

EUROPEAN BRAIN COUNCIL

NEWSLETTER - June 2021

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EBC Activities



Brain
Innovation
Days

Save the Date and Call for Applications Launched for the Brain Innovation Days

We are excited to announce that after one year of digital sessions, the **Brain Innovation Days** will take place in person on **12-13 October 2021** in **Brussels, Belgium**.

Under the overarching theme, **United for Brain Innovation**, the Brain Innovation Days will bring together key opinion leaders and stakeholders from the ever-growing brain innovation ecosystem to create synergies and showcase the importance of brain innovation.

[Read more](#)



New Brain Talks episodes

In the new Brain Talks episode with **Dr Matilde Leonardi**, Director of the Italian WHO-Collaborating Centre Research Branch “IRCCS Istituto Neurologico C. Besta”, we take a look at the main points of the story that led researchers to identify the connections between the pandemic and its effects on the brain.

With **Professor Paul Boon**, President Elect of the European Academy of Neurology (EAN), we discuss the rise of telemedicine and teleneurology during the pandemic.

In the latest episode, **Professor Peter Falkai**, President of the European Psychiatric Association (EPA), explained how psychiatric clinics are modifying their practice in order to guarantee care and support to persons with mental health problems.

[Listen to the Brain Talks](#)

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

The **Value of Treatment for Brain Disorders (VOT)** is a health economics and outcomes research project. EBC conceptualized the Value of Treatment research framework to address the increasing burden of brain disorders – both neurological and mental alike.

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

The preliminary findings of the case studies were presented at the **Value of Treatment 2 Synthesis Meeting on 8 June 2021**.

[Read more](#)



EBC at the 7th Congress of the European Academy of Neurology

EBC took part in the **7th 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** "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.

The European Brain Research Area (EBRA) organised a **roundtable** addressing the importance of cooperation and collaboration in the European brain space and presenting more about the project.

[Read more](#)



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

In 2016, the **Declaration for Good Off-Label Use Practice (GOLUP)** was launched, supported by a coalition of European organisations dedicated to ensuring that high standards of patient care are upheld and that progress in medical research and innovation is achieved.

Five years later, the time has come to take a step forward, to look back at what has been achieved and to prepare for future developments.

The purpose of this event, that took place on **17 June**, was to allow an exchange of ideas and experience among stakeholders and local actors, to understand which paths to take in individual Member States and to allow a continuous exchange of ideas and information on the off-label use of medicines.

[Read more](#)



EBC at the Africa – Europe Science and Innovation Platform

AERAP (Africa-Europe Science and Innovation Platform) is a response to the call of the European Parliament, through the adoption of its Written Declaration 45 “on Science Capacity Building in Africa: promoting European-African radio astronomy partnerships”. This call was repeated by the Heads of State of the African Union, through their decision “Assembly/AU/Dec.407 CXVIII”, for radio astronomy to be a priority focus area for Africa—EU cooperation.

Monica Di Luca, EBC president, participated in a panel on **15 June 2021**, opened by Maria Cristina Messa, Italian Minister for Universities and Research.

[Read more](#)



Event Report: VOT2 Case Studies on Rare Diseases & Mental Disorders present findings at Synthesis Meeting

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

The meeting brought together all experts from within VOT2 as well as external experts and a wider audience from the community. The experts presented their preliminary findings, which can be read in more detail in the full **event report** as well as the **full recording** of the event.

[Read more](#)

New Value of Treatment stream on Transversal Topics currently underway

Kicked off in December 2020, a third stream of the Value of Treatment project on **Transversal Topics** is officially underway over a three-year period from 2021 to 2023. A case study on chronic pain has begun and soon a case study on sleep and wake disorders is to follow, potentially among others.

The group study on **chronic pain**, 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), officially began its work in December 2020 and a final report study is expected to be released by the end of 2022.

[Read more](#)



Explore EBC's first virtual exhibition | Living with MS during COVID-19: A case for rethinking MS care in the EU

In occasion of World Multiple Sclerosis Day, on 30 May, key European stakeholders joined EBC's **first virtual exhibition** and showed their support for EBC's call to renew attention to the care and cure needs for people living with MS. From Hans Henri P. Kluge, Director of the WHO's Regional Office for Europe, and Sandra Gallina, Director-General for the Health Directorate in the European Commission, to MEPs Dolores Montserrat and Tomislav Sokol, and many more, health policy-makers shared their thoughts on the pressing need to learn from the challenges revealed by the COVID-19 pandemic and to rethink the way MS care is delivered.

[Visit the exhibition](#)



EBC supports statement on "Better mental health together"

EBC was happy to support a statement of the European Psychiatric Association (EPA) and the Europe Region World Physiotherapy on "**Better mental health together**", launched on the occasion of the 2021 European Public Health Week.

[Read more](#)

EBC raises awareness on International Phenylketonuria Day

EBC was happy to recognise and support **International Phenylketonuria (PKU) Day**, which takes place annually on 28 June — the birthday of two stalwarts of PKU, Robert Guthrie (1916-1995) and Horst Bickel (1918-2000).

The ongoing 2019-2021 **Value of Treatment (VOT)** project for Brain Disorders and its recent synthesis meeting on 8 June 2021 aimed to provide preliminary findings on the Value of Early Coordinated Care for Rare Diseases, among them Phenylketonuria.

[Read more](#)

EBC Members



2021 ECNP Congress goes hybrid!

The 34th ECNP Congress, 2-5 October 2021, Lisbon, Portugal will be a hybrid congress.

What is a hybrid congress? Hybrid means you have a choice: you can join in-person in Lisbon or online.

[This video](#) explains how it works.

[Read more](#)



Addressing the impact of COVID-19 on the lives of people living with neurological disorders

The European Federation of Neurological Associations (EFNA) has published a report on the impact of COVID-19 on people living with neurological disorders in Europe. The report summarises evidence gathered from organisations across the European neurology community. 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.

[Read more](#)



Join us at the virtual FENS Regional Meeting 2021

With an exciting programme of plenary lectures, symposia, panel discussions and special interest events, the FENS Regional Meeting (FRM) will present the latest developments in neuroscience research. The FRM 2021 will take place on 25-27 August 2021 as a virtual event.

[Read more](#)



COVID-19 survey

2021
GAMIAN-Europe
Covid-19 Survey
Report



We have all been affected by the current COVID-19 pandemic - and mental health has never been so much in the spotlight. This situation has presented an opportunity to underline the importance of mental health and to ensure an appropriate understanding of the needs of patients. For this reason, GAMIAN-Europe took the initiative to carry out a survey, focusing on the impact of the pandemic on pre-existing patients. The survey was translated into 13 languages and gathered over 500 respondents across Europe. The findings of the survey have been put together in a report, together with lessons learned from the crisis and recommendations to services and governments. The findings were also presented during the European Public Health Week and at the High-Level Commission event on mental health.

As a follow up to this survey, we will be launching a second survey aimed at evaluating the current state of mental health services from the patient's perspective (both new and pre-existing). The survey will be disseminated across European countries and conducted in collaboration with the European Psychiatric Association.

[Read more](#)

Have a nice summer!



The monthly EBC Newsletter will be paused during the summer months of July and August. Keep an eye out for a joint Summer Newsletter to be released in September when we go back to our usual communications schedule.

We wish you all wonderful summer breaks!

For your Agenda

26 July 2021 - [3rd IBRO Global Neuroscience Horizons Webinar](#), Virtual

25-27 August 2021 - [FENS Regional Meeting](#), Virtual

1-3 September 2021 - [7th European Stroke Organisation Conference](#), Virtual

2-5 October 2021 - [ECNP Congress](#), Lisbon (Portugal) & Virtual

3-7 October 2021 - [EANS Congress](#), Hamburg (Germany)

12-13 October 2021 - [Brain Innovation Days: United for Brain Innovation](#), Brussels (Belgium)

7 December 2021 - [Encephalitis Conference 2021](#), Royal College of Physicians, London (UK) & Virtual

2-5 April 2022 - [30th European Congress of Psychiatry](#), Budapest (Hungary)

28 April-2 May 2022 - [14th European Paediatric Neurology Society Congress](#), Glasgow (UK)



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