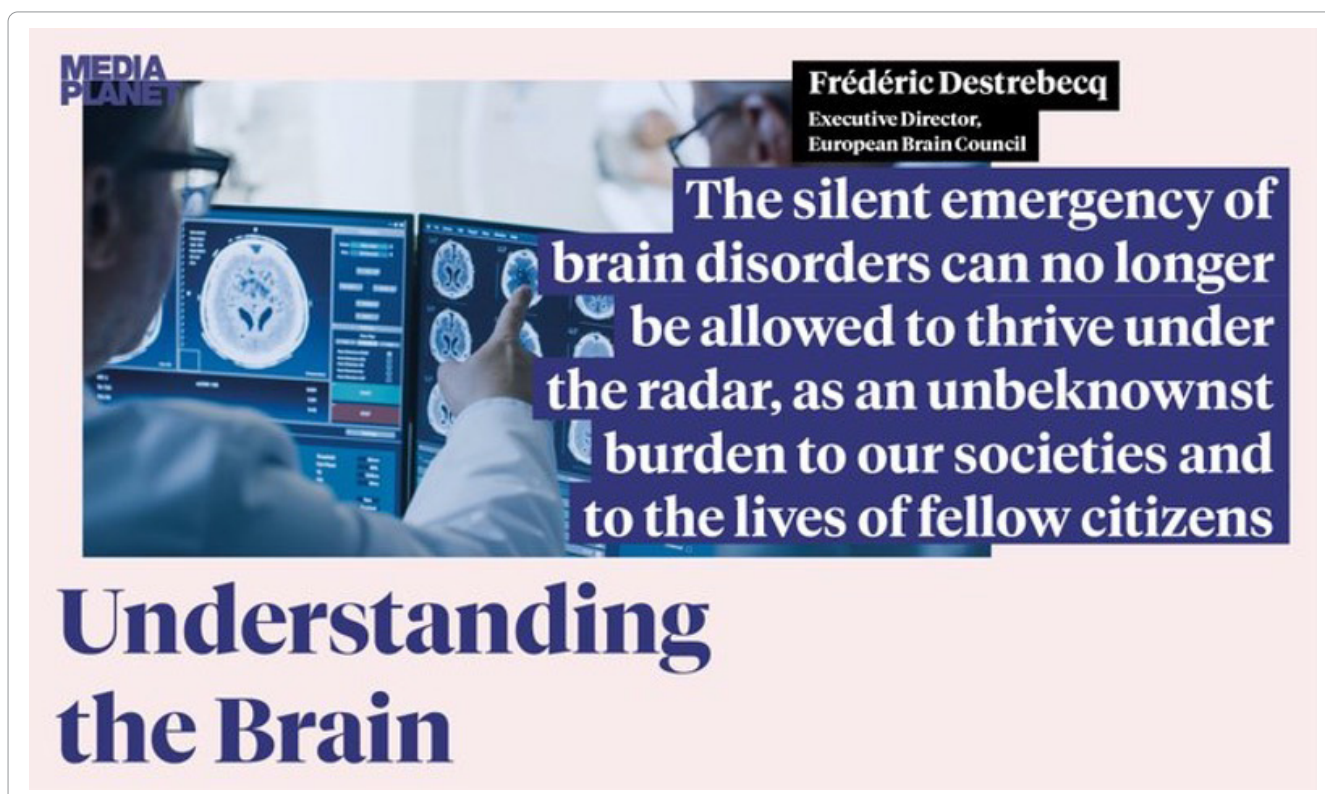
MEDIA REPORT

*Raising public awareness
on brain research*



The silent emergency of brain disorders - Mediaplanet

In March, [EBC was featured](#) in the online publication Health Awareness, a Mediaplanet website that publishes healthcare news, information and personal insight stories. This article was part of the 'Understanding the Brain' campaign, which coincided with the 2020 Brain Awareness Week. The article, entitled "The silent emergency of brain disorders", called attention to disorders of the brain and the fact that investment into brain research lacks the awareness and recognition they are due.



The article was also included in a special insert within the Guardian newspaper.

👁 Article link:

https://www.healthawareness.co.uk/neurology/the-silent-emergency-of-brain-disorders/?utm_source=OrganicMP-distro&utm_medium=TwitterXX

Prioritising brain research - Parliament Magazine

In March 2020, in recognition of Brain Awareness Week, [EBC was featured in Parliament Magazine](#) with a Thought Leader piece by EBC President, Prof. Monica Di Luca, focused on encouraging further leadership from Europe and the European Union in the fight against brain conditions and in the continued quest to understand them.

The Thought Leader was accompanied by a call for strengthened EU vision in addressing brain disorders and prioritising brain research in the future by MEPs Tomislav Sokol (EPP, HR), Petra De Sutter (Greens/EFA, BE) and Frédérique Ries (Renew, BE). The MEPs highlighted that EU decision makers can play important roles in transforming Europe into a leader in developing new treatments, providing innovation-friendly environments and encouraging and sustaining scientific breakthroughs in the fields of both neurological and mental disorders.

BRAIN AWARENESS

Prioritising brain research

The EU needs a vision that addresses brain research as one key priority, argue MEPs **Tomislav Sokol**, **Petra De Sutter** and **Frédérique Ries**

Tomislav Sokol (HR, EPP), **Petra De Sutter** (BE, Greens/EFA) and **Frédérique Ries** (BE, RE) are all members of Parliament's MEP Interest Group on Brain, Mind and Pain

The brain is undoubtedly the most important organ in the human body, yet it remains one of the most mysterious. Understanding the brain has intrigued and astounded scientists for years and we are still striving to find cures or truly effective means of delaying or reducing the burdens placed on individuals and society by its disorders. Ahead of this year's Brain Awareness Week - the global campaign to foster public enthusiasm and support for brain science - we want to make our case for the brain and the mechanisms available to

living with brain disorders is extremely challenging. The complexity of brain disorders is a testament to the need for a multidisciplinary approach to tackling them. Engaging patients and scientific and clinical communities at all levels is required to ensure that Europe's citizens can benefit from discoveries and that advances in neuroscience are translated into new diagnostic tools and treatments for brain disorders. Multi-stakeholder engagement is needed to create an enabling environment that can foster investment in innovation in brain disorders and propose concrete avenues to remove

to treatments. The redesign of health-care systems to become proactive rather than reactive can play a significant role in the prevention of these disorders and the improvement of care for EU citizens. Around a third of the world's population will be affected by a mental or neurological disorder during their lives. Global data, particularly those from European studies, indicates that these disorders are a major public health problem.

"Developing treatments that can significantly improve the lives of those living with brain disorders is extremely challenging. The complexity of brain disorders is a testament to the need for a multidisciplinary approach to tackling them"

the European Union to make a difference in developing research and improving the lives of the 179 million Europeans living with brain disorders, both neurological and mental.

Despite the prevalence of brain disorders in Europe, there are currently no disease modifying treatments available to cure a wide range of mental and neurological conditions. Developing treatments that can significantly improve the lives of those

existing barriers.

EU decision makers can also play a major role in ensuring Europe transforms into a global leader in the development of new treatments by creating an innovation-friendly environment that can sustain scientific breakthroughs in the field of brain disorders. It should be highlighted that well-evidenced improvements to clinical care are crucial to patients' quality of life and to improved access

with brain disorders ranking among the leading causes of ill-health and disability. The burden is growing due to the epidemiological transition from acute to chronic diseases and the increase in life expectancy, but also because of several socioeconomic, environmental and behavioural health determinants. Discussions on health care too often focus on the increase



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EUROPE CAN MAKE AN IMPACT IN THE FIGHT AGAINST BRAIN CONDITIONS, SAYS MONICA DI LUCA

THE PARLIAMENT MAGAZINE'S THOUGHT LEADER

One in three people in Europe live with a brain condition — neurological or mental — and it is becoming increasingly clear that this number is an underestimation. With an ageing population and a wide range of challenging disorders with no disease-modifying treatment available to cure them, Europe is falling behind in the race to not only find a cure but also to develop a basic understanding of our most vital organ.

Medical research is expanding our understanding of the human brain and of the treatments currently available for patients. Scientists are working in labs across Europe to understand the mechanisms behind the diseases, however, manufacturers are facing, on average, 18-year pipelines in producing drugs and devices that can penetrate our central nervous system.

As the world becomes more competitive, steps are needed to help maintain Europe's global leadership with respect to scientific breakthroughs, research and innovation and treatment development.

"How is the time for Europe to shine and be bold at international level, to join global efforts and make an impact in the brain community?"

As we transition from Horizon 2020 (H2020) to Horizon Europe, this presents us with a window of opportunity to make a difference. During this shift, it is essential that funding is uninterrupted and that adequate resources continue to be dedicated to addressing the burdens brain disorders place on society. It is also crucial that Horizon Europe begins with a robust and appropriate structure for research,

particularly through maintained collaboration opportunities and other coordination mechanisms such as a unified and ambitious co-funded brain health partnership.

The H2020-funded European Brain Research Area, coordinated by the European Brain Council (EBC), was launched with the aim of identifying research communities active in the field and to provide them with coordination and support. In parallel, a community-wide strategic reflection has been initiated on the future of brain research within Horizon Europe and beyond, involving key large-scale initiatives that fund brain research in Europe today, including the Human Brain Project, Neuron, the EU Joint Programme on Neurodegenerative Disease Research, the Innovative Medicines Initiative and other initiatives coordinated by the Commission.

Now is the time for Europe to shine and be bold at international level, to join global efforts and make an impact in the brain community. To this end, we will convene a roundtable meeting on global brain research collaboration, involving relevant actors in the field from across the world at the upcoming neuroscience forum in Glasgow.

We are rapidly approaching what can only be described as a state of emergency when it comes to noncommunicable diseases, with brain conditions leading as the highest cause of ill-health and disability worldwide. Dementia numbers are set to double within the next ten years and the leading cause of years lost due to ill-health, disability or early death by 2030 is projected to be unipolar depressive disorders. It is clear we cannot wait much longer to recognise that we have a non-communicable pandemic brewing among us.

Professor Monica Di Luca is President of the European Brain Council



WWW.THEPARLIAMENTMAGAZINE.EU

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👁 Article link:

<https://library.myebook.com/the-parliament/issue-511-16-march-2020-1/2342/#-page/16>

Brain diseases at the time of the COVID-19 pandemic - Open Access Government

In July 2020, a few months into the COVID-19 pandemic, EBC was featured in Open Access Government with an article on brain diseases at the time of the COVID-19 pandemic. EBC President, Prof Monica Di Luca, highlighted the importance of continuous prioritisation and attention to brain research during the COVID-19 pandemic. Open Access Government is a digital publication that provides an in-depth perspective on key public policy areas from all around the world, including health and social care, COVID-19, research and innovation, technology, government, environment and energy.

NEURODEGENERATIVE DISEASES

Brain diseases at the time of the COVID-19 pandemic

Prof Monica Di Luca, President, European Brain Council, highlights the importance of continuous prioritisation and attention to brain research during the COVID-19 pandemic

The year 2020 seemingly started like any other, but has quickly evolved into a test for global society, as the novel coronavirus, or COVID-19, came, as if overnight, in full force. In Europe, in particular, everyday life was brought to a halt as the disease spread like wildfire across the continent, pushing healthcare systems to their limits and paralysing economies throughout the European Union (EU) Member States and beyond.

Brain community vs COVID-19
The brain community as a whole has watched the pandemic unfold from an uncomfortable distance, not directly involved but progressively affected. Society has seen a worrying increase in mental health issues and chronic illnesses face deprioritisation in the face of this emergency. It is becoming clearer to the community as the pandemic rages on that the danger COVID-19 poses on vulnerable societies — like those living with brain conditions and other pre-existing conditions — is undeniable. Researchers and physicians note growing evidence of not only the threats of COVID-19 to patients but also the direct neurological impact the virus has started manifesting, with physicians working to better understand how exactly COVID-19 has affected their patients.⁽¹⁾

Brain researchers
The brain research community, in particular, has seen their daily work and lives shift significantly. Many are severely affected by the outbreak of COVID-19 in Europe as well as by the containment measures introduced by many EU countries. In April, multiple calls to the European Commission were launched — including by the European Brain Council (EBC) — to ask the European Commission to postpone deadlines for Horizon 2020 calls, as the containment measures hindered researchers in their efforts to collaborate with partners

NEURODEGENERATIVE DISEASES



Prof Monica Di Luca

in other EU-countries, travel across Europe, organise meetings, gather relevant experts and conduct their research or prepare their project proposals as normal. Furthermore, medical societies are calling for support for medical and research societies to ensure continued guidance for healthcare professionals during the COVID-19 Pandemic⁽²⁾, specifically since the medical and research societies that health professionals rely on for up-to-date information on clinical practice are facing serious challenges during this time.

Nevertheless, it is important to realise that infectious disease pandemics like this one are unpredictable and that, meanwhile, on a daily basis, millions of people across the world are living in “pandemics” of their own, be it cancer, cardiovascular disease or brain conditions.

Treatment: Increasing urgency
Though one in three Europeans are set to live with a brain disease at some point of their life⁽³⁾ — neurological and mental alike — conditions of the brain remain without disease-modifying treatments or cures and research is disproportionately underfunded compared to other comparable or less-threatening disease areas. While no diseases should be neglected or go without treatment or cures, it's important to make this comparison to demonstrate the lack of urgency afforded to the brain. The longer it takes society to understand how to respond to these diseases, the more crucial it will become to do so. As the numbers grow due to our rapidly ageing population and with the brain leading as the highest cause of ill-health and disability worldwide, the closer we get to a noncommunicable diseases state of emergency.

Horizon Europe
The transition from Horizon 2020 to Horizon Europe must be used as a window of opportunity for the brain community and the EU to take on a leadership role with respect to research breakthroughs, innovation and treatment development. Funding should remain uninterrupted and adequate resources should continue to be dedicated to addressing the burdens brain disorders place on our society. It is crucial that the new framework programme begins with a robust and appropriate structure for research, particularly through maintained collaboration opportunities but also by other coordination mechanisms such as, for instance, a unified and ambitious co-funded brain health partnership.

The European Commission made it clear that its priority for brain research and the brain community was to better understand the existing landscape, the potentials and lack thereof within the field and what more can be done. The H2020-funded European Brain Research Area (EBRA) project⁽⁴⁾, coordinated by the European Brain Council (EBC), was launched in 2018 with the exact aim to identify existing brain research communities across Europe and to provide them with coordination and support. In parallel, a community-wide strategic reflection has been initiated on the future of brain research within Horizon Europe and beyond, involving key large-scale initiatives that fund brain research in Europe today, that include: the Human Brain Project (HBP), Neuron, EU Joint Programme – Neurodegenerative Disease Research (JPNDR), the Innovative Medicines Initiative (IMI) and other joint programmes and initiatives coordinated by the European Commission.

If COVID-19 has taught us anything, it is that, as a society, we are not yet fully prepared nor capable to tackle the majority of health epidemics we are currently facing or will potentially face in the coming future. Now is the opportunity for Europe to apply the lessons learned and be bold at the international level, to reflect on what ails our community and to join global efforts and make an impact in the brain community.

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👁 Article link:

<https://www.openaccessgovernment.org/brain-diseases-at-the-time-of-the-covid-19-pandemic/86498/>

Brexit impact: Health and brain research - Open Access Government

EBC was featured in Open Access Government a second time, in the October 2020 edition, this time with an article focused on the impact of Brexit on health and brain research. The article highlighted how crucial it is that the EU-UK partnership and collaboration remains, for the sake of cross-border science, education and for the future of brain research and those it impacts.

SECTION

Brexit impact: Health and brain research

Prof Monica Di Luca, President, European Brain Council, sheds light on the greater impact of Brexit in terms of health and brain research being up for negotiation

Over the last decades, collaboration between the EU27 countries and the UK has been an important factor driving research and innovation in a wide range of therapeutic areas and ensuring the availability of innovative treatments, including in the brain research space. The UK has been a major contributor to health research and clinical trials in Europe and UK partners are often closely involved in research projects funded by the EU. The UK has supported and participated in a wide range of EU health-related programmes, platforms and networks, with many UK-based institutions leading research consortia.

COVID-19

Moreover, the EU27 and UK currently closely cooperate as regards the authorisation, testing and mutual recognition of medicines and medical devices, which is crucial for ensuring patient access to potentially life-saving treatments. These issues have become even more important in light of the COVID-19 pandemic, which makes it paramount that health collaboration, to the greatest possible extent, is maintained after the transition period ends on 31st December 2020.

If the COVID-19 pandemic has taught us anything, it's that, as a Union, we are not fully prepared nor capable of individually tackling the majority of health epidemics we are currently facing or will potentially face in the coming future. Understanding even the basic mechanisms of cancer took researchers decades and still today, an EU cancer plan and mission is a basic necessity for the continued research behind the disease. What can be said for diseases of the brain, which continue to both confound and fascinate researchers all over the world? COVID-19 shook European health systems to their cores and continues to do so until some

form of normal can be found through the discovery of a vaccine. In times of lockdown and the unknown, we forget that many other diseases exist – albeit non-communicable – that continue to affect people without proper treatment or cures in sight.

Non-communicable diseases (NCDs)

The work of organisations like the European Brain Council, calling on the European institutions to acknowledge the full burden of brain disorders, stems from a disproportionate response from most health and research-related frameworks in addressing the burden. In outlining its recent plans for the EU4Health programme, the European Commission speaks of non-communicable diseases (NCDs) and mentions mental health in areas where action is required, but neurology has been omitted, as previously, from the Commission's health priorities.

Brain disorders – neurological and mental alike – join musculoskeletal disorders, cardiovascular disorders and tumours to make up the largest burden of noncommunicable diseases (NCDs) in Europe and worldwide. In fact, due to a rapidly ageing society, brain disorders, when combined, lock set to become the leading burden on society. Strikingly, brain disorders account for roughly a third of total years lost to death and disability from all diseases globally¹ and neurological disorders alone are the leading cause of death worldwide, second only to heart disease.² Despite progress by researchers, this burden continues to grow as the population ages and science cannot keep up with the pace. The brain community can, for the most part, identify the largest needs: sustained funding and support play a key role, but strengthened and improved frameworks for collaboration in research play the largest role if any progress can be made to address this NCDs epidemic.

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EU research schemes

The UK and the EU27 countries are currently in the process of negotiating the agreement on the future relationship between the two blocs. Given the many health-related issues that are at stake, it is crucial that health does not get overlooked in the current negotiations. Amongst other issues, this would entail that customs cooperation on medicines and medical devices as well as reciprocal healthcare arrangements are maintained and preserved as part of the future relationship.

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Prof Monica Di Luca

Furthermore, the UK has contributed greatly to health research funded under EU research schemes. As part of the ongoing negotiations, the UK and the EU have been discussing the possible participation of the UK in EU programmes, including in the Horizon Europe programme that is set to start in 2021. In order for this important collaboration in health and research to prosper, it is key that decision-makers commit to full association of the UK to the Horizon Europe programme as well as UK inclusion in Europe-wide research projects and partnerships.

No further barriers should be put in place that hinder EU and UK scientists in their efforts to work, travel and conduct research in both blocs and UK and EU regulations across research and clinical trials should remain aligned. This would not only enable the "extended Europe" to remain a hub for research and innovation, but it would ultimately also strengthen the work of both the UK and EU governments to address the impact of brain disorders, which are widespread and highly disabling conditions.

We must learn from the COVID-19 experience that we are stronger and more capable when working in collaboration. Though the UK breaks away from the

Union, it is crucial that our partnership and collaboration remains, for the sake of cross-border science, education and for the future of brain research and those it impacts.

References

1 Burden of brain disorders in Europe in 2017 and comparison with other non-communicable disease groups: Alberto Raggi, Matilde Leonardi, The Journal of Neurology, Neurosurgery and Psychiatry, <http://dx.doi.org/10.1136/jnnp-2019-320466>

2 The global burden of neurological disorders: William M Carroll, The Lancet Neurology, [https://doi.org/10.1016/S1473-3099\(19\)30029-8](https://doi.org/10.1016/S1473-3099(19)30029-8)

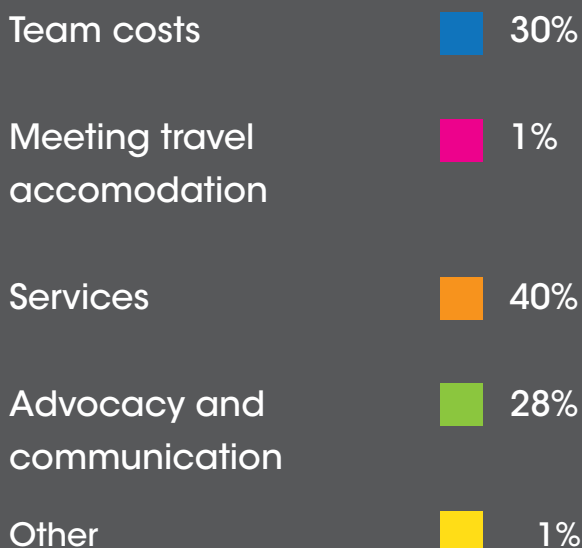
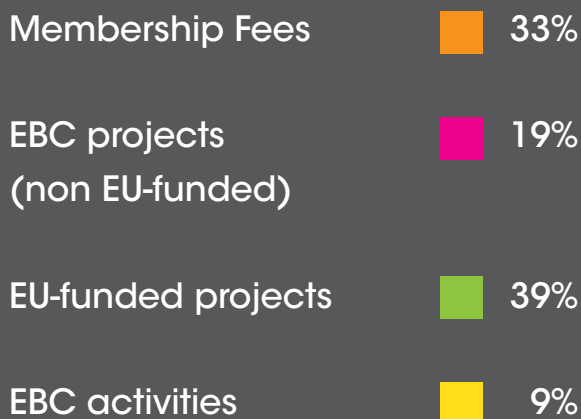
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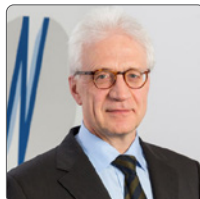
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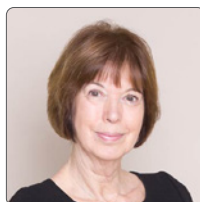
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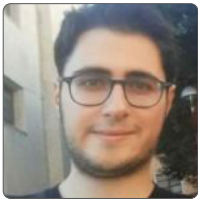


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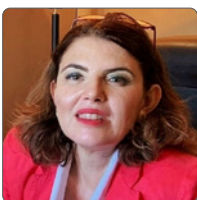
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ANNEX

MEETINGS ATTENDED

- 3-4 February 2020 - Human Brain Project Summit, Athens, Greece
- 30 January 2020 - Major Depressive Disorder Coalition Meeting, Virtual
- 6 February 2020 - Meeting with hub.Brussels, Brussels, Belgium
- 7 February 2020 - Meeting with Buro Fondsenwerving, Virtual
- 17-18 February 2020 - EFNA Advocacy Workshop, Brussels, Belgium
- 18 February 2020 - "Brain Health as a Global Priority" Parliament Event, Brussels, Belgium
- 18 February 2020 - Rare Diseases Day European Parliament Exhibition, Brussels, Belgium
- 3 March 2020 - MULTI-ACT Project 4th Consortium Meeting, Virtual
- 22 April 2020 - Web Conference with Fiona Godfrey of the EU Cancer Mission Board, Virtual
- 27 April 2020 - Politico Event: Managing chronic diseases in the time of coronavirus, Virtual
- 1 July 2020 - Making Neurology a Public Health Priority, Virtual
- 4-7 July 2020 - EPA Congress, Virtual
- 11-15 July 2020 - FENS Forum, Virtual
- 15 July 2020 - FKNE Special Interest Event at FENS Forum: Neuroscience Research Funding in Europe Post-COVID-19, Virtual
- 16 July 2020 - Genomic medicine and Horizon Europe: making the promise real, Virtual
- 12-15 September 2020 - ECNP Congress, Virtual
- 16 September 2020 - EBC & Scotland Brain Health Strategy Introduction, Virtual
- 17 September 2020 - The Future of Brain Health in Europe, Incisive Health Breakfast Club, Virtual
- 22 September 2020 - Making Neurology a Public Health Priority, Virtual
- 30 September 2020 - The Potentials of Increased Collaboration in Science, Digital Science @UNGA75, Virtual
- 30 September 2020 - Do the SDGs address the global burden of disease?, Digital Science @UNGA75, Virtual
- 15 October 2020 - EU Cognitive Decline Workshop | Hearing Health Forum EU, Virtual
- 26 October 2020 - EU Health Summit, Virtual
- 28 October 2020 - Societal Impact of Pain (SIP) Stakeholder Forum, Virtual
- 28 October 2020 - Brain Health for the EU, Stakeholders Meeting, Virtual
- 29 October 2020 - International Brain Initiative (IBI) Coordinating Body Meeting, Virtual
- 10 November 2020 - Meeting of the MEP Alliance for Mental Health: 'Campaigning for a dedicated European Year for Mental Health', Virtual

- 13 November 2020 - Shared European Brain Research Agenda PSC Meeting, Virtual
- 18 November 2020 - Digitalisation & AI in Healthcare, EHMA Conference 2020, Virtual
- 24 November 2020 - GOLUP Nordic Workshop, Virtual
- 25-26 November 2020 - EBRA: Shared European Brain Research Workshop, Virtual
- 26 November 2020 - BioMed Alliance General Assembly, Virtual
- 26 November 2020 - Incisive Health Morning Club: Countdown to the new Diagnostics Regulation: What challenges for patients, users and manufacturers?, Virtual
- 27 November 2020 - Making Neurology a Global Public Health Priority - Working Conference, Virtual
- 1 December 2020 - EPICLUSTER workshop on epilepsy funding, governance and patient engagement strategies, Virtual
- 1 December 2020 - 'European Research and Innovation Beyond 2020', EBRAINS Politico Event, Virtual
- 2 December 2020 - EPIXCHANGE II, Virtual
- 4 December 2020 - MQ Data Science Meeting, Virtual
- 16 December 2020 - 5th MULTI-ACT Consortium Meeting, Virtual

CREDITS

This report was compiled by the team of EBC's Brussels Office.

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This report has been designed in line with best practice guidelines of visual accessibility.

We welcome feedback and suggestions for maximising the readability of our publications.

Please email your comments to: **info@braincouncil.eu**





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