

**SCORING  
POINTS  
EVERY DAY  
TO IMPROVE  
BRAIN  
KNOWLEDGE  
& ADVOCACY**

**EBC • 2021**  
**ANNUAL REPORT**

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# ANOTHER YEAR



# SPENT

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# FINDING THE WORDS THAT BRING PEOPLE TOGETHER

## Letter from EBC President & Executive Director

Dear Colleagues,

We are delighted to share with you the EBC Annual Report for 2021. Despite the ongoing COVID-19 pandemic, we are pleased to have managed to continue to successfully conduct and pursue ongoing projects such as: the Value of Innovation (from which stemmed the development of the EBC Policy Roadmap), MULTI-ACT and the European Brain Research Area (EBRA). In addition, we have held the 1<sup>st</sup> in-person edition of the Brain Innovation Days, which reunited scientists/researchers, clinicians, patients, and many other passionate members of the brain space, including new faces such as start-ups and investors.

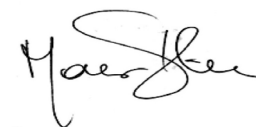
Many of us adapted our lives to constantly changing pandemic restrictions and are slowly coming back to the new reality. Nevertheless, EBC has not ceased in its efforts to support brain research in Europe. This year was remarkable for us, as we forged and strengthened not only the established partnerships, but also, created new cooperations.

In this regard, we consider 2021 as challenging but successful year, and we are proud to share with you this Annual Report. EBC would like to thank its members, partners, and every individual who supports us in striving for raising the awareness on the burden of brain disorders and we are looking optimistically to the future of brain research!

Yours faithfully,



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 read 'Frédéric Destrebecq'.

# SPEAKING WITH ONE



## EBC Mission & vision

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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.



# STAYING LINKED IN DIFFICULT TIMES

## EBC Highlights

### POLICY ROADMAP

On the occasion of Brain Awareness Week 2021, EBC released its Policy Roadmap, '[Brain Health in Europe: Fostering Innovation, Improving Outcomes](#)', inviting the community join in calling for the establishment of an EU-wide and public health combined Brain Plan.

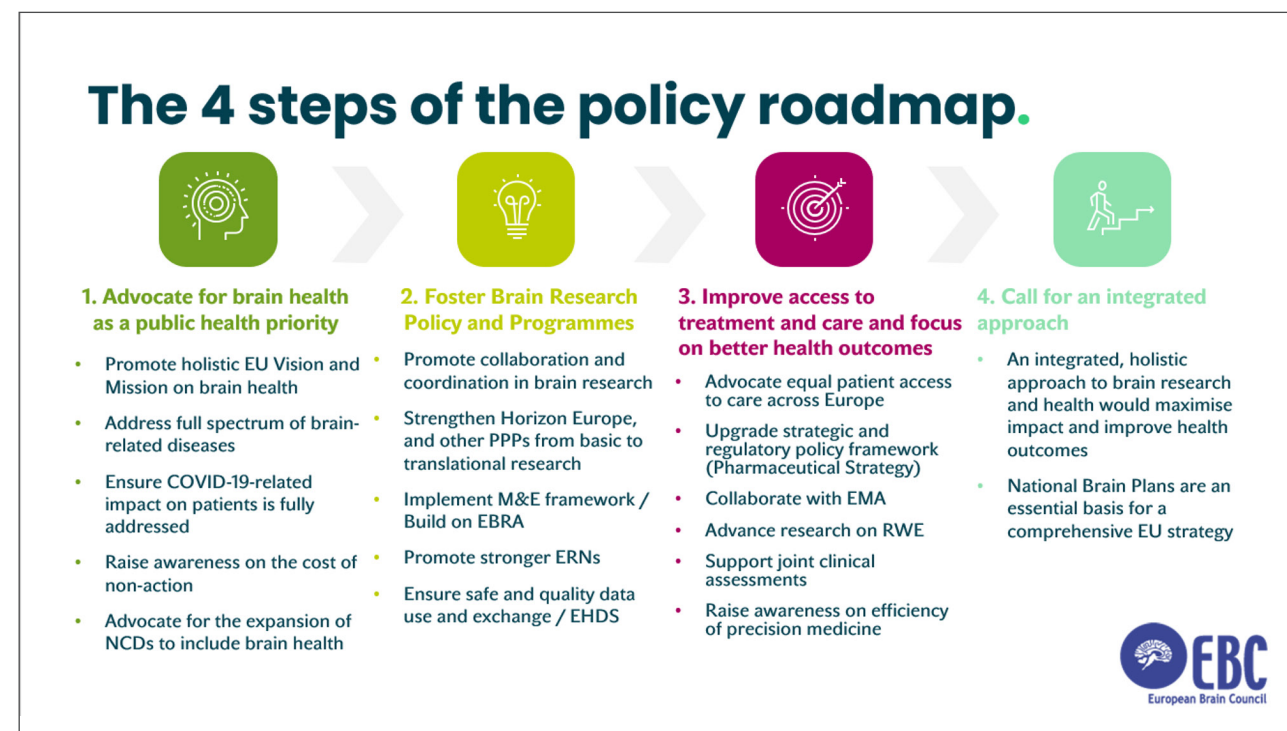
More than ever, EU health stakeholders need to come together and ensure that brain health is at the centre of the Union and its Member States' public health agenda. Efforts need to be combined to foster innovation in research and treatment for mental and neurological disorder and to improve the quality of life of affected patients. The paper aimed to demonstrate EBC's belief that enhanced multi-stakeholder engagement in the brain health ecosystem is needed to foster dialogue, exchange knowledge, facilitate business development, showcase ongoing projects, and accelerate investment in brain disorders, research and innovation for the benefit of patients.

One month after its launch, on 20 April 2021, a [virtual policy roundtable](#) was held, hosted by the European Brain Council and Members of the European Parliament (MEP) Maria da Graça Carvalho (EPP, Portugal) and Tomislav Sokol (EPP, Croatia), both members of the MEP Interest Group on Brain, Mind and Pain. The panel and the audience comprised of an array of key stakeholders, with representatives from the European Parliament, the European Commission, the Organisation for Economic Co-operation and Development (OECD), the scientific and clinical community, patient organisations and industry.

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



The roadmap set up four main pillars of EBC's policy work: advocating for brain health, fostering brain research, improving access to care and calling for an integrated approach. This document continues to be the guidance behind EBC's work since.



## BRAIN INNOVATION DAYS

The Brain Innovation Days concept was established by the European Brain Council in 2019-2020, stemming from within the wider brain community, including start-ups fusing together to showcase the potentials within the wider brain space. Around the world, researchers, clinicians, businesses and more are working to not only understand the brain further but to use this understanding to develop novel treatments and care for the diseases within our most vital organ. This event aims to act as a **platform** to bring together science and society and an **annual event** where leaders in the brain ecosystem, researchers, industry, start-ups, innovators, policymakers, investors, health care professionals and patients are invited to encourage interaction between the communities within the brain space, build strong matchmaking and networking opportunities and to showcase ongoing innovation.

The Brain Innovation Days were launched with a virtual session in 2020, kicking off one full year of brain innovation, consisting of 3 digital sessions (including a virtual Pitch Competition) and culminating in a physical event (held in Brussels) in October 2021.

The first event of 2021 was the second digital session of the series, held on 26 January 2021, under the theme [“From Innovative Ideas to Creative Brain Interventions”](#). The two-hour session hosted the first Brain Innovation Days Pitch Competition, co-organised with beLean.net, where a number of start-ups went head-to-head to pitch their business for the chance to win Best Pitch, awarded by a jury of esteemed experts in related fields. Furthermore, a panel discussion on the challenges faced by innovators in Europe took place – from idea to business – and the support structures that exist to alleviate and guide the process.

The second digital session, held on 27 April 2021, focused on [“Fast-tracking brain innovation in times of COVID-19”](#), exploring the positive direct and indirect results of COVID-19 pandemic response and research on the brain innovation ecosystem, what lessons have been learned, what countries have come out winning, what advancements have been made and what threats lie ahead – particularly when and if the world returns to the pre-COVID status quo. The session featured testimonials from key opinions leaders, patients, representatives from the EU and WHO level and the industries that were forced to adapt to this rapid change of pace in innovation.

With the COVID-19 pandemic stabilising towards the end of 2021, the first [in-person Brain Innovation Days event](#) was able to be held in Brussels on 12-13 October, made up of plenary, breakout and Agora sessions, Innovation Showcases, Brain Talks and an open exhibition space, bringing together around 200 stakeholders from the wider brain community. The topics – all submitted by the community – included cannabis in medicine, teleneurorehabilitation, business development panels, gender issues in neurology, financing your start-up, virtual tech for epilepsy, entrepreneurship in healthcare and [more](#).



**Brain  
Innovation  
Days**  
12-13 October 2021  
Brussels on-site event





Alongside the Brain Innovation Days events, the concept expands beyond, aiming to foster connections between the wider brain community throughout the year. On the Brain Innovation Days website and social media channels, stakeholders can keep up with the latest news in the brain innovation space, share their work through articles and job opportunity posting as well as take part in the [Brain Talks podcast series](#), an exciting endeavour by the Brain Innovation Days team to shine the spotlight on inspiring key opinion leaders in the field. The podcast series has helped expand on topics covered within the digital sessions

as well as explore new areas of interest, including discussions on artificial intelligence, creating a successful medtech start-up, neurotech, telemedicine, video technology, brain machine interfaces with high-level guest speakers including Pierre Meulien of the Innovative Medicines Initiative (IMI), Padraic Ward, Head of Roche Pharma International and Florence Butlen, Senior Scientific Officer at the European Medicines Agency (EMA).



## EUROPEAN BRAIN SUMMIT

The European Brain Council and the EBRAINS Research Infrastructure held the first [European Brain Summit](#) on 12 October 2021 in Brussels, in conjunction with the Brain Innovation Days and Human Brain Project Summit.

Leading researchers and policy makers presented their vision of the future of European brain research in the context of the European Health Union and highlighted innovative solutions and latest technological advancements. They were joined by a total of 550 registered participants, with almost 200 meeting on-site and a majority following the live stream from across Europe and beyond.

Panels of renowned scientists and different societal stakeholders discussed world-wide collaboration and partnerships, technology and medical innovation, patient involvement, and the European Health Data space.

The Summit also dialled in to a virtual workshop of the [European Parliament's Panel for the Future of Science and Technology \(STOA\)](#), moderated by EBC President, Prof Monica Di Luca. The session was opened with a Keynote from Nobel Prize Winner, Prof Edvard Moser, who stressed the massive challenge of understanding the activity of the brain with its complex networks requires cooperation not only between individual research groups but between whole countries and continents.

Read the event report [here](#) and watch the full recording of the Summit, available [on YouTube](#).



*Speakers and Organisers (L-R): Hilary Sutcliffe (Director, Society Inside); Paweł Świeboda (Director General, Human Brain Project and CEO, EBRAINS); Prof Petra Ritter (Head of the Section Brain Simulation, Charité University Hospital); Prof Viktor Jirsa (Director, Systems Neuroscience Institute); Prof. Philippe Amouyel (Chair, JPND); Prof Steven Vermeulen (Chief Infrastructure Officer, EBRAINS; Innovation Director, Human Brain Project); Pierre Delsaux, Deputy Director General at DG SANTE, European Commission); Joke Jaarsma (Treasurer, European Brain Council & President, European Federation of Neurological Associations); Prof Pierre Magistretti (Professor Emeritus, Brain Mind Institute, EPFL); Prof Pieter Roelfsema (Director, Netherlands Institute for Neuroscience); Prof Monica Di Luca (President, European Brain Council); Frédéric Destrebecq (Executive Director, European Brain Council)*



*Prof. Christina Messa,  
Minister of University and Research, Italy*



*Panel Discussion with Claire Giry (Director General of Research and Innovation at the Ministry of Higher Education, Research and Innovation, France) and François Jacq (French Alternative Energies and Atomic Energy Commission), moderated by Frédéric Destrebecq (Executive Director, European Brain Council) and France Nivelle (Chief Communications and Content Officer, EBRAINS)*

# GENERATING KNOWLEDGE FOR FURTHER

A<sub>1</sub> C<sub>3</sub> T<sub>1</sub> I<sub>1</sub> O<sub>1</sub> N<sub>1</sub>

## Projects & Initiatives

### EBC PROJECTS > VALUE OF TREATMENT

#### Value of Treatment for Brain Disorders (VOT)

The [Value of Treatment for Brain Disorders \(VOT\)](#) is a health economics and outcomes research project. According to the World Health Organization, disorders of the brain – both neurological and mental alike – affect up to one in three people worldwide. The study addresses current unmet needs in healthcare and the increasing all-age burden of brain disorders by answering three questions:

1. What impact do care pathways have on outcomes?
2. What is the cost of optimised care pathways?
3. How to translate evidence on best healthcare interventions into policy recommendations?

EBC conceptualised in 2015 the Value of Treatment research framework with a first VOT study (2015-2017). Two additional rounds were developed respectively in 2019 (Rare Brain Disorders and Mental Disorders) and in 2020 (Transversal Topics).

#### Value of Treatment: 2<sup>nd</sup> Round



The second round of the Value of Treatment (VOT 2) project consists of 6 case studies.

- **3 case studies on rare brain diseases (ataxia, dystonia, phenylketonuria):** the study is looking at early intervention and explores the benefits and consequences of coordinated care through the examination of health services, patient outcomes and patterns of multidisciplinary care. Results will provide insight on the value of specialist centres for ataxia and dystonia and metabolic care units for phenylketonuria in terms of diagnosis, management of patients with rare brain conditions.

- **3 case studies on mental disorders (anorexia nervosa, autism, major depressive disorder):** the study is looking at early intervention and examines the benefits of improved detection, continuity of care and treatment and collaborative care patterns (also addressing mental health problems with comorbid medical conditions) on outcomes to patients and costs. Results will provide insight on the value of early intervention to improve children and young people's mental health and the causes of mental ill-health.



Case studies which combine a care pathway analysis followed by an economic evaluation (economic modelling) are analysed in collaboration with academic partners in line with the research framework, applying empirical evidence from different European countries.

Research collaboration:

#### ► Rare diseases case studies



Research conducted in closed collaboration with the European Reference Networks (ERN-RND and MetabERN).

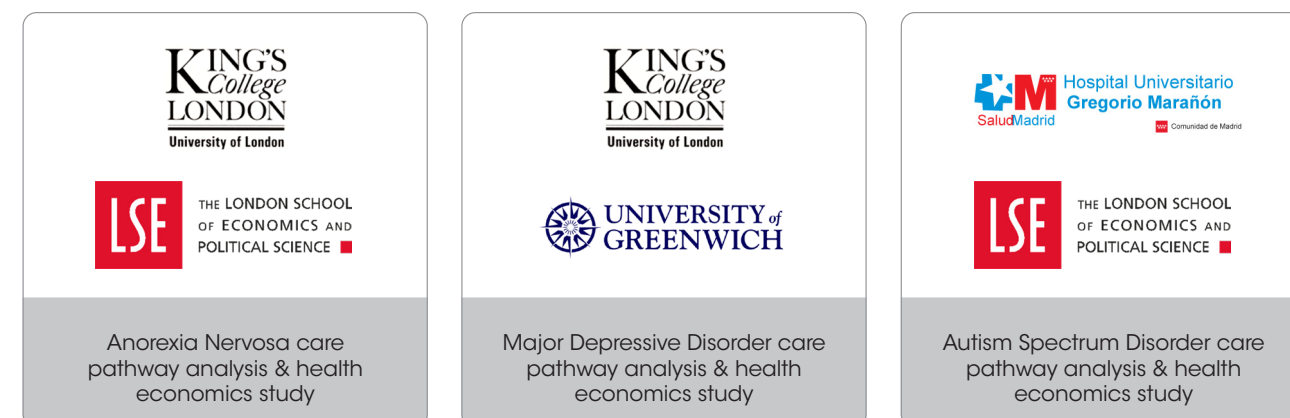
They are two of the 24 European Reference Networks (ERNs) approved by the ERN Board of Member States.

[ERN-RND](#) : neurological diseases

[MetabERN](#) : hereditary metabolic disorders



#### ► Mental disorders case studies



Moving on towards the project last phase (phase 3 “final results and publications”), EBC together with its members (EAN, EANS, ECNP, EFNA, EPA, EPNS, EUFAMI, FENS, GAMIAN-Europe, IBRO) and experts who are participating in the research convened a meeting on 8 June 2021 to present a synthesis of the VOT2 research project results so far. Summaries of case study results as well as a call to action will be released on the occasion of Brain Awareness Week 2022 to be followed by scientific publications. Beyond the research design and considering current context, the impact of COVID-19 on treatment and healthcare transformation will be also further explored during 2022.

## EBC PROJECTS > VALUE OF TREATMENT

### Value of Treatment: Transversal Topics

Kicked off in December 2020, a third stream of the [Value of Treatment](#) project on *Transversal Topics* is underway with a first case study on chronic pain disorders.



The working group study chaired by Professor Rolf-Detlef Treede nominated by the European Pain Federation (EFIC), includes experts nominated by the European Academy of Neurology (EAN), the European Psychiatric Association (EPA) and patient representatives from Pain Alliance Europe (PAE).

The scope of the study was defined and includes the following objectives:

1. To explore the patient pathway of adults of working age in three selected chronic pain diseases: fibromyalgia, painful diabetic neuropathy and non-specific low-back pain.
2. To compare Interdisciplinary Multimodal Chronic Pain Management with current care (monomodal therapy) in adults of working age.

The study seeks in particular to address the long waiting times to access primary care and lack of referrals to secondary & tertiary care identified as major gaps in the chronic pain disorders.

Results of the economic modelling/ cost effectiveness analysis are expected towards the spring 2023.

## EBC PROJECTS &gt; RETHINKING PROJECTS

## Rethinking the management of brain disorders

Despite improvements and innovation in recent years, people living with brain conditions face variations in access to optimal treatment and care. There is a lot about brain disorders that is not fully understood and the high-quality care and support needed by people living with these conditions is often unavailable.

# RETHINKING

## THE MANAGEMENT OF BRAIN DISORDERS

The aim of the [RETHINKING Projects](#) is to develop policy priorities around challenges in brain disorders and present a consensus on what needs to be achieved to resolve the most pressing challenges in brain conditions, today and in the future. There is a clear need to rethink the management of the brain disorders and redesign the care pathways to ensure optimal treatment and care for all people living with brain disorders in Europe.

## EBC PROJECTS &gt; RETHINKING PROJECTS

## RETHINKING MS in times of COVID-19

The COVID-19 pandemic affected us all, but it did not affect us all equally. People living with chronic conditions, such as Multiple Sclerosis (MS), have faced uncertainty and disruptions in their care pathways, and as a consequence, have dealt and will continue to deal with the long-term physical and emotional implications of not receiving optimal care.



The objective of this new chapter "[RETHINKING MS in times of COVID-19](#)", launched on the occasion of **World MS Day** on 30 May 2021, was to provide concrete and tangible testimonies from relevant stakeholders – clinicians, MS patients, patient advocates, pharma representatives – impacted by the disruption in care, which proved both an obstacle and an accelerator for the implementation of good practices.

We highlighted how the lives of people living with MS and their families have been affected by COVID-19. In addition to providing a voice to those side-lined by the pandemic response, the gathered testimonies shed light on the need to rethink MS and MS care in terms of coordination, integration and prioritisation in order to ensure optimal care for people living with MS in Europe. Our aim was to contribute to continued awareness raising of MS at EU policy level as well as to feed into the current European policy debate on the direct and indirect consequences arising from the COVID-19 pandemic and encourage stakeholder engagement in EU health policy making.



The launch of the policy report “RETHINKING MS in times of COVID-19” was accompanied by a virtual exhibition [‘Living with MS during COVID-19: A case for rethinking MS care in the EU’](#). This unique virtual exhibition featured people living with MS, clinicians, care givers, policymakers and industry representatives who want to make a difference in how MS care and treatment are delivered in Europe. The visitors of the exhibition could also explore videos and infographics showcasing the critical need for improved, patient-centred treatment.



EBC PROJECTS > RETHINKING PROJECTS

RETHINKING Migraine in times of COVID-19

Remaining second among the world’s causes of disability and first among young women according to findings from the Global Burden of Disease (GBD 2019), migraine is a complex neurological disease that has been identified as the leading cause of years lived with disability in people under the age of 50 years. Migraine often starts at puberty and mostly affects adults in their productive years, but it can also be present in children and the elderly. It is found to be the second most frequently identified cause of short-term absence for employees and amongst the five leading causes of emergency department visits. Patients with migraine also have an increased incidence of co-morbid psychiatric and medical conditions, resulting in complex cases of chronic multidimensional migraine. Despite the considerable individual and societal consequences, migraine remains undiagnosed and under-treated in at least 50% of patients and less than 50% of migraine patients consult a physician. Worldwide, physicians receive only minimum education on headache disorders during their medical training.



The objective of the project “RETHINKING Migraine in times of COVID-19”, to be launched in 2022, is to shed light on how people living with migraine have been impacted by the pandemic, which good practices have been put in place, how we can make them sustainable and what lessons can be learnt from this experience to provide optimal care. We will conduct a comprehensive literature review of the recent publications and provide concrete and tangible testimonies of all relevant stakeholders. Clinicians, migraine patients, patient advocates and pharma representatives have been impacted by the disruption in care, which proved both an obstacle and an accelerator for the implementation of good practices. Qualitative research undertaken through semi-structured interviews will allow us to gather valuable insight into the stakeholders’ personal experiences during the COVID-19 pandemic: the challenges they faced and the strategies they used to handle them.

## EBC PROJECTS &gt; GOLUP

## GOLUP

The Declaration on Good Off-Label Use Practice (or GOLUP Declaration) was created in 2017 to develop a homogeneous regulatory framework on the use of off-label medicines in Europe and received support from 12 organisations.



Promoting **good** practice for the off-label **use** of medicines

Off-label use is defined as the practice of using a medicine outside its authorised indication. It plays an important part in some medical areas, since it can be of benefit to patients when no other treatment option is available, such as it is often the case in rare diseases or in the case of child and adolescent care.

The GOLUP Declaration recommends that off-label use of medicinal products should only occur if certain criteria are met. These criteria, drawn together by independent experts, stem from decades of research and clinical practice and serve to provide a clear framework on when and how the off-label use of medicinal products could safely take place.

During the 2021, the consortium that supports the Declaration promoted a series of initiatives to revitalise the document linking it with many health-related issues that were connected to the principles of this Declaration (e.g. EU Pharma Strategy, revision of the cross-border care directive, Green Paper on Ageing).

Two events were organised, involving patients, clinicians and stakeholders. The first event took place on 17 June 2021 on the topic of [“Patient safety and informed consent: The importance of good off-label use practices”](#), during which was premiered the [video](#) made in collaboration with Euractiv to explain what the Declaration is to a wider audience. The second event took place on 30 November 2021 on the topic of [“Best practices for patient safety: An EU-wide view on the use of medicines off-label”](#).

Articles about GOLUP Declaration have been featured in the [Stockholm Science City website](#) and the [Parliament Magazine](#).

👁 [braincouncil.eu/golup](https://braincouncil.eu/golup)

## EU-FUNDED PROJECTS &gt; EBRA

## European Brain Research Area (EBRA)

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 2021, the following EBRA activities took place:

- A landscape of brain research in Europe was re-submitted to the European Commission
- Writing of the Shared European Brain Research Agenda (SEBRA)
- 2 new brain research communities (clusters) were selected
- 7 cluster meetings took place and 1 overarching data sharing workshop
- 1 quality assurance workshop
- 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 assigned to each project. The number of projects per topic, the budget and other relevant parameters were analysed. The European Research inventory and mapping report – was submitted to the European Commission in October 2021 and approved in November 2021. It will be shared with the brain research community through different channels (website, social media, articles) in 2022.

More info: [www.ebra.eu/mapping-report/](https://www.ebra.eu/mapping-report/)



## 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 serves 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. In 2021, the future priorities and enabling actions were written down. This document will be shared for consultation with the broader brain research community in 2022.

### EBRA's clusters<sup>1</sup>

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 2021, 2 new EBRA clusters have been selected: the Predictive Models Systems (PREMOS) cluster and the European Cluster for Imaging Biomarkers (ECIB).

The PREMOS cluster is led by Prof. S. Höltér-Koch and aims to enhance the alignment of EU disease model development resources and preclinical research expertise with clinical and brain research community needs across academia and industry.

More info: [www.ebra.eu/premos/](http://www.ebra.eu/premos/)

The ECIB cluster is led by Prof. T. Van Eimeren and Prof. S. Cappa and their ambition is to achieve transformative leaps in the translation of “big-imaging-data”-research into scientific and medical innovations by creating critical synergies between neuro-imaging projects at both European and global level.

More info: [www.ebra.eu/ecib/](http://www.ebra.eu/ecib/)

## Cluster Activities

In total, 7 cluster meetings were organised in 2021.

On the 23<sup>rd</sup> and 24<sup>th</sup> of February, the Prevention of Severe Mental Disorders (PSMD) cluster, coordinated by Prof. Paolo Fusar-Poli and Prof. Ole A. Andreassen, undertook the important initiative of organizing a two-day workshop on the ethics of precision psychiatry. The workshop involved key leaders from different professional backgrounds and stakeholders (including individuals with lived experiences) and gathered consensus on a core blueprint to advance ethics of precision psychiatry. The output of this workshop consists of a white paper presenting a critical review of the evidence and practical recommendations to manage ethical barriers to precision and preventive psychiatry.

On March 19<sup>th</sup>, the PREMOS cluster held its first working group meeting on the translational value of animal models. During the meeting, the coordinators of the 3 main large networks INFRAFRONTIER, PRISM and EQUIPD discussed the priorities of their networks with respect to the identified translational gaps. A 2<sup>nd</sup> working group meeting was organised on the 1<sup>st</sup> of July. Clinicians were asked about their requirements for animal models to be considered clinically relevant and having predictive value. A 3<sup>rd</sup> working group was organised in Brussels on the 11<sup>th</sup> of October. During this meeting, the cluster worked on a consensus on the way forward to present to the stakeholders (including patient groups) in 2022.

On May 10<sup>th</sup> the first meeting of the ECIB cluster took place. The coordinators introduced ECIB and the aims of the project and discussed several aspects of their survey (aims, target audience, methods, categories, questions, answer categories) on imaging biomarkers.

On October 6<sup>th</sup>, EPICLUSTER organised their 3<sup>rd</sup> activity “*Accelerating Patient Involvement in European Epilepsy Research*”. With the goal to showcase ways and best practices for bringing people with epilepsy and researchers to work together on common ground. The EPICLUSTER event aimed to unveil the opportunities arising from patient involvement in epilepsy research. The workshop began with an overview of definitions, trends, and key themes around PPI and how they could successfully advance epilepsy research. Hints and case histories lead participants to learn the “why”, “how”, and “what” of patient involvement in research.

On October 18<sup>th</sup> and 19<sup>th</sup>, the BRAINFOOD cluster came together to discuss the state of the art and the problems and gaps in the BRAINFOOD field and the potential of nutrition for brain health. Neurologists and psychiatrists as well as representatives from patient organisations and the food industry joined and shared their perspectives on the topic. This meeting will result in a policy paper: Towards new nutritional policies for an improved brain health: A research perspective on future actions.

More info: [www.ebra.eu/existing-clusters](http://www.ebra.eu/existing-clusters)

## Addressing data - related challenges

On the 17<sup>th</sup> of March 2021, the European Brain Research Area (EBRA) workshop "Everything You Always Wanted to Know About Data Sharing" took place virtually from 9 am to 1 pm. This workshop was co-organised by EBC, EPFL-EBRAINS and ERANET-NEURON. It was designed to support the EBRA clusters regarding data-related challenges and for them to share their needs and questions. A report of the workshop can be found here: [https://www.ebra.eu/wp-content/uploads/2021/04/EBRA\\_DataSharingWorkshop\\_Report\\_20210406-1.pdf](https://www.ebra.eu/wp-content/uploads/2021/04/EBRA_DataSharingWorkshop_Report_20210406-1.pdf)

## Promoting quality assurance

In November 2021, the EBRA partner, ERANET-NEURON, organised a workshop on robust evidence in translational biomedicine for experienced researchers, PostDocs and Principal Investigators (PIs) at the BIH QUEST Center – Charité in Berlin, Germany. Besides presentations on translational validity, reliability and robust evidence a major part of the program concerned interactive rounds to discuss these complex issues in an open and constructive way.

## EBRA goes global

General awareness has been raised on EBRA and SEBRA during digital events. In March 2021, SEBRA was featured in an article in the European Academy of Neurology (EAN) Pages, a monthly circular shared within EAN's network of over 45,000 neurologists. This article was titled "The Future of Brain Research: EU-Initiatives and Experts Together for a Shared European Brain Research Agenda". In April 2021, an introduction to SEBRA was included in an EBRA session in the context of the European Psychiatric Association annual congress (EPA Virtual Congress) of over 3000 attendees, accompanied by a spotlight on a number of EBRA's clusters entitled "A Catalysing Initiative for Brain Research Stakeholders to Streamline Brain Research across Europe". In June 2021, SEBRA was presented within an EBRA Special Session as the European Academy of Neurology (EAN) Virtual Congress, which in 2021 brought together over 11,000 virtual delegates worldwide. In August 2021, SEBRA was again featured, this time within a Special Session at the Federation of European Neuroscience Societies (FENS) Virtual Regional Meeting. A full recording is also available for further dissemination online, which has been circulated on the EBRA social media channels. In October 2021, SEBRA was presented at the EMEAC Digital Day, organised by the International Federation of Clinical Neurophysiology (EMEAC-IFCN), alongside a presentation by one of the clusters, EPICLUSTER. Finally, a FENS webinar on the importance of coordination and collaboration in the brain space was organised in December 2021, and chaired by FENS President, Prof. Jean-Antoine Girault.

More info: [www.ebra.eu/news-events](http://www.ebra.eu/news-events)

🐦 [@EBRA\\_EU](https://twitter.com/EBRA_EU)

🌐 [ebra.eu](http://ebra.eu)

👁️ [ebra.eu](http://ebra.eu)

## EU-FUNDED PROJECTS > MULTI-ACT

### MULTI-ACT

The [MULTI-ACT project](#) "A Collective Research Impact Framework and multivariate 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 1<sup>st</sup> of May 2018 received funding from the EU Horizon 2020 Research and Innovation Programme and ended in May 2021.

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 multistakeholder 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.

After 3 years of work, the MULTI-ACT project [final conference "The MULTI-ACT model: the path forward for participatory governance in health research and innovation"](#) took place virtually on 23 March 2021 with a view to showcase the work done and the results achieved over the past years by the project consortium. The conference was led by EBC as the partner responsible for communication and dissemination. The main outcomes of the event can be watched in the [highlights video](#).

EBC was also responsible for testing and applying the tools and guidelines in specific areas of brain disorders.

🐦 [@MULTIACTProj](https://twitter.com/MULTIACTProj)

🌐 [MULTI-ACT Project](http://MULTI-ACT Project)

👁️ [multiact.eu](http://multiact.eu)

## EU-FUNDED PROJECTS &gt; ADDP

## Alzheimer's Disease Detect and Prevent (ADDP)



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 personalized 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.

The project came to an end in November 2021.

 [@addp\\_eu](https://twitter.com/addp_eu)

 [Alzheimer's Disease Detect and Prevent](https://www.linkedin.com/company/alzheimer-s-disease-detect-and-prevent/)

 [addp.eu](https://addp.eu)

## EU-FUNDED PROJECTS &gt; BRAINTEASER

## Brainteaser



Officially started on the 1<sup>st</sup> of January 2021, the EU-funded project [BRAINTEASER](#) aims to integrate societal, environmental and health data to develop patient stratification and disease progression models for Amyotrophic Lateral Sclerosis (ALS) and Multiple Sclerosis (MS). ALS and MS are two very complex degenerative neurological diseases, but with very different clinical picture, evolution, prognosis and therapies. Common features are that both these chronic diseases affect the nervous system and progressively modify the quality of life of the patients and their families in a significant way.

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

The project brings together 11 partners, a multidisciplinary consortium from academia, industry, clinical settings and the non-profit sector coming from six European countries. EBC leads the coordination activities with related EU-funded and other projects to foster the exchange of information and collaboration on common issues. EBC also supports the project co-design activities as well as BRAINTEASER communication, dissemination and exploitation initiatives.

 [@brainteaser2020](https://twitter.com/brainteaser2020)

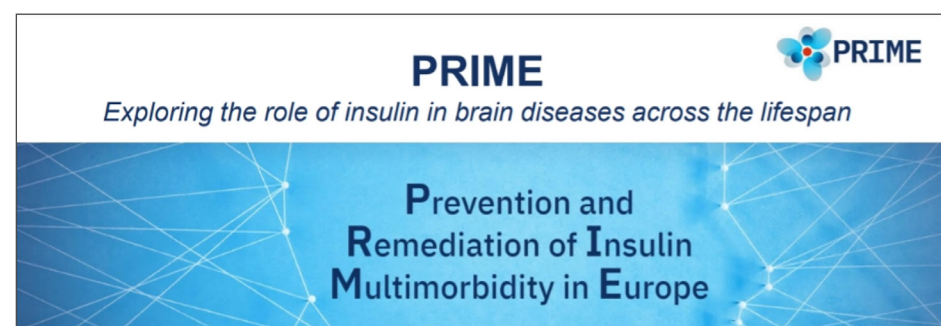
 [BRAINTEASER Project](https://www.linkedin.com/company/brainteaser-project/)

 [brainteaser.health](https://brainteaser.health)



## EU-FUNDED PROJECTS &gt; PRIME

## PRIME



EBC is one of the dissemination and communication partners in 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).

🐦 [@PRIME\\_H2020](https://twitter.com/PRIME_H2020)

🌐 [PRIME Horizon2020](https://www.prime-horizon2020.eu/)

👁️ [prime-study.eu](https://prime-study.eu)

## EU-FUNDED PROJECTS &gt; ASCTN-TRAINING

## ASCTN-Training



ASCTN-Training is a four-year project (2018-2022) funded by the European Union Horizon 2020 Programme under the Marie Skłodowska-Curie Initial Training Network. ASCTN-Training is addressing existing gaps within Human Stem Cell-based Neuronal disorders (NDs) Modelling (NDM) for research to develop new medicines for the treatment of neurological disorders (e.g. Parkinson's, Huntington's and Demyelination's diseases), which occur as a result of acute or progressive loss of cells, glial or neuronal, and structures and function in the brain.

In April 2021, EBC organised a workshop for the ASCTN early-stage researchers on the role of science in the European policy-making process with the aim to empower them with ways to become a voice for neuroscience research throughout their careers. Participants were introduced to the European policy-making environment and took part in mock-up sessions engaging with policy makers on different scenarios. They could also interact in a panel discussion on career opportunities in science policy and advocacy.

🐦 [@asctntraining](https://twitter.com/asctntraining)

🌐 [ASCTN Training](https://www.asctn-training.net)

👁️ [asctn-training.net](https://asctn-training.net)



# ENGAGING THE COMMUNITY

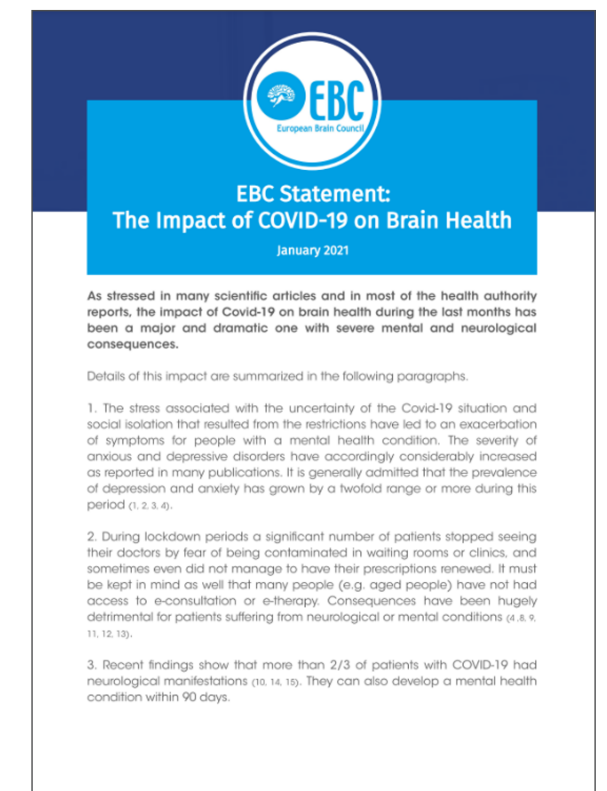
## Advocacy & Outreach

### ADVOCACY & OUTREACH > COVID-19

In 2021 – over a year into the COVID-19 pandemic – EBC continued to monitor the growing evidence of its impact on the brain. Following the first EBC statement [on Lessons learned from COVID-19: the importance of putting health and research first](#) in April 2020, the scientific and medical worlds grappled to understand COVID-19 and the pathophysiological mechanisms underlying the disease, and EBC continued to gather concrete information made available by ongoing research.

In January 2021, EBC released a statement on [the impact of COVID-19 on brain health](#) highlighting the severe mental and neurological consequences of the disease and the strict confinement regulations most governments around the world had put in place. The statement also listed what was known at the time of the relations between COVID-19 and the brain, concluding with the recommendation to recognised COVID-19 as a brain disease, with increased mental and neurological disorders, and for this perspective has to be taken into consideration when choosing the most appropriate and effective way to support research linked to the epidemic.

Throughout the year, the [COVID-19 resources page](#) was also continuously updated with the latest information and with activities led by EBC's members around the pandemic.



Additionally, EBC also centred a few of its core activities around COVID-19, including a Brain Innovation Days event and an extension of the RETHINKING MS project.

The Brain Innovation Days Digital Session, [“Fast-tracking brain innovation in times of COVID-19”](#), took place on 27 April 2021, and explored the positive direct and indirect results of the COVID-19 pandemic response and research on the brain innovation ecosystem. The session featured key opinions leaders, patient testimonials, clinicians, representatives from the EU and WHO level and the industries that were forced to adapt to this rapid change of pace in innovation.

On the occasion of World Multiple Sclerosis Day (30 May 2021), a new policy paper, [“RETHINKING MS in times of COVID-19”](#), was released. This new paper accompanied the original “RETHINKING MS in Europe”, a research-driven project offering tangible policy changes to improve the lives of people living with MS across Europe, building on the 2017 Value of Treatment report. A virtual exhibition was also opened to view portraits featuring people living with MS, clinicians, care givers, policymakers and industry representatives who want to make a difference in how MS care and treatment are delivered in Europe.



## ADVOCACY & OUTREACH > VISIBILITY

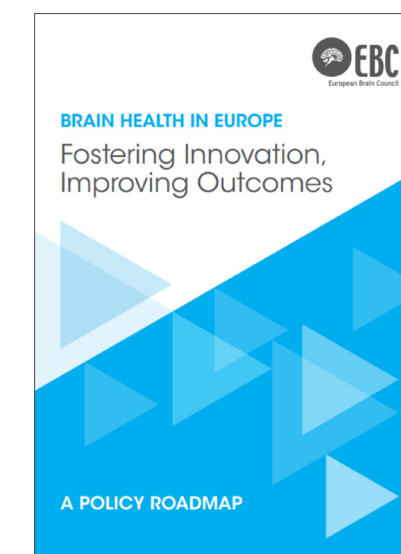
### Brain Awareness Week

Brain Awareness Week 2021, despite the ongoing pandemic hindering EBC from hosting its annual European Parliament event, was busy nonetheless.

On Tuesday, 16 March, EBC held a virtual Brain Awareness Week event in partnership with members European Federation of Neurological Associations (EFNA) and GAMIAN-Europe, focused on [Patient Engagement in EU-Funded Brain Research Projects](#), which brought together patients/patient representatives, policymakers and European Commission representatives as well as project/initiative leads. The event explored the current state of patient engagement in EU-funded Brain Research projects, looking at IMI and MULTI-ACT as concrete examples and solutions and analysing in discussion with key officials what has been done and what can still be done in order to guarantee change.

The release of the EBC Policy Roadmap, [Brain Health in Europe: Fostering Innovation, Improving Outcomes](#), was also officially announced at the Brain Awareness Week event and circulated online throughout the week. Driven by the belief that enhanced multi-stakeholder engagement in the brain health ecosystem is needed to foster dialogue, exchange knowledge, facilitate business development, showcase ongoing projects, and accelerate investment in brain disorders, research and innovation for the benefit of patients, the paper sets out key recommendations to stimulate investment in brain disorders and to implement change, highlighting the need to create an enabling environment which promotes brain health in Europe.

EBC was also pleased to be part of the launch of the [One Neurology](#) initiative, conceived by the European Federation of Neurological Associations (EFNA) and the European Academy of Neurology (EAN). The OneNeurology initiative 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 One Voice for Neurology podcast series was also released which included episodes featuring EBC's President, Monica Di Luca and Executive Director, Frédéric Destrebecq. The initiative also includes multiple resources, including infographics and key neurology facts.





[illegible]

Research Article  
 DOI: 10.31840/2574-2809.2023.12121

Journal of  
 Clinical Neurology and Neurosurgery  
 Open Access

# Rethinking MS in Europe: Prioritizing Time, Integrated Care for People with Multiple Sclerosis

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<sup>9</sup>Department of Clinical Neurology, University of Oxford, Oxford, UK  
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<sup>11</sup>Department of Clinical Neurology, University of Oxford, Oxford, UK  
<sup>12</sup>Department of Clinical Neurology, University of Oxford, Oxford, UK  
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**Abstract**

**Background:** Multiple Sclerosis (MS) is a progressive neurological disease that has a wide clinical spectrum. It is one of the most prevalent causes of disability in young adults in Europe. With the 2019 European Union Affected Areas European Neurological Disorders (EUNED) survey, we explored the current state of MS in Europe, with a focus on the impact of the COVID-19 pandemic on MS care and the need for a more integrated and patient-centered approach to MS care.

**Methods:** We study in-depth reported data regarding patient experience and current evidence on diagnosis, management, and the impact of the COVID-19 pandemic on MS care. We also explore the impact of the COVID-19 pandemic on MS care and the need for a more integrated and patient-centered approach to MS care.

**Results:** Despite significant progress in the understanding of MS, there is still a need for a more integrated and patient-centered approach to MS care. The COVID-19 pandemic has highlighted the need for a more integrated and patient-centered approach to MS care.

**Conclusion:** Rethinking MS in Europe is a necessary process to ensure patient care and support of all people with MS. The COVID-19 pandemic has highlighted the need for a more integrated and patient-centered approach to MS care.

**Keywords:** Multiple Sclerosis (MS), COVID-19, Neurological Disorders, European Union, Multiple Sclerosis, COVID-19, Neurological Disorders, European Union, Multiple Sclerosis, COVID-19, Neurological Disorders, European Union

## Introduction

Multiple Sclerosis (MS) is a progressive neurological disease that can have a wide clinical spectrum. It is one of the most prevalent causes of disability in young adults in Europe. With the 2019 European Union Affected Areas European Neurological Disorders (EUNED) survey, we explored the current state of MS in Europe, with a focus on the impact of the COVID-19 pandemic on MS care and the need for a more integrated and patient-centered approach to MS care.

Despite significant progress in the understanding of MS, there is still a need for a more integrated and patient-centered approach to MS care. The COVID-19 pandemic has highlighted the need for a more integrated and patient-centered approach to MS care.

Rethinking MS in Europe is a necessary process to ensure patient care and support of all people with MS. The COVID-19 pandemic has highlighted the need for a more integrated and patient-centered approach to MS care.

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Brain Awareness Week 2021 also saw a series of EBC-led publications launch, including an article in Health Europa Quarterly on ["The importance of prioritising brain health"](#), a publication in the inaugural edition of Aging Brain on ["Future of the aging brain: Bridging the gap between research and policy"](#) as well as the publication of the Rethinking MS project findings, ["Rethinking MS in Europe: Prioritising Timely, Integrated Care for People with Multiple Sclerosis"](#), in the Journal of Clinical Neurology and Neurosurgery.

[illegible][illegible]Journal of Clinical Neurology  
and Neurosurgery

## ADVOCACY & OUTREACH > 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.

This year, EBC joined the community on **Rare Disease Day (28 February)**, highlighting the project “Bridging the gaps and achieving seamless, coordinated care for people affected by rare diseases”, which is currently underway as part of the [Value of Treatment](#).


The **World Multiple Sclerosis Day (30 May)** was marked by the launch of the EBC policy paper [“RETHINKING MS in times of COVID-19”](#), seeking to renew attention and prioritisation of the needs of people living with multiple sclerosis (MS) in Europe, and, above all, to call for timely, personalised and adapted care. The launch of the paper was accompanied by the virtual exhibition [“Living with MS in times of COVID-19: A case for rethinking MS care in the EU”](#) featuring portraits of people supporting the RETHINKING MS call.


European Brain Council  
@EU\_Brain

300 million people live with a rare disease worldwide.

On [#RareDiseaseDay](#) it's fundamental to remember that people living with a rare disease need equitable access to diagnosis, treatment and [#care](#).  
[@rarediseaseday](#) [@eurordis](#)  
Read more [▶ bit.ly/3knBWFZ](#)

**"A RARE DIAGNOSIS  
DOES NOT  
DEFINE HER."**



 RARE DISEASE DAY® [VIEW ANGELINA'S STORY AT RAREDISEASEDAY.ORG](#)

 **European Brain Council**  
@EU\_Brain

📣 On the occasion of [#WorldMSDay](#), EBC launches a new policy paper "RETHINKING MS in times of [#COVID19](#)" 🦠!

👤 Read the paper & visit the virtual [exhibition](#), featuring people who want to make a difference in [MScare](#) 🖱️ [bit.ly/3yJZ770](https://bit.ly/3yJZ770)



👤 EFNA and 9 others



European Brain Council  
@EU\_Brain

Today we recognise **#WorldBrainDay2021!** 🧠

Let's make everyday **#brain** day and promote **#brainresearch** with the goal of improving the lives of the estimated 179 million Europeans living with brain conditions, mental & neurological alike.

 [braincouncil.eu](https://braincouncil.eu)



World Brain Day  
22 July 2021

12:41 pm • 22 Jul 2021 • Hootsuite Inc.



European Brain Council  
@EU\_Brain

The risk for major depression is **3** times higher for a person with alcohol dependence.

This is why it is important to raise awareness on alcohol-related harms during this **#AWARH21**. Follow **@AwarhEurope** & visit [awarh.eu](https://awarh.eu) to discover all the initiatives.



Awareness Week on Alcohol Related Harm™ 2021

Depression Risk

Harmful use of alcohol or dependence may be a risk factor for depression and vice versa

Awareness Week on Alcohol Related Harm™ 2021

#awarh21 - [www.awarh.eu](https://www.awarh.eu)

11:40 am • 15 Nov 2021 • Hootsuite Inc.

EBC joined the world brain community on **World Brain Day (22 July)** which this year's theme was "Stop multiple sclerosis" to ensure early diagnosis, provide better access to life-changing treatments and advocate for improved quality of life for those living with multiple sclerosis (MS) and their caregivers.

EBC is one of the official partners of the **Awareness Week on Alcohol Related Harm (15-19 November)**, initiated in 2013 by a group of like-minded organisations following three roundtable meetings on an integrated approach to alcohol-related harm. The 9<sup>th</sup> edition was held under the theme "A Safer Europe" with a focus on two specific safer interventions: the restrictions or bans of alcohol marketing, sponsorship and promotion; and the use of taxation and pricing policies as a way of reducing alcohol-related harm to society.

# ADVOCACY & OUTREACH > VISIBILITY

## Disease fact sheets

[EBC disease fact sheets](#) provide 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.

The fact sheets on the following diseases are currently available: Alzheimer's disease, depression, epilepsy, migraine, multiple sclerosis, Parkinson's disease, schizophrenia and stroke.



I ❤️ MY BRAIN

Alzheimer's disease

Fact Sheet

What is Alzheimer's disease?

Key facts

History

Risk factors of Alzheimer's disease

Diagnosis

Symptoms

Further information

References

Acknowledgements



# KEEPING BRAIN RESEARCH IN THE SPOTLIGHT

## Media report

### Thought Leader: Putting brain health at the top of Europe's health agenda

Brain health must take centre stage in the EU's renewed focus on health policy, wrote Prof. Monica Di Luca, EBC President, in the Parliament Magazine Thought Leader article titled ["Putting brain health at the top of Europe's health agenda"](#). A European brain health strategy is critical to fostering innovation and to improving the lives of those affected by brain disorders, encompassing both neurological and mental disorders alike. Brain disorders are widespread and highly disabling conditions that are often difficult to treat.

The Thought Leader piece was accompanied by an editorial raising awareness of the need to prioritise brain disorders, a call led by MEPs Maria da Graça Carvalho (EPP, Portugal) and Tomislav Sokol (EPP, Croatia).



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

Prof. Monica Di Luca, EBC President, Frédéric Destrebecq, EBC Executive Director and Stephanie Kramer, EBC Head of Communications, Advocacy & Policy, contributed to the inaugural issue of Aging Brain with a publication on ["Future of the aging brain: Bridging the gap between research and policy"](#), examining the current state of brain research and looking ahead at our vision for research and policy on the ageing brain in the next decades. While Brain Research, has been considered a priority for European funding, and it has been a recipient of the European budget for medical research, the significant burden of brain conditions, neurological and mental alike, on society explains the growing societal need to expand brain research in Europe and to increase the overall funding. Only through continued and coordinated support can it be hoped that real solutions will be found. Relentless prioritisation efforts are therefore needed to make sure that brain disorders remain high on the health policy agenda at EU and global level.

## The importance of prioritising brain health

Stephanie Kramer, EBC Head of Communications, Advocacy & Policy, discussed with Health Europa, addressing the need for collaboration, research and increased support for brain health, in the article entitled [“The importance of prioritising brain health”](#). She explained the role and the main objectives of the EBC in the European brain health sector and the key challenges currently facing the management and treatment of brain conditions, both mental and neurological alike. It was also discussed how increased collaborative efforts between the medical, industry and policy fields could accelerate research and innovation as well as notable developments or current issues in the world of brain research, such as the growing evidence of the severe mental and neurological consequences of COVID-19.

## Brain conditions, mental and neurological alike

Prof Monica Di Luca, President, European Brain Council, shed light on brain conditions, mental and neurological alike, starting with comment on the burdens presented in the article [“Brain conditions, mental and neurological alike”](#) featured in Open Access Government. Brain conditions, mental and neurological alike, account for a large burden on the European population. In 2017, 307.9 million neurological disease diagnoses alone were counted in the EU28 countries — 540.3 million neurological diseases in the WHO European region. Despite this high prevalence, numerous conditions of the brain are shrouded in mystery and remain without disease-modifying treatments or cures. Compared to other disease areas, the pace of innovation in this field has traditionally been hindered by multiple factors, starting with the complexity of the brain itself.

**HEALTH EUROPA**

Home > News > Research & Innovation News > The importance of prioritising brain health

**The importance of prioritising brain health**

10th March 2021



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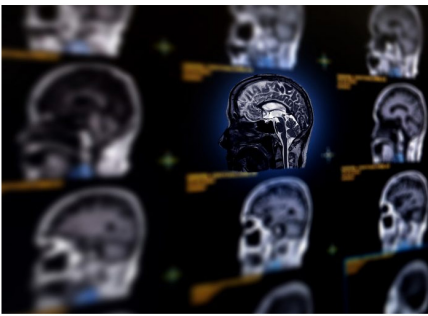
**The European Brain Council's Stephanie Kramer tells HEQ about collaboration, research and the need to support brain health.**

Brussels-based non-profit organisation [the European Brain Council](#) (EBC) aims to act as a single voice for the 179 million Europeans living with mental or neurological brain conditions. EBC Head of Communications, Advocacy and Policy Stephanie Kramer talks about prioritising brain health and the burden, treatment and policy needs of brain conditions.

Home > Open Access News > Research & Conditions News > Brain conditions, mental and neurological alike

**Brain conditions, mental and neurological alike**

November 20, 2020



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**Prof Monica Di Luca, President, European Brain Council, sheds light on brain conditions, mental and neurological alike, starting with comment on the burdens presented**

## A harmonised EU approach to the off-label use of medicines?

The European Brain Council's Frédéric Destrebecq and MEP Cyrus Engerer explained in the Parliament Magazine article [“A harmonised EU approach to the off-label use of medicines”](#) how European patients can benefit from a properly regulated off-label medicine framework. The COVID-19 pandemic has shown us how important coordination among countries is when responding to health threats. It also revealed the crucial role the EU can play in promoting joint health responses that fully respect each Member States' role in governing their health systems.

**COMMERCIAL CONTENT**

**EU ACTION NEEDED ON OFF-LABEL MEDICINES**

**The EU has a role to play in regulating the use of off-label medicines, says Cyrus Engerer**

The COVID-19 pandemic has shown us how important coordination among countries is when responding to health threats. It also revealed the crucial role the EU can play in promoting joint health responses that fully respect each Member States' role in governing their health systems.

However, despite this robust EU system of approval, medicines are routinely used that are not approved, this is called "off-label" use (meaning that the medicine is not used for their approved indication or method). It is a

development and approval of medicines is sometimes needed. When Europe was scrambling for a possible COVID-19 treatment there was, for example, a growing call for identifying the effectiveness of existing drugs for treating COVID-19, a practice called repurposing. In October, the European Medicines Agency launched "Repurposing of authorised medicines pilot to support not-for-profit organisations and academia" a project which forms part of the Pharmaceutical Strategy which aims to support the repurposing of existing medicines for a wide range of disease areas.

However, despite this robust EU system of approval, medicines are routinely used that are not approved, this is called "off-label" use (meaning that the medicine is not used for their approved indication or method). It is a

**"EU patients should receive the same access to safe and effective treatments, irrespective of where in the Union they live"**

legal and mostly necessary practice in many disease areas, where there are currently no suitable approved alternatives available. This means physicians are left to determine, at their own discretion, whether an individual patient will have greater medical benefit from an off-label alternative drug.

However, some authorities take advantage of the existence of this prescriber freedom to promote off-label use at a wide scale, aimed at driving down health care costs. This is unacceptable since it increases the risk for patients that would otherwise have received an approved and safe alternative

MEP Cyrus Engerer is a member of Parliament's Environment, Public Health and Food Safety Committee

**GOLUP**

Promoting good practice for the off-label use of medicines

stakeholders, we call for a Good Off-Label Use Practice, a blueprint for a clear, European-wide framework to ensure patients' safety and help healthcare professionals make more informed decisions when prescribing medicines "off-label". The Practice states that off-label should only be used when a qualified health care professional feels that there is a clear medical need. If there are no other on-label treatments available or authorised treatments have failed, if there is scientific evidence in the literature that supports the use, if patients are adequately informed of the possible risks and benefits of the medicines, and the results must be reported by the healthcare professional in the patient file and also by patients themselves.

However, gradually this system is being bypassed, bringing real risks to patients in Europe. Just in May last year, EURACTIV reported that the practice of using medicines "off-label" to induce labour in pregnant women had led to severe health implications and even death. There is always a varying chance of adverse reactions if and when people are prescribed medicines not approved for that particular use - a practice which is commonly referred to as using medicines "off-label".

Doctors are free to prescribe the use of a medicine "off-label", when there is no good alternative medicine, and the doctor believes the possible benefit to the patient outweighs the safety risk. This happens in many disease areas, including oncology, psychiatry, paediatrics and rare disease, to name a few.

Everyone agrees that this concept of "off-label" use is positive, since it is based on the trust placed in doctors to make the best decision for their patients. An important part of this exception is the discussion between doctor and patient - it is the responsibility of the doctor that the patient is fully aware that the medicine is "off-label", and understands the risks involved.

However, off-label use is now increasingly being used in health systems to save money, with off-label medicines deliberately being given to patients when there are already approved medicines available. And in most cases patients are not adequately informed

**There are serious safety concerns with large-scale off-label use of medicines, says the European Brain Council's Frédéric Destrebecq. This is why we have come together with other Brussels health stakeholders to propose common European guidelines for when and how off-label prescription should take place.**

**Best Practices for Patient Safety: An exchange on off-label use**

You are invited to join us on **30 November**, between 0.30 - 4.00 pm (CET) for a discussion among patients, clinicians and policymakers about how we can ensure greater awareness of the use of medicines off-label through the exchange of ideas and best practices from different European countries.

**SCAN TO REGISTER**

**THIS CONTENT WAS COMMISSIONED BY GOOD OFF-LABEL USE PRACTICE (GOLUP) AND PRODUCED BY DOGS**

1. European Commission drug use to induce labour in pregnant women in Europe: <https://www.ecdc.europa.eu/en/health-consumers/news/news-articles/medicines-agency-advise-on-use-of-off-label-drugs-to-induce-labour> (Date of Access: 07.11.2021)

## THE PARLIAMENT

POLITICS, POLICY AND PEOPLE MAGAZINE



“In most cases patients are not adequately informed about what is happening, nor being told about the risks involved, and are therefore exposed unnecessarily to increased risks of adverse events”



“EU patients should receive the same access to safe and effective treatments, irrespective of where in the Union they live”



# TOGETHER FOR THE

B<sub>3</sub> R<sub>1</sub> A<sub>1</sub> I<sub>1</sub> N<sub>1</sub>

## EBC Collaboration

### COLLABORATION

#### ONE NEUROLOGY

The [OneNeurology initiative](#), conceived by the European Federation of Neurological Associations (EFNA), launched on the occasion of Brain Awareness Week. Under the OneNeurology Partnership, international neurological organisations and regional umbrellas are united to make neurology a global public health priority. It is a multi-stakeholder, patient-focused partnership which aims to strengthen neurology-related groups to stimulate collaborative advocacy, action and accountability for the prevention, treatment and management of neurological disorders worldwide.



From advocacy to capacity-building to awareness raising – the partners want to demonstrate what makes all neurological disorders ONE and what's in it for the community, and wider society, if they are all addressed together, in parallel to disease specific advocacy activities, the central element of the Initiative is a Global Partnership. Here international disease specific organisations and regional umbrellas are uniting to make neurology a global public health priority!

The focus of this Partnership in 2021 was influencing the development of the World Health Organisation's new Global Action Plan on epilepsy and other neurological disorders [GAP]. The GAP represents a unique opportunity to build an integrated response to neurology across the life course and within healthcare systems – to improve lives of people living with neurological disorders worldwide. To succeed the community needs to mobilise to ensure that the plan serves the needs of all those living with neurological disorders across the globe.

## SCIENTIFIC CONGRESSES

### EPA CONGRESS

EBC took part in the 29<sup>th</sup> European Congress of Psychiatry, organised by the European Psychiatric Association on 10 - 13 April 2021. In the framework of the congress, the European Brain Research Area (EBRA) held a workshop on the topic ["The European Brain Research Area: a catalysing initiative for brain research stakeholders to streamline brain research across Europe"](#).

EBC had the possibility to showcase some of the ongoing projects such as EBRA and the 2<sup>nd</sup> Round of Value of Treatment and for the first time the EBC Policy Roadmap.



## "THE EUROPEAN BRAIN RESEARCH AREA: A CATALYSING INITIATIVE FOR BRAIN RESEARCH STAKEHOLDERS TO STREAMLINE BRAIN RESEARCH ACROSS EUROPE"

29<sup>th</sup> European Congress of Psychiatry  
Monday, 12.04.2021  
15:30 - 17:00 - Channel 5



## SCIENTIFIC CONGRESSES

### EAN CONGRESS

EBC took part in the 7<sup>th</sup> Congress of the European Academy of Neurology, that took place virtually on 19-22 June 2021. The attendants of the congress visited our booth where they could find more information about the ongoing activities and projects.

The Value of Treatment project was presented by Prof. Wolfgang Oertel at the Scientific Theatre with a session entitled "The Value of Treatment Project: The Value of Early Coordinated Care for Patients Affected by Rare Neurological Diseases", which was held on 21 June 2021. Motivated by addressing the existing gaps in the care pathways, the EBC Study on Ataxia, Dystonia and Phenylketonuria (PKU) aimed 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 European Brain Research Area (EBRA) held a roundtable in Room Seville addressing the importance of cooperation and collaboration in the European brain space and presenting more about the project. EBRA clusters, partners, policymakers, clinicians and patient representatives participated discussing the priorities, gaps and enabling actions in brain research in Europe and how to promote European brain research in the world.



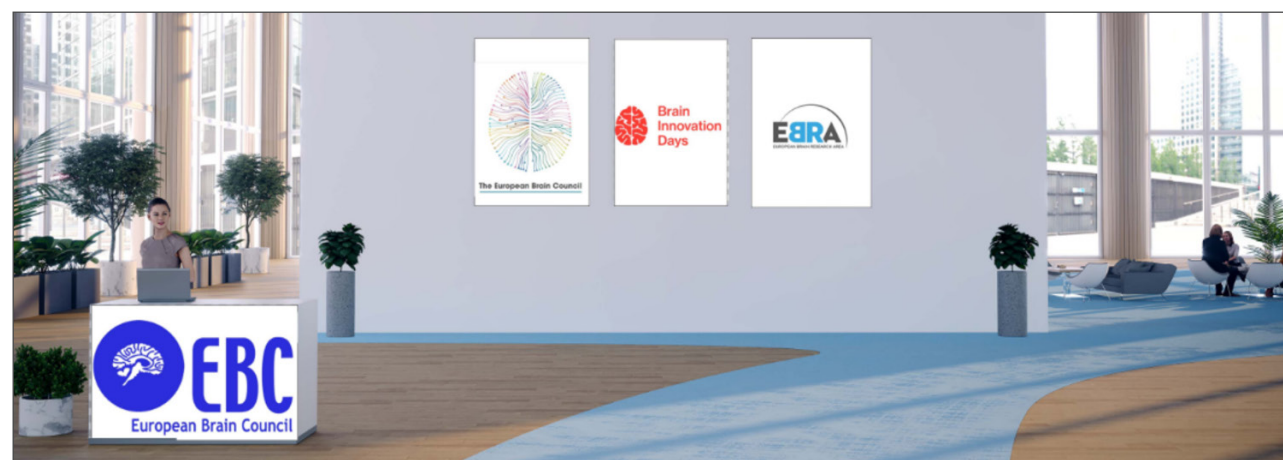


## SCIENTIFIC CONGRESSES

### ECPN CONGRESS

The European Brain Council showcased its current projects during the 34<sup>th</sup> ECPN Congress, held in Lisbon and online on 2-5 October.

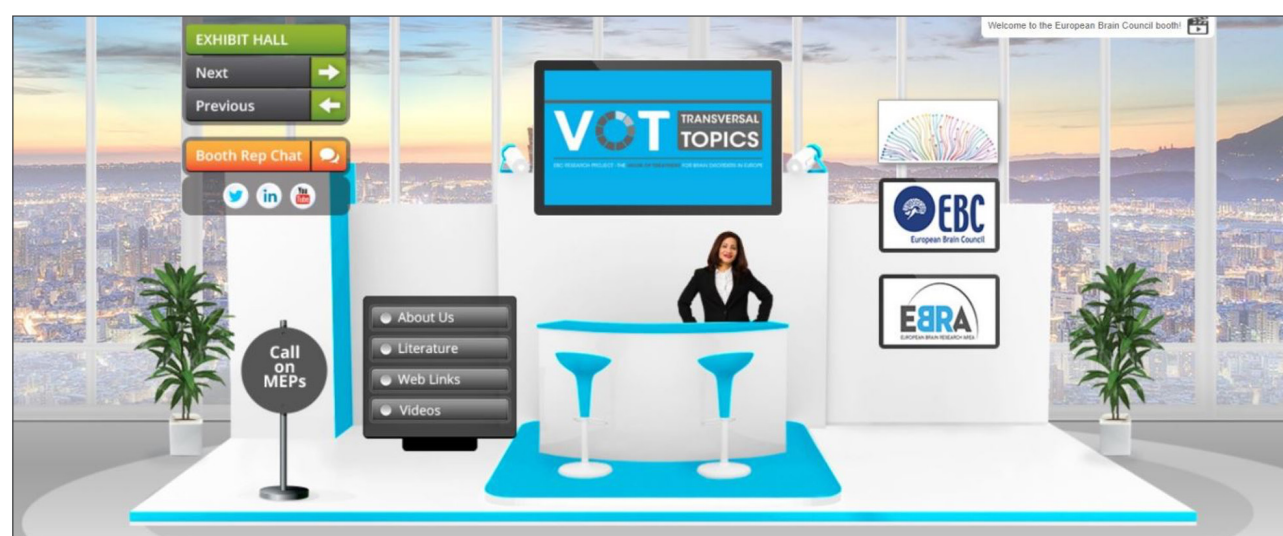
In the context of the event, EBRA was highlighted with a poster on-site available for all the attendees.



## SCIENTIFIC CONGRESSES

### VIRTUAL PAIN EDUCATION SUMMIT

EBC took part in the Virtual Pain Education Summit, organised by the European Pain Federation EFIC on 4-6 November 2021. Visitors of the Summit had a chance to learn more about the ongoing EBC projects such as the European Brain Research Area (EBRA), the Brain Innovation Days, the Value of Treatment and many more.



## OTHER COLLABORATIONS

### EBC supports European Stakeholder Group statement on maintaining the exchange of critical health data

EBC supported the [statement](#) released by CPME, on behalf of the European Stakeholder Group, on the draft adequacy decision on the UK data protection regime issued by the European Commission on 19<sup>th</sup> February 2021 to protect the benefits of the free flow of personal data. EBC welcomed the call to the European Data Protection Board and the European Parliament to support the ruling and National Governments to approve the draft decision.



### The EU Health Coalition calls on the Portuguese Presidency of the Council of the European Union to work towards the establishment of a forum for better access to health innovation

EBC welcomed the [EU Health Coalition Calls](#) on the Portuguese Presidency of the Council of the European Union to work towards the establishment of a forum for better access to health innovation. The Coalition is a multi-stakeholder initiative that aims to promote a shared vision of health in Europe, based on jointly developed recommendations. The purpose is to raise health high on the political agenda and bring the necessary changes to address the unprecedented challenges and opportunities driven by an ageing population and increased prevalence of chronic diseases that healthcare systems and citizens across Europe are facing.



OTHER COLLABORATIONS

EBC at the Africa – Europe Science and Innovation Summit

Prof. Monica Di Luca, EBC President, participated in a panel on 15 June 2021 opened by Maria Cristina Messa, Italian Minister for Universities and Research, during the Africa – Europe Science and Innovation Platform. The summit was organised by AERAP Science, the Africa-Europe Science Collaboration and Innovation Platform that organises the stakeholder forum convened to define priorities for science and innovation cooperation between Africa and Europe.



EBC supports statement on "Better mental health together"

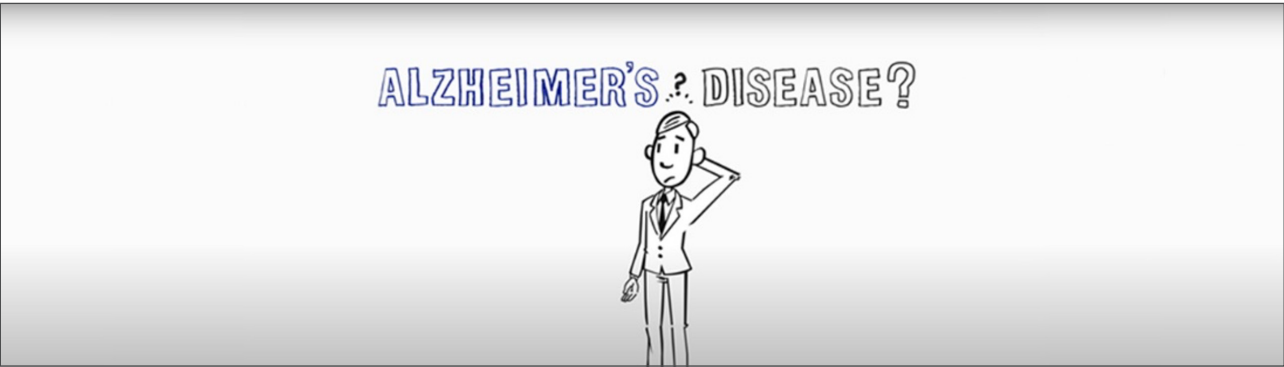


EBC supported the [statement](#) released by the European Psychiatric Association and the Europe Region World Physiotherapy on the importance of health-care professionals' collaboration to optimize mental and physical health care on the occasion of the 2021 European Public Health Week.

OTHER COLLABORATIONS

EBC supports the need to prioritise the rapidly growing challenge of Alzheimer's disease

EBC supported and shared the [message](#) delivered by MEPs Sara Cerdas (S&D, PT), Tomislav Sokol (EPP, HR) and Claudia Gamon (Renew, AT) in a video produced by POLITICO Studio, Biogen and supported by EBC, EU40 – the network of young MEPs and the Global Coalition on Aging, with the aim of raising awareness on Alzheimer's Disease.



EBC signed the ALBA Declaration on Equity and Inclusion

EBC supported the [ALBA Declaration](#) on Equity and Inclusion that focuses specifically on two contributing factors to perpetual underrepresentation in STEM: implicit bias & workplace culture. ALBA is a network of brain scientists committed to fostering fair and diverse scientific communities.





# AS USUAL, COLLABORATION IS KEY

## 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](http://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](http://www.gamian.eu) 🐦 @GamianE



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](http://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](http://www.eans.org) 🐦 @eansonline



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](http://www.ecnp.eu) 🐦 @ECNPtweets



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.

👁 [www.europsy.net](http://www.europsy.net) 🐦 @Euro\_Psychiatry



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](http://www.epns.info) 🐦 @EPNSnews



\*Joined as Full Member in 2021

## 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](http://www.fens.org) 🐦 @FENSorg



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](http://www.ibro.org) 🐦 @ibroSecretariat





## Associate Members

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](http://www.eufami.org) 🐦 @EUFAMI



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](http://www.ifcn.info) 🐦 @IntFedCNP



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](http://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](http://www.esrs.eu) 🐦 @ESRS\_Sleep



\*EBC Member as of 1 January 2020

## National Brain Councils



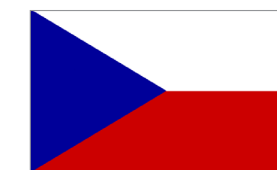
Belgium



Bulgaria



Croatia



Czech Republic



The Netherlands



Finland



France



Germany



Hungary



Ireland



Luxembourg



Norway



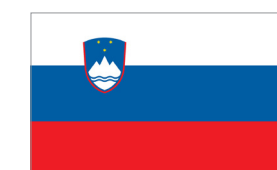
Poland



Portugal



Serbia



Slovenia



Spain

## National Brain Councils

### 7<sup>th</sup> Academy Meeting of National Brain Councils

The [7<sup>th</sup> Academy Meeting of National Brain Councils](#) was held virtually on 15<sup>th</sup> April 2021. Prof. Monica Di Luca, President of the European Brain Council, started the meeting with words of welcome to the participants, followed by an Opening Address by MEP Tomislav Sokol (HR, EPP) on the perspective of a European Health Union. Pierre Delsaux, Deputy Director-General of the Directorate-General for Health and Food Safety, delivered his keynote speech and replied to the questions from the audience, focusing on the key role of Member States in developing and establishing a European brain health agenda.



## Industry Partners









# WORK IN



## Members Highlights

### GAMIAN – Europe

#### 1. Quality of Life

2021 saw the expansion of GAMIAN-Europe's activities on quality of life, a topic close to our members' hearts. GAMIAN-Europe convened several workshops with people with lived experience, exploring specific themes such as relationships, hobbies, self-worth, identity and communication with carers. The information gathered from the workshops served to co-create [a guide for patients and carers entitled "Top Tips for Managing A Better Quality of life"](#). The guide features patients' perspectives on the issue, complemented with the latest research in the area.

As a way to capture the subjectivity and complexity behind the concept of quality of life, GAMIAN-Europe also produced a [series of individual patient stories](#). The guide and patient stories were launched as part of a European-wide social media campaign for World Mental Health Day, and were widely shared amongst our members' networks.

#### 2. Understanding the impact of the pandemic on patients, clinicians and services

In 2021, GAMIAN-Europe took the initiative to carry out [a survey to explore the challenges faced by pre-existing mental health patients during the COVID-19 crisis](#). The survey was translated in 13 languages and gathered over 500 respondents. GAMIAN-Europe was invited to present the findings of its survey report the European Public Health Week and at the High-Level Commission Event on Mental Health.

We have gone on to develop [another survey, in collaboration with EPA](#), in which we explore how mental health services are coping in a pandemic context, both from the patient and clinician's perspectives. This survey was launched in November 2021 and is available in 11 European languages.

### Other collaborations

#### 3. The Little Book of Small Conversations

Open and honest conversations about depression are an important step towards ensuring that people get the support they need. For this reason, we have collaborated with Janssen and EUFAMI to develop [The Little Book of Big Conversations](#), as part of the Breaking Depression project. This digital book is full of pieces of practical advice to help make those big conversations about depression a little bit easier.



#### 4. EU-Research projects

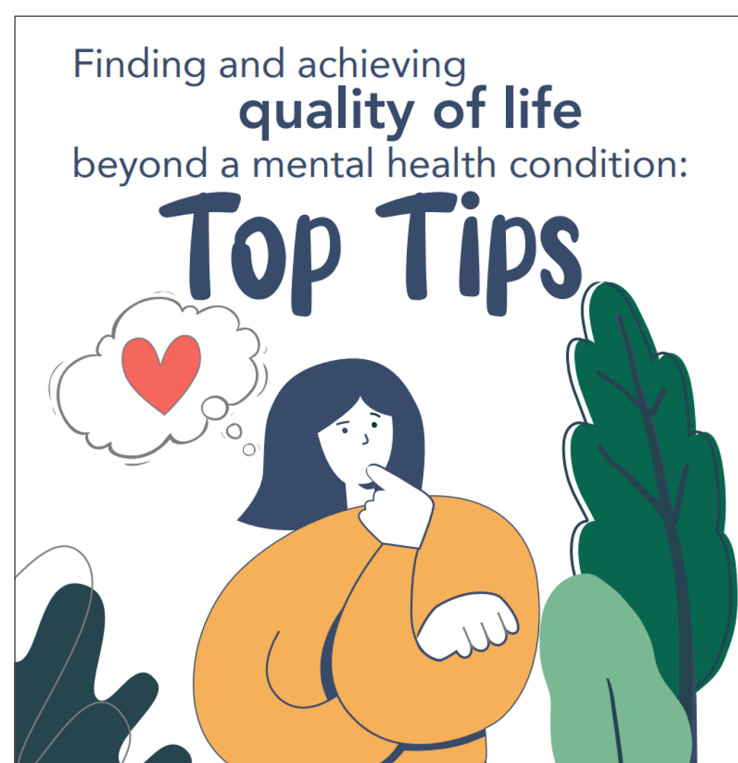
Our work on EU research projects continued throughout the whole of 2021. In projects such as CAPICE, SYNCHROS, PSY PGX, IT4ANXIETY, InALMH and IMPLEMENTALL, we strived to make research information easily accessible and widely available to patient communities and other relevant stakeholder groups. GAMIAN-Europe also ensured quality involvement of patients within these projects. For instance, we set up patient advisory boards involved at various stages of the research process, and helped co-develop digital tools with users.

#### 5. European Year for Mental Health

The MEP Alliance for Mental Health, with the support of GAMIAN-Europe, has launched a campaign to ensure that one of the future European Years will be dedicated to Mental Health. European Years are EU-wide awareness campaigns aimed at educating European citizens and attracting the attention of Member States to a particular issue, in order to change attitudes and behaviours at both the national and European level. A dedicated [European Year of Mental Health](#) could be a tangible and coordinated initiative to raise awareness, provide a platform for exchanges and sharing, promote and facilitate discussion and contribute towards improving mental health across the board.

So far, action has been taken to bring other mental health-related organisations on board and urge the European Commission to agree to a Year. This effort has resulted in [a strong statement signed by many relevant parties including some 40 MEPs](#).

Until now, the European Commission has not yet come forward with a proposal for a Year. Therefore we have started stepping up the campaign and addressing relevant policymakers at the national level.



### European College of Neuropsychopharmacology (ECNP)

2021 was overshadowed by the ongoing corona crisis and the double challenge it presented of how to adapt the College's activities to this disrupted environment; and how to contribute scientifically to understanding and mitigating the disease's far-reaching effects, especially its mental health impact.

#### Science

Although four annual ECNP meetings earlier in the year were held virtually (ECNP Workshop for Early Career Scientists in Europe, the ECNP New Frontiers in Digital Health Meeting, ECNP School of Child and Adolescent, ECNP School of Neuropsychopharmacology, the **34<sup>th</sup> ECNP Congress**, on 2-5 October, in Lisbon, Portugal, went ahead as the first hybrid meeting in the field since the beginning of the pandemic. The congress attracted over almost 5,000 participants (in-person and online).

Other activities continued only marginally impaired. The **ECNP Networks** and **Thematic Working Groups** (TWG) of pan-European research partnerships welcomed the Physical And meNtal Health – PAN-Health TWG, chaired by Marco Solmi.

The **ECNP Neuropsychopharmacology Award** was conferred upon Valery Grinevich, Germany, for his exceptional research contributions to the study of neuropeptides; the ECNP Rising Star Award for outstanding early career researchers was awarded to Covadonga M. Díaz-Caneja, Spain and to Dominique Endres, Germany.

The **Best Negative Data Prize in Clinical Neuroscience** was awarded to C.G. Abdallah et al. for 'Modulation of the antidepressant effects of ketamine by the mTORC1 inhibitor rapamycin' in *Neuropsychopharmacology* (2020) 45, pp. 990-97; and the **ECNP Citation Award** upon Christiaan H. Vinkers et al. for 'Stress resilience during the coronavirus' (*European Neuropsychopharmacology* 35, 2020, 12-16).

**Neuroscience Applied** is ECNP's fully open-access scientific journal, targeting the intersection between neuroscience, applications and new treatment horizons. The journal encompasses original basic, clinical and integrative research that has translational relevance for mental health, focusing especially on mechanisms of disorders, biological, psychological and social treatments, prevention and policies that apply a neuroscientific approach to brain disorders. Editor-in-chief: Andreas Meyer-Lindenberg; Associate editors: Suzanne Dickson, Mark Millan.

The **Neuroscience-based Nomenclature** (NbN) project released its third revised edition and marked the 88,000th download of its free app worldwide. The NbN, now recognised by journals, textbooks and medical associations around the world is on track to becoming the accepted scientific standard for the denomination of psychotropic medications across the international psychiatric research community.

## Education

The ECNP Workshop for Early Career Scientists (scheduled for 3-5 March, Nice France), the ECNP School of Child and Adolescent Neuropsychopharmacology (scheduled for 24-26 March in Venice, Italy), and the ECNP School of Neuropsychopharmacology (scheduled for 30 June-2 July in Oxford, United Kingdom) were all casualties of the crisis, being held virtually.

The **ECNP Workshop on Clinical Research Methods**, 3-5 November, was able to be held in-person in Barcelona.



Over 580 early career scientists were also able to present their posters at the 34<sup>th</sup> ECNP Congress Hybrid, 2-5 October, Lisbon, Portugal.

## Outreach

The science of corona-related stress and mental illness were featured at ECNP scientific meetings with three sessions at the 34<sup>th</sup> ECNP Congress (2-5 October, in Lisbon, Portugal): a patient session entitled 'Mental health care at the time of COVID-19 pandemic'; a symposium on 'The COVID-19 pandemic: implications for physical and mental health of people living with Schizophrenia'; and a campfire session on 'The effects of COVID-19 infection in the brain'.

ECNP also continued dissemination support for seven major EU projects. For the European Brain Council, ECNP continued its participation in the Value of Treatment, Brain Innovation Days and European Brain Research Area (EBRA) projects, with the ECNP Nutrition, Prevention of Mental Disorders and Mental Health Promotion, Down Syndrome and Other Genetic Developmental Disorders Network, Neuroimaging, and Preclinical Data Forum Networks all contributing to EBRA clusters (Brainfood, PSMD, Trisomy-21, ECIB and PREMOS clusters respectively).

Although necessarily adjusted to the constraints imposed by the pandemic, ECNP was able to continue its role as the leading independent and non-institutional providers of applied and translational research and education in Europe.

### Website & Social Media Channels:

 [ecnp.eu](https://ecnp.eu)

 [facebook.com/myECNP](https://facebook.com/myECNP)

 [instagram.com/ecnp.eu/](https://instagram.com/ecnp.eu/)

 [twitter.com/ECNPtweets](https://twitter.com/ECNPtweets)

 [linkedin.com/company/european-college-of-neuropsychopharmacology-ecnp-/](https://linkedin.com/company/european-college-of-neuropsychopharmacology-ecnp-/)

## European Federation of Neurological Associations (EFNA)

### Brain, Mind and Pain MEP Interest Group

The [MEP Interest Group on Brain, Mind and Pain](#) is an initiative of the European Federation of Neurological Associations [EFNA] and Pain Alliance Europe [PAE].

Due to the ongoing travel and meeting restrictions in 2021, EFNA was unable to organise its face-to-face MEP Interest Group meetings. However, two successful online conferences were held.

On 15 June 2021, the Group organised a virtual working session entitled "[Achieving health equity after the Covid-19 pandemic](#)". The event's main objective was to understand the long-term impact of the Covid-19 outbreak on different population groups affected by BMP disorders, and to define and frame the inequalities and challenges they experience. The working session was attended by EU policy-makers, healthcare professionals, patient organisations and industry representatives.

On 19 November 2021, the MEP Interest Group hosted a virtual event entitled "[Turning principles into action: best practice in reducing health inequities](#)". This event's objective was to discuss how the Interest Group can advance meaningful policies and interventions to address the drivers of health inequity, whilst taking a practical look at examples of best practices that can be scaled up and applied to these disease areas.

### OneNeurology

A global initiative to address neurological conditions as ONE

Conceived by EFNA and founded together with the [European Academy of Neurology](#) (EAN), the OneNeurology Initiative launched in March 2021.

[OneNeurology](#) is a global partnership of international disease-specific organisations and regional umbrellas uniting to make neurology a global public health priority. It is a multi-stakeholder, patient-focused partnership which aims to strengthen neurology-related groups to stimulate collaborative advocacy, action and accountability for the prevention, treatment and management of neurological disorders worldwide.

OneNeurology Partners include Alzheimer's Disease International, World Stroke Organization, the World Federation for NeuroRehabilitation, World Sleep Society and more. The Initiative is also endorsed by over 40 regional associations.

Learn more at [oneneurology.net/](https://oneneurology.net/)

### Training Initiatives for Neurology Advocates

In 2020, as part of EFNA's Training Initiatives for Neurology Advocates (TINA), [a pilot series of e-learning modules](#) was developed. The courses are video-based and divided into sections that can be watched independently at times that suit the viewer. Each module includes supporting notes and worksheets, as well as the option to take a quiz on the content and receive a personalised certificate of completion.



Building on the success of the pilot modules, two further series of e-learning modules were developed in 2021, each containing five modules. The first of these series, on Personalised Healthcare, was developed in partnership with the Women's Brain Project, while the second series, on EU Funding, was developed with the support of Weber Shandwick.

Two webinars were held in 2021, as part of the TINA initiative.

The first, *'Together for Brain Research'* (April 20/21), was a two-day virtual workshop aimed at bringing together people affected by neurological conditions, experienced funding panel lay reviewers and secretariat members from ERA-NET NEURON to discuss the role of patients, carers and family members in shaping and funding research, and to prepare anyone interested in becoming a lay reviewer to participate in ERA-NET NEURON's latest funding call.

The second event, *'Personalised Healthcare: The Future of Neurological Care?'* (November 3), introduced the concept of personalised healthcare/precision medicine in neurology – with a focus on identifying key themes for those living with neurological disorders and their representatives in the years to come. A recording of the webinar is available [from EFNA's YouTube channel here](#).

## EFNA Advocacy Awards 2021

The [EFNA Advocacy Awards](#) recognise the contribution of an individual or group to the development and promotion of advocacy for people with neurological disorders in Europe. In 2021 the awards focused on the topic of *'Action against stigma'*.

As part of Brain Awareness Week celebrations, EFNA were delighted to announce the winners of the 2021 awards, each of whom would receive a prize of €2,000 to assist with the continuation and development of their projects.

Winner of the individual advocate category was Natalie Davidson- a British teacher who lives with Tourette Syndrome. One of Natalie's goals has been to educate teachers on different strategies to enable them to reach their highest potential within the classroom and beyond.

Winner of the organisational category was the European Migraine and Headache Alliance (EMHA) for their video *'The Truth Behind Migraine'*. This portrays real testimonies of how migraine affects the day to day of those who suffer from it.

## EFNA Grants 2021

In 2021, EFNA once again provided grants to support work on one of our chosen advocacy themes. This year's focus was on *'Personalised Health and Social Care'*.

29 applications were received from across Europe, all featuring exciting and worthwhile projects. A fund of €30,000 was made available for this scheme, which was divided among six projects. You can [learn about the successful projects here](#).

In 2022, EFNA's Grants scheme will return, this time with a focus on *'Promoting Gender Equity in Neuroscience Research and Neurological Care'*.

## Publications

As global, EU and national policy priorities turn towards post-COVID-19 recovery planning, to future pandemic preparedness and efforts to make healthcare systems more resilient, the impact that the pandemic has had, and continues to have, on those living with neurological disorders needs to be accounted for. In June 2021 EFNA published a report entitled *'Addressing the impact of Covid-19 on the lives of people living with neurological disorders'*.

This report summarises evidence gathered from organisations across the European neurology community about the impact of COVID-19 on people living with neurological disorders in Europe. It shows how care pathways for the neurology patient community were reconfigured during the early waves of the pandemic and makes key recommendations that policymakers and decision-makers should follow in order to ensure that any future changes to service delivery are made in the interests of patients and those affected by neurological disorders – rather than, solely, in the interests of the healthcare system.

Separately, EFNA partnered with the European Academy of Neurology (EAN) to investigate, via a survey, the impact of the first wave of the COVID-19 pandemic on individuals with neurological diseases, as well as the hopes and fears of these patients about the post-pandemic phase. [Access the publication here](#).

[efna.net](https://efna.net)

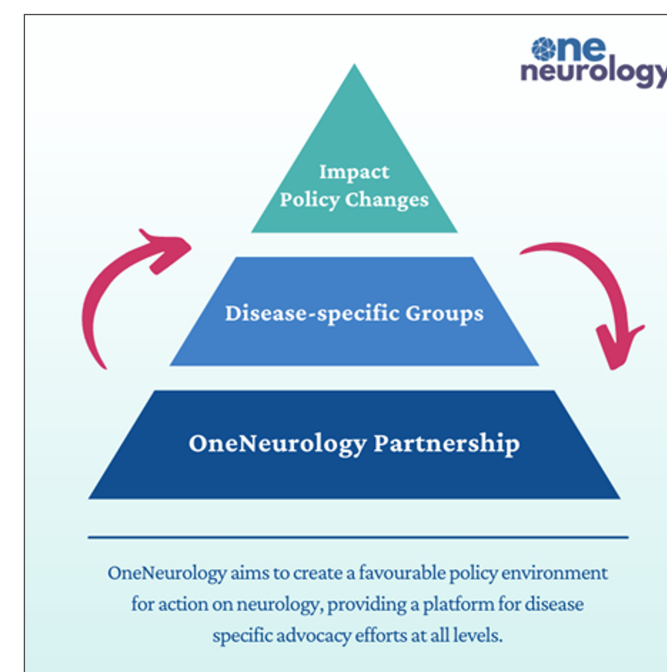
[twitter.com/EUneurology](https://twitter.com/EUneurology)

[facebook.com/European-Federation-of-Neurological-Associations-173781099807815/](https://facebook.com/European-Federation-of-Neurological-Associations-173781099807815/)

[instagram.com/euneurology/](https://instagram.com/euneurology/)

[linkedin.com/company/11281270/](https://linkedin.com/company/11281270/)

[youtube.com/channel/UCY3r6AoeWnCUZNOmWIFgwGg](https://youtube.com/channel/UCY3r6AoeWnCUZNOmWIFgwGg)





## European Paediatric Neurology Society (EPNS)

Despite the disruptions caused by the Covid-19 global pandemic, 2021 has been a busy and productive year for the European Paediatric Neurology Society (EPNS). We have adapted to the challenges and continued to play an important role in and beyond Europe by delivering a platform for advocacy, education, training, and science in the field of Paediatric Neurology.

The impact of the pandemic has been particularly severe for children with neurological disorders. Losing access to education has also meant reduced access to ongoing specialist therapy which is so critical for children with chronic diseases. Families and children faced isolation, with care for medical and behavioural problems falling almost exclusively on them. Paediatric neurologists have changed practices embracing innovations to deliver the best possible care.

The EPNS enjoyed its first year as a full European Brain Council (EBC) member in 2021 and it has been our pleasure to join the team in promoting brain research to improve the quality of life of those living with brain disorders. Being part of the EBC has given the EPNS an opportunity to network with the key players in this field, collaborate in research and add focus to childhood brain health. Key EPNS members participate in the main EBC working groups which has given us the opportunity to raise the voice of child neurology, and we look forward to working together in the future.

EPNS partners with OneNeurology and we were invited to contribute to a consultation by the World Health Organisation (WHO) on an Intersectoral Global Action Plan on epilepsy and other neurological disorders (IGAP) to address challenges and gaps in providing care and services for people with neurological disorders. It was our goal to ensure there was a strong message about the concept of lifelong neurological disorders and antenatal/maternal health influencing neurological disorders. The World Health Assembly will meet in 2022 and we hope the outcome will be that neurology will be raised as a global public priority.

In recent years the EPNS has developed its role as an advocate for paediatric neurology through strengthened partnerships and new connections at a European level and beyond. As a result, a new EPNS Advocacy and Collaboration Committee has formed and will continue establishing formal, strong, and fruitful relationships with many other societies, partners, and patient groups.

The EPNS Education & Training Committee experienced continued success of the monthly EPNS educational webinars, the virtual EPNS Latvian hosted training courses, EPNS fellowships, EPNS Visiting Teachers and on online training courses. Plans are also well underway for the roll-out of the EPNS Training Guide and EPNS Exam.

The EPNS Scientific & Research Committee organised a virtual EPNS Research Meeting in 2021 which provided a highly successful forum for exchanging scientific ideas of the highest standard and developing new collaborations.

The EPNS hosts biennial congresses which provide an opportunity to learn about the latest developments in the rapidly evolving field of child neurology, including basic science, diagnostic methods, and novel treatments.

Please accept our invitation to join us for the 14<sup>th</sup> EPNS Congress taking place from 28 April until 2 May 2022 <https://epns-congress.com/>. This was previously planned to take place in June 2021; however, it was postponed due to the Covid19 pandemic. Our Congress in 2022 will be a hybrid event taking place in person at the Scottish Event Campus (SEC) in Glasgow, United Kingdom and on a virtual platform.

The planning for future congresses has started with an inspiring programme taking shape for our EPNS Congress in Prague, Czech Republic on 20-24 June 2023. Our congratulations are extended to the team in Munich, Germany on their successful bid to host EPNS Congress on 8-11 July 2025.

The Young EPNS (YEPNS) formed in 2021 and is a highly motivated and enthusiastic group brings together younger members of the EPNS to learn, collaborate and network. These future leaders of our specialty have already made a significant contribution to EPNS activities. The YEPNS host Case Discussion and Journal Club webinars, will have dedicated events at EPNS Congress 2022 and are playing a vital role in the recently established Guidelines Committee.

During 2021 the EPNS reflected on the experience of 2020, addressing which activities need to be restored, adapted, and renewed. It has been an opportunity to consider sustainable development, the environment and how we can reduce our impact on climate change. Consequently, this year we introduced an EPNS Green Policy, which is a recurring agenda item at all EPNS Board meetings.

In 2022 we will welcome a new EPNS Board for the term 2022-2026. Sincerest thanks are extended to the 2018-2022 EPNS Board members for their energy and contributions and we wish the new board continued success for the next four years.

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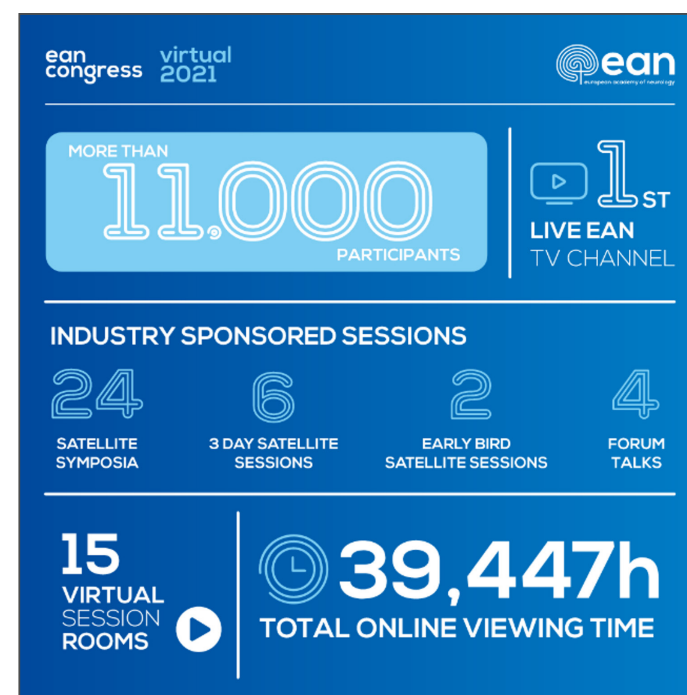


## European Academy of Neurology (EAN)

The European Academy of Neurology (EAN) enjoyed a very productive year in 2021, taking some significant first steps into the realm of advocacy, while continuing to increase the range of opportunities and resources offered to members in education, science and professional issues.

As usual, the high point of the year in 2021 was the annual congress. Following the success of EAN's first virtual congress in 2020, it was a straightforward decision to organise another for 2021, given the ongoing restrictions affecting travel and gatherings. The **7<sup>th</sup> EAN annual congress** took place on June 19-22 with the overarching theme of 'Towards Precision Neurology'. Diagnosis of neurological disorders has always relied on precision, but we are moving ever closer to precision neurology, with the goal of synergising continuous advances in clinical and experimental neurosciences to provide individualised diagnoses and treatments. Areas of knowledge such as epidemiology, genetics, body fluid biomarkers, imaging, and targeted treatments based on personalised decisions and supported by new technologies such as artificial intelligence, all play a role in precision neurology. This broad and exciting theme, touching on many areas of cutting-edge science and clinical practice, was the focus of many sessions at a highly engaging congress that attracted more than 11,000 participants.

The congress also saw the first announcement of EAN's intention to make advocacy a key priority moving forward, with the introduction of a series of Advocacy Talks at the congress. EAN has since been actively involved in promoting advocacy, specifically with regard to Brain Health. **The First National Neurological Forum** was launched in December 2021 and brought together more than 40 different societies and their representatives under a common goal – to ensure neurology's prime role in the future of policy making. In the follow-up, EAN managed to gather signatures from 43 different national societies to a Joint Communiqué showing support for WHO's GAP (Global Action Plan). EAN remains in close collaboration with EFNA on the OneNeurology project and is looking to launch another event. The Brain Health Forum will take place on 31 May, 2022 and will be available online. EAN also recently joined the European Chronic Disease Alliance (ECDA), adding its voice to the coalition of European health organisations combating preventable chronic diseases through European policies that impact health.



Working in partnership is a key determinant for success in promoting excellence in neurology and achieving the EAN's aims and vision. The organisation has established Memoranda of Understanding (MoUs) with several subspecialty societies this year, as well as societies in fields related to neurology, to foster cooperation in areas such as guideline production, educational events and the organisation of joint congress sessions. Currently 28 such agreements are in place. To integrate the subspecialty partner societies into various activities and strengthen cooperation, their representatives are included on the relevant EAN Scientific Panels.

Education is always a key area of EAN activity and 2021 saw some especially healthy progress, with the launch of some new initiatives alongside regular projects. A new **Student Teaser Fellowship** was announced during the congress, as well as the first **EAN Science School** for early career neurologists (both of which will take place in 2022) and the EAN Mentorship Programme was launched to pair experienced neurologists with mentees in the early stages of the careers. With distance learning becoming increasingly more relevant over the last two years, a series of webinars was hosted for the first time. These will eventually form part of a wider range of content that will be available in the EAN eLearning platform, a work-in-progress that has also been a major focus for the education team this year.

Turning to professional issues, EAN adopted a **new guideline production strategy** in 2021, adding a new 'top-down' approach to the existing 'bottom-up' system that allows members to propose a guideline at any time. Since the number of proposals received has risen, there was a need to develop clear, transparent and methodologically solid prioritisation criteria to ensure that the most clinically relevant guideline topics are selected and the limited resources available are adequately allocated. EAN will open a regular Call for Topic Proposals and invite EAN Scientific Panel Members, Individual Members, National Societies, Partner Societies, and EFNA to submit guideline topics. The EAN Guideline Production Group, Scientific Committee, and Board will then review and select topics that are the most clinically relevant based on the newly established EAN prioritisation criteria. Once EAN's priority topics are selected, a Call for Conducting Guidelines on Priority Topics will be opened to invite members of the EAN community to submit a proposal and undertake the development of full clinical practice guidelines.

The ultimate goal of the new strategy is to promote the development of timely, high-quality, high-impact guidelines to assist healthcare of the most important neurological diseases. In addition, the EAN Guideline Production Group will gradually build in-house intellectual capital for supporting GL development and thus increase GL production efficiency.

Another valuable resource, the **EAN Neuro-covid ReGistrY (ENERGY)**, established in May 2020 to collect epidemiological data on neurological manifestations of COVID-19, grew further during 2021. Currently, 40 centres from 27 countries worldwide have entered data about 2,242 patients. Documents are available in various languages and the Registry has established collaborations with various centres across the world, including US, Europe and Latin America, helping to strengthen partnerships throughout the pandemic.



Finally, EAN established a new **Student Task Force** in 2021, with the aim of promoting EAN activities and the neurology domain among medical students and recruiting new, young and driven future neurologists who could later become leaders and mentors. The task force has already overseen the development of a number of new initiatives, including the labelling of congress sessions considered relevant for students; the 'Why Neurology?' essay competition; a future collaboration with the International Federation of Medical Students Associations (IFMSA); and the forthcoming 'Students' Corner' series on the *EAN newsblog*, *EANpages*. We look forward to more Student Task Force activities in 2022, the European Year of Youth.

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## European Psychiatric Association (EPA)

### EPA Advocacy activities

Following the work done in 2020, the European Psychiatric Association (EPA) took further action to ensure that its agenda and priorities at EU-level were focused on promoting the role of psychiatry in Europe, and understanding and reducing the impact of COVID-19 on mental health. In this regard, the EPA participated in the "WHO Europe Summit on COVID-19 and the Mental Health impacts for health and care workforce", held in July 2021, and joined the WHO Pan-European Mental Health Coalition, launched in September 2021. The EPA also contributed with a keynote speech by its President Elect, Geert Dom, to an online event organised by the EU Commission on the impact of the COVID-19 pandemic on mental health. The online event was opened by the EU Commissioner for Health and Food Safety, Stella Kyriakides.

To raise awareness on the topics related to mental health, the EPA joined several campaigns and released statements over 2021. The EPA joined GAMIAN-Europe, the MEP Alliance for Mental Health and other European associations, in a call to the EU Commission to designate 2023 as the European Year for Mental Health. In November, the EPA endorsed the 9<sup>th</sup> edition of the Awareness Week on Alcohol Related Harm (AWARH), and on the occasion of the 2021 European Public Health Week, the EPA joined forces with the Europe Region World Physiotherapy to launch a statement on the importance of healthcare professionals' collaboration to optimise mental and physical health care. On World Mental Health Day (10 October), the EPA released a video to promote the importance of ensuring equal access to mental health care. For this video, the EPA had the privilege of including a message from Mr Stelios Kym-pouropoulos MEP, Member of the EU Parliament and a supporter of the MEP Alliance for Mental Health, together with a message from the EPA President, Prof. Peter Falkai.

As part of its Ambassadors Programme, and following on from a successful 2020 edition which saw the publication of an article in *European Psychiatry* in June 2021, the EPA released its second Ambassadors Survey, focused on decision-making style approaches in clinical practice. The Survey collected more than 900 replies from mental health professionals in Europe and beyond. In October 2021, the EPA also launched a survey, together with GAMIAN-Europe, with the title "Are mental health needs being met by services?", which was addressed to both patients and clinicians.

In 2021, the EPA continued contributing to 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. Moreover, the EPA continued the interaction with the European Medicines Agency (EMA), thanks to its participation in the network of healthcare professionals' eligible organisations.

### EPA Congress and Forum 2021

Guided by the motto "Personalising and integrating mental health care in the digital era", the 29<sup>th</sup> European Congress of Psychiatry was, for the second year, organised as a fully virtual Congress and took place from 10 to 13 April. In 2021, the virtual Congress showcased upgraded features in order to enhance the online experience and increase possibilities for interactions. In addition to hosting over 350 speakers for more than 120 sessions, the EPA introduced "EPA TV", a daily channel for session updates, speaker interviews, and delegate interaction. Over 3,300 participants from more than 100 countries joined the virtual Congress, demonstrating that the mental health field remains very active despite the challenging circumstances.

The 2021 EPA Forum was held on 10 April, preceding the 29<sup>th</sup> European Congress of Psychiatry. The year's topic was "Quality Indicators of Services and Care for Mental Health in Europe, from Clinician to Patient Perspective: A Paradigm Shift?". The Forum was exceptionally opened with a keynote speech by Mr John Ryan, Director for Public Health at the EU Commission, and saw the participation of speakers and delegates from international and EU organisations.





## EPA Training activities

In 2021, the EPA developed many training projects through its Education Committee. On 10 September, World Suicide Prevention Day, the EPA launched its 4<sup>th</sup> online course on "Focus on Suicidal Behaviours", led by Profs. Emilie Olié and Jorge Lopez-Castroman. This course includes lecture videos, role-plays and international experts' presentations.

Because of the COVID-19 situation, the EPA Summer School 2020 was postponed. The Summer School came back in 2021 in a fully virtual format for its 10<sup>th</sup> edition. On 23 and 24 September 2021, the EPA Summer School on Research took place, welcoming 21 participants from 16 different countries.



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## Federation of European Neuroscience Societies (FENS)

The year 2021 continued to present a number of Covid-related challenges, but the Federation of European Neuroscience Societies (FENS) was able to advance its mission in supporting the neuroscience community with a number of impactful activities. The FENS Regional Meeting (FRM) 2021, jointly organised by the Polish Neuroscience Society and the Lithuanian Neuroscience Association, took place from 25-27 August 2021. The FRM 2021 hosted participants worldwide by creating an engaging virtual experience with an excellent scientific programme that attracted more than 2,000 people. During the FRM, FENS proudly organised three special interest events:

### Pitch your science communication project

Six competitors were selected from a satellite workshop to pitch their science communication project in front of a jury of experts composed of members from FENS committees. The three projects were selected from the following categories: online science communication (I and II) and science communication for younger audiences. The audience was also able to participate and vote for their favourite project.

### Career pathways in neuroscience and training opportunities

Organised by the FENS Committee for Higher Education and Training (CHET), this Special Interest Event was dedicated to students and early career scientists interested in interacting with inspiring representatives from the business, pharma, publishing and public sectors. During this live online event, the speakers revealed how their neuroscience background successfully contributed to their career-paths and responded to questions throughout the open Q&A session.

### Promoting continuity of international collaboration in animal neuroscience research

The FENS Committee on Animals in Research (CARE) organised a debate to examine the benefits of international scientific collaboration and identify current challenges and opportunities, including 3Rs strategies relevant to researchers working with animal models.

FENS was also proud to have hosted the Brain Conference "RNA Mechanisms and Brain Disease" from 20-23 October in Rungstedgaard, Denmark. This meeting was co-chaired by Giovanna Mallucci (University of Cambridge and UK DRI, United Kingdom) and Erin Schuman (MPI Brain Research, Germany) and explored how neurons regulate RNA molecules and protein synthesis and how these mechanisms represent vulnerabilities for various neurological diseases.

The Brain Conference counted the participation of 121 attendees, including 22 speakers, covering a broad and diverse area with attendees coming from 22 different countries. The celebration of this Brain Conference created the perfect in-person immersive experience that the neuroscience community was aiming for. The event allowed the exchange of ideas and the connection of scientists at different levels of careers who were eager to tackle fundamental questions in neuroscience.



As a member of the European Brain Council, FENS actively participates in many EBC initiatives and participates in its governance. Through EBC, it is a third-party partner of the European Brain Research Area (EBRA) project. During the FRM 2021, EBRA presented the Shared Brain Research Agenda (SEBRA) project, which aims to identify research opportunities and research and innovation gaps to be addressed in the field and to provide recommendations on future areas for brain research in Europe. Moreover, FENS hosted together with EBRA and EBC, the FENS Friday webinar "The importance of coordination and collaboration in brain research" with 115 attendees.

In 2022, FENS and the Société des Neurosciences are looking forward to welcoming back the neuroscience community at the FENS Forum 2022 in Paris (France) on 9-13 July. The FENS Forum is Europe's largest international neuroscience meeting and the 2022 edition will be the first big in-person global gathering of neuroscientists after a long interruption. The scientific programme will cover all aspects of neuroscience, from basic to translational research, and the Forum overall will provide a unique opportunity for researchers from around the world to come together and enjoy excellent science, special interest events, and networking and career development opportunities.

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## International Brain Research Organization (IBRO)

The International Brain Research Organization (IBRO) is a global federation of neuroscience organizations that aims to promote and support neuroscience around the world through training, education, career development, outreach and engagement activities, and the publication of two journals, Neuroscience and IBRO Neuroscience Reports. IBRO's efforts are driven by its goal to support excellence and rigor in neuroscience, with a unique, strong focus on inclusion, equity and diversity.

In spite of the challenges posed by the pandemic over the past year, IBRO has continued to support opportunities for career development and engagement across the globe, and is implementing new methods to ensure that all of the actions its supports are carried out in as fair and accessible a manner as possible. Following the launch of IBRO's first strategic plan, spanning 2020-2025, IBRO has refined its programmatic structure in order to best support the needs of scientists worldwide across all career stages, while maintaining opportunities to take into account varying regional priorities and facilitate cooperation across all IBRO regions. The diversity of the IBRO community is reflected in the supports it provides; in 2021, IBRO was able to award grantees from a record 64 countries across the world.

The IBRO Pan-Europe Regional Committee (IBRO-PERC), through which IBRO is a member of EBC, launched two new initiatives of note in 2021. The new Support for Soft Skills Training program provided financial support to 5 training activities across the region, focussed on the soft skills needed to increase scientists' chances of success in their careers. Meanwhile, the National Neuroscience Society Partnership initiative was conceived to reinforce the link between PERC and national neuroscience societies, through the organization of ad hoc sessions and symposia at meetings taking place across Europe, with six events supported in 2021. Considering IBRO-PERC's overall activities in 2021, it is worth highlighting IBRO-PERC's participation in the IBRO Diversity Grants program, through which it was able to support two events aiming to promote regional and gender diversity in neuroscience within the region.

Looking forward, work has already begun to prepare for the IBRO World Congress which will take place in September 2023 in Grenada, hosted by the Spanish Society of Neuroscience. As the scientific community begins to enjoy the benefits of in-person interactions once again, IBRO is already anticipating this exciting opportunity for the scientific community to meet and exchange in a stimulating and distinctive setting.

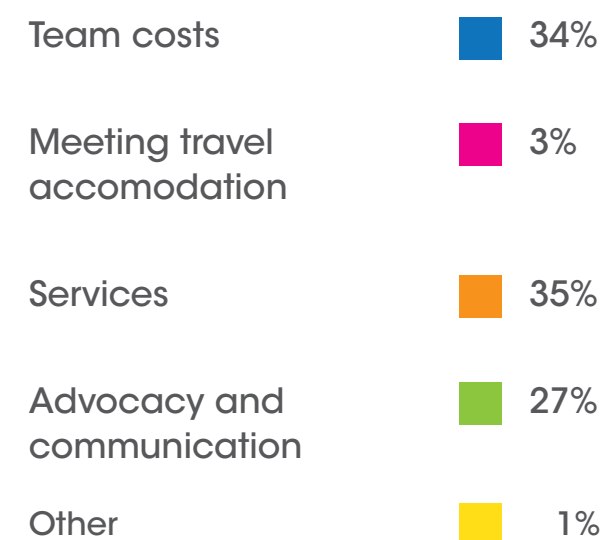
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# MEET THE EUROPEAN BRAIN COUNCIL

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President



**Wolfgang Oertel**  
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Executive Director



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**Cécile Grebet**  
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**Vinciane Quoidbach**  
Public Health & Policy,  
Research Project Manager





WHEN  
YOU HAVE  
CAUSES  
TO DEFEND,  
YOU HAVE  
NO TIME  
TO LOSE

## Meetings attended

- **14-15 January 2021**  
PRIME General Assembly meeting, Virtual
- **26 January 2021**  
Brain Innovation Days "From Innovative Ideas to Creative Brain Interventions", Virtual
- **26 January 2021**  
EBRA-NEURON workshop on neuroethics and quality assurance, Virtual
- **27 January 2021**  
ERA-NET NEURON Cofund2 Kick-Off Meeting, Virtual
- **28-29 January 2021**  
BRAINTEASER Kick-off meeting, Virtual
- **22 February 2021**  
Unlocking innovation and access for rare disease patients in Europe, Virtual
- **23-24 February 2021**  
EBRA Prevention of Severe Mental Disorders (PSMD) Cluster - Ethics in Precision and Preventive Psychiatry Workshop, Virtual
- **4 March 2021**  
Value Based Healthcare Conference, Virtual
- **5 March 2021**  
EBRA Annual Consortium Meeting, Virtual
- **16 March 2021**  
Patient Engagement in EU-Funded Brain Research Projects - Brain Awareness Week 2021
- **17 March 2021**  
EBRA data sharing workshop – "everything you always wanted to know about data sharing", Virtual
- **19 March 2021**  
EBRA Predictive Model Systems (PREMOS) working group meeting 1, Virtual
- **23 March 2021**  
MULTI-ACT Final Conference "The MULTI-ACT model: the path forward for participatory governance in health research and innovation", Virtual
- **30 March 2021**  
PRIME Webinar Neurodevelopmental Disorders (ASD, ADHD and OCD), Virtual
- **10-13 April 2021**  
Congress of the European Psychiatric Association, Virtual
- **15-16 April 2021**  
BRAINTEASER 1st plenary meeting, Virtual
- **17 April 2021**  
7<sup>th</sup> National Brain Councils Academia, Virtual
- **20 April 2021**  
Policy roundtable on Brain Health in Europe: Fostering Innovation, Improving Outcomes, Virtual
- **20-21 April 2021**  
Training on Advanced Stem Cell Technologies in Neurology (ASCTN-Training), Virtual

- **27 April 2021**  
Brain Innovation Days “Fast-tracking brain innovation in times of COVID-19”, Virtual
- **12 May 2021**  
EBRA European Cluster for Imaging Biomarkers (ECIB) meeting, Virtual
- **17 May 2021**  
PRIME Webinar Retinal and cognitive dysfunction in type 2 diabetes: unravelling the common pathways and identification of patients at risk of dementia, Virtual
- **19-20 May 2021**- OECD workshop “Neurotechnology in and for society: Deliberation, stewardship and trust, Virtual
- **26 May 2021**  
Workshop European Research Strategy, Virtual
- **27 May 2021**  
“Brain and machine: Improving MS care in a digital age”, Virtual
- **3 June 2021**  
Open co-design workshop on next generation tools to manage Amyotrophic Lateral Sclerosis and Multiple Sclerosis, Virtual
- **8 June 2021**  
Value of Treatment 2 Synthesis Meeting, Virtual
- **9 June 2021**  
Myalgic Encephalomyelitis in Europe: Roundtable of European Stakeholders and Policymakers, Virtual
- **9-11 June 2021**  
EMSP 2021 Annual Conference, Virtual
- **15 June 2021**  
Africa - Europe Science and Innovation Platform, Virtual
- **17 June 2021**  
Patient safety and informed consent: The importance of good off-label use practices, Virtual
- **19-22 June 2021**  
7<sup>th</sup> Congress of the European Academy of Neurology, Virtual
- **1 July 2021**  
EBRA Predictive Model Systems (PREMOS) working group meeting 2, Virtual
- **1 July 2021**  
MULTI-ACT Final review, Virtual
- **7 July 2021**  
EBC Workshop on the Pharmaceutical Strategy for Europe, Virtual
- **29 June 2021**  
OneNeurology Global Advocacy Workshop, Virtual
- **25-27 August 2021**  
FENS Regional Meeting, Virtual
- **1-3 September 2021**  
7<sup>th</sup> European Stroke Organisation Conference, Virtual
- **2-5 October 2021**  
34<sup>th</sup> ECNP Congress, Virtual
- **3-7 October 2021**  
21<sup>st</sup> European Congress of Neurosurgery, Virtual

- **6 October 2021**  
EBRA EPICLUSTER Activity 3 - Accelerating Patient Involvement in European Epilepsy Research, Virtual
- **6 October 2021**  
Third European Patient Advocacy Summit – Inclusion of the Patient Voice in HTA, Virtual
- **11 October 2021**  
EBRA Predictive Model Systems (PREMOS) cluster working group meeting 3, Brussels, Belgium
- **12-13 October 2021**  
Brain Innovation Days “United for brain innovation, Brussels, Belgium
- **12 October 2021**  
European Brain Summit, Brussels, Belgium
- **18-19 October 2021**  
EBRA BRAINFOOD cluster stakeholder workshop, Brussels, Belgium
- **26 October 2021**  
IFCN-EMEAC Digital Day, Virtual
- **23 November 2021**  
PRIME Webinar Alzheimer’s Disease pathophysiology and vascular contributions, Virtual
- **24-25 November 2021**  
European Innovation Council Summit 2021, Virtual
- **29 November 2021**  
EBRA TRISOMY21 cluster Activity 2: Thematic Workgroup on Down syndrome research priorities: Research infrastructures and biocollections, Hybrid (Virtual/Barcelona, Spain)
- **30 November 2021**  
Best practices for patient safety: An EU-wide view on the use of medicines off-label, Virtual
- **9-10 December 2021**  
EAN-EBRAINS Joint Workshop: The Future of Medical Data Sharing in Clinical Neurosciences, Virtual
- **10 December 2021**  
FENS Friday: The importance of coordination and collaboration in brain research, Virtual
- **17 December 2021**  
OneNeurology European Summit, Virtual

## Credits

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

Graphic design by **Cookdesign srl**

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](mailto:info@braincouncil.eu)



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