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20 YEARS OF UNITING THE BRAIN COMMUNITY



MAKING BRAIN HEALTH A PRIORITY IS MAKING EVERYONE'S LIFE A PRIORITY.

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PRESIDENT ¢ EXECUTIVE DIRECTOR

Letter from EBC President & Executive Director

Dear Colleagues,

We are delighted to share with you the European Brain Council (EBC) Annual Report for 2022.

This year was a key milestone for EBC, as it marked its 20th anniversary. Twenty years ago, EBC was the answer to the need for increased unity within the brain community, building a more connected network of key players in the brain space — scientists, clinicians, patients, industry — encompassing basic neuroscience, neurology, neurosurgery and psychiatry. Its mission remains the same today: to unite the brain community and promote brain research with the goal of improving the lives of these who live with brain conditions, neurological and mental alike.

With a new leadership in place, we were pleased to continue our successful running of key projects and flagship initiatives such as the remarkable second in-person edition of the *Brain Innovation Days*, which hosted the official launch of the European Brain Foundation. The Final Conference of the European *Brain Research Area (EBRA)* project concluded four years of tremendous work, paving the way to a European brain health partnership. We strengthened engagement at the global level through the activities under *Fostering Global Partnerships in Brain Research* which culminated in the organisation of a high-level roundtable in the framework of the Science Summit at the 77th United Nations General Assembly in New York. The project series *Rethinking the management of brain disorders* came a long way this year, with a new focus on Alzheimer's disease – and more to come in 2023!

This year was truly outstanding for EBC, as we strengthened established activities and expanded to a global scale, all while continuing to develop our growing portfolio of projects and advocacy efforts, again ensuring EBC as the key voice for the brain community in Brussels and beyond.

EBC would like to thank its members, partners and every individual who supports our work in striving to raise awareness and ensure brain health – for the sake of all Europeans – is recognised as a priority at every level.

Kind regards,



Prof. Wolfgang Oertel
President

Wolfgang Once



Suzanne Dickson, Incoming President

Suzame L Dichson



Frédéric Destrebecq Executive Director



EBC Mission & Vision



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

EBC strives for a world where:

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

EBC realises this through:

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

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



EBC Highlights



THE EUROPEAN BRAIN COUNCIL CELEBRATES ITS 20TH ANNIVERSARY

EBC celebrated 20 years of existence in 2022, marking "20 years to this day" on the exact anniversary of its formation: 22 March. The brain child of Prof. Jes Olesen, EBC was the answer to the need for increased unity within the brain community, building a more connected network of key players in the brain space — scientists, clinicians, patients, industry — encompassing basic neuroscience, neurology, neurosurgery and psychiatry.

In the last two decades, EBC was built from its humble beginnings to become a leading voice for the brain at the EU and (more recently) global level, with a permanent secretariat in Brussels and dedicated Executive Committee and Board. Through flagship projects like the Value of Treatment and the Cost and Burden study, EBC has put itself on the map as the leading reference for the political, societal and economic impact of brain disorders and the argument for prioritisation and support of brain research in Europe.

EBC has been involved in many projects ever since its creation and continues to be, both EU-funded and EBC/partner-funded. As a celebration of these twenty years, the EBC team launched an <u>interactive timeline</u>, detailing major milestones in EBC's history. Journey back through time — starting from foundation in March 2002 until present day — to experience an overview of major projects, statements, activities and more. Additionally, to mark this special occasion, a full year of social media content was created and shared to keep the memories alive and inspire for the future, including <u>videos</u> and graphics highlighting key milestones.

EBC extends its thanks for all for your continued commitment and support – we look forward to a bright future for EBC and ongoing collaboration.



BRAIN INNOVATION DAYS



On 11-12 October 2022, EBC was pleased to host its second in-person Brain Innovation Days in Brussels. Held in conjunction with the Final Conference of another major EBC project, the European Brain Research Area, the event brought together the main circle of influence in the brain sector,

with key players in the brain research and innovation field networking together: investors, researchers, clinicians, patient representatives, policymakers and more.

The focus of the 2022 event was to enable space and opportunity for **open discussion** and showcasing, prioritising matchmaking and networking within the community, particularly of stakeholders who don't always have the opportunity to connect in their day-to-day. In this regard, the event space allowed for two areas: dynamic presentations of cutting-edge innovations and ample networking and showcasing space. Without parallel sessions, participants were able to focus on the main programme of Brain Talks, Panel Discussions and How-To Sessions in the main Auditorium and spend their breaks in the Innovation Hall to meet fellow participants and view tangible tools and solutions for the brain. High-level experts such as Dr Laura-Joy Boulos, Prof Peter Falkai, Josep Figueras, Prof David Nutt were part of the programme alongside patient representatives (Tim Buckinx, Epihunter and Donna Walsh, International Bureau of Epilepy), funders (Enric Claverol-Tinturé, European Innovation Council and Tomasz Dylag, European Commission), investors (Diana Saraceni, Panakes Partners and François Véron, Newfund Capital) and many more.

The much-anticipated 2nd Brain Innovation Days Pitch Competition also took place, with five finalists pitching their start-ups in a nail-biting 180 seconds to a jury of high-level investors and funding agency representatives for the chance to win the Jury Award and Audience Award of Best Pitch. On stage were: Amir Bozorgzadeh pitching Virtuleap, Jonathan Balfour pitching Panaxium, Jurij Dreo pitching BrainTrip, Mai Nguyen pitching Optoceutics and Mehrdad Seirafi pitching Alpha Brain Technologies – with Panaxium eventually hailed Best Pitch by the Jury and BrainTrip awarded Best Pitch by the Audience vote.

Attendees were not short of activities during the Days. The networking lunch show-cased just how eager the wider community was to connect, with plenty of one-on-one matchmaking and spontaneous discussions underway. Others took the opportunity to discuss over a game or two of checkers in the gaming area or while exploring the RETHINKING Migraine in times of COVID-19 exhibition.

Additionally, <u>15 companies showcased</u> their work in the Innovation Hall via an Innovation Showcase stand or poster presentation, with impressive work and tools such as Epicranial electrical stimulation, cobots, Al-optimized EEG-based biomarker, novel interactive <u>BRAINTEASER</u> tools for Amyotrophic Lateral Sclerosis (ALS) and Multiple Sclerosis (MS) management and more on display.

BRAIN INNOVATION DAYS

The Brain Innovation Days also hosted the official launch of the <u>European Brain Foundation</u>, an independent multidisciplinary and multi-stakeholder charity whose founding members represent leading European neurological, neurosurgical, and psychiatric clinical societies as well as neuroscience research societies and patient organisations. Its goal is to support research aiming at reducing the burden of brain disorders for European citizens. Board Members Prof. Patrice Boyer, Audrey Craven and Prof. Philip Gorwood presented its main mission and what was to come.

Masters of Ceremony Bettina Hausmann and Usman Khan welcomed all attendees to Save the Date for the Brain Innovation Days 2023, to be held on 26-27 October in Brussels.



In addition to the in-person Brain Innovation Days, a second season of the Brain Talks podeast series was produced in the months leading up to the event, featuring key opinion leaders and stakeholders from the ever-growing brain ecosystem, discussing the latest breakthroughs, ongoing research and other exciting topics related to brain innovation. This season focused on brain in the life course, with guests representing the EBC membership.







@BrainDays

in Brain Innovation Days

Brain Innovation Days

Brain Innovation Days , 11-12 October 2022





FINAL CONFERENCE OF THE EUROPEAN BRAIN RESEARCH AREA (EBRA)



EBC's four-year, EU-funded <u>European Brain Research</u> <u>Area (EBRA)</u> project came to a close at the end of October 2022, its forged partnerships and successes officially celebrated in a Final Conference held in Brussels, Belgium on 11 October.

Launched in 2018, the EBRA project — led by the European Brain Council in partnership with

the <u>Network of European funding for Neuroscience research (NEURON)</u>, the <u>Joint Programme - Neurodegenerative Disease Research (JPND)</u> and the <u>Human Brain Project (HBP)</u> — was created as a catalysing platform for brain research stakeholders (researchers, clinicians, patients, governments, funders and public institutions) to streamline and better co-ordinate brain research across Europe while fostering global initiatives. EBRA has worked at reducing the fragmentation and duplication of research efforts and at fostering synergies through enhanced coordination of brain research efforts at the EU and global level.

The event was an occasion to bring the wider brain research community and key players together, to discuss key aims of the project: the current state of brain research in Europe, increased patient engagement and public awareness, research infrastructures and data sharing and the future potentials and need for a brain health partnership going forward.

In a room of over 200 participants, experts from within the EBRA ecosystem (including high-level researchers and EU officials) – including representatives from all four partners—spoke in panels dedicated to the next steps for the future of collaborative brain research in Europe, translation from basic to clinical research, digital innovation, technology, and data-sharing, patient and public involvement and finally, shaping the future brain research and brain health landscape in Europe and globally. Key project outcomes such as the mapping report, the Shared European Brain Research Area (SEBRA) and all six clusters were showcased.

The high-level conference drew to a close with concluding remarks from Prof Monica Di Luca, EBRA Coordinator and EBC Past President, who celebrated the achievements of the brain research community, the EBRA project and looked toward a bright future for brain research in Europe: "I believe we are all looking forward to continue working together to face the great challenge of the brain".

On behalf of the EBRA Consortium, thank you for being part of the journey and we look forward to continued collaboration for the future of brain research very soon, paving the way towards a European and global partnership for the brain.







FOSTERING GLOBAL PARTNERSHIPS IN BRAIN RESEARCH

Enhancing global collaboration in the domain of research and innovation is key for effectively addressing today's societal challenges and improving the health and well-being of citizens. This is particularly true for brain disorders, including both neurological and mental conditions, which are widespread and highly disabling diseases that are often difficult to treat.

In line with its work within the European Brain Research Area project, particularly its Shared European Brain Research Agenda (SEBRA), EBC has been working to engage further at the global level and foster partnerships for the benefit of brain research.



Building on previous meetings and events at the 2020 FENS Forum and Science Summit at the 75th United Nations General Assembly, EBC ramped up its presence and partnerships at the global level with additional events and meetings in the area, including hosting a high-level roundtable. On 26 September 2022, in the framework of the Science Summit

at the 77th United Nations General Assembly, EBC and Cohen Veterans Bioscience, in partnership with the Brain Capital Alliance and OECD Neuroscience-inspired Policy Initiative convened a meeting on Global Partnerships in Brain Research in New York, USA. Bringing leaders in neuroscience around the table, the meeting highlighted existing global partnerships and aimed to explore collaboration and alignment in the brain research space for the future.

On EBC's side, Executive Director, Frédéric Destrebecq, opened the meeting with an introduction of EBC, the advocacy work undertaken to further brain research and our main projects, particularly the European Brain Research Area (EBRA), which has a key focus on fostering and enhancing global partnerships in brain research. He explored how EBRA could be used as a model for collaboration in brain research for the future, particularly as the project comes to an end this month and discussions for the future are underway.



Attendees around the table included high-level representatives from the Michael J. Fox Foundation, the European Commission (DG RTD), IHI, Nature Neuroscience, Milken Institute, IMPACT at Deakin University (Australia), Society for Neuroscientee, Brain Health Nexus, Mount Sinai (USA), Society for Neuroscientists of Africa, GreyMatter Capital, Brain and Mind Centre – University of Sydney (Australia), Yale University (USA), Western University (Canada), Drexel University (USA), Sharper Sense, Novartis, Global Brain Health Institute/American University Cairo (Egypt), Simons Foundation, UT Southwestern Medical Center (USA) and Boston University (USA).

Additionally, EBC was also invited to attend the University of Texas Systemwide Brain Research Summit by the Meadows Mental Health Policy Institute, an interesting showcase of the impressive work done across the Atlantic and insight into key areas for transatlantic lesson-learning and collaboration.

These meetings paved the way for continued dialogue and building alliances with partners at the international level, to be continued in a global partnership in brain research event during Brain Awareness Week 2023 in Brussels.



EUROPEAN BRAIN FOUNDATION (EBF)

The <u>European Brain Foundation</u> (EBF) was founded on 8 October 2021 in Brussels, Belgium. The idea of Foundation was born a few years ago during a meeting in San Francisco, suggested by EBC's President at the time, Prof. Monica Di Luca. The EBF is an independent multidisciplinary and multi-stakeholder charity whose founding members represent leading European neurological, neurosurgical, and psychiatric clinical societies, as well as neuroscience research societies and patient organisations. Its goal is to support research aiming at reducing the burden of brain disorders for citizens from Europe and beyond and to raise funds for brain research and to allocate them to projects corresponding to its mission. The EBF is the first charity in Europe of its kind, focused specifically on brain research.

Its goal is to raise funds for brain research and to allocate them to projects corresponding to the EBF mission. It is worth mentioning that EBF is the first charity in Europe focusing on brain research.

The European Brain Foundation was officially launched during the annual <u>Brain Innovation Days</u> in October 2022. The EBF relies on broad and diverse expertise from its Board Members, and three were featured in a panel on the day: Prof. Patrice Boyer (Chair), Ms Audrey Craven (Vice-Chair), Prof. Philip Gorwood and Frédéric Destrebecq (Executive Director), who presented the EBF's objectives. The outcome of this session can be summarized in Ms Craven's words: "The future belongs to those who give the next generation hope".

After the Brain Innovation Days, the EBF got its work started with the launch of its first activity – a Fundraising Gala Dinner planned for 16 March, during Brain Awareness Week 2023. Held around the theme "Healthy Brain – a key to future generations in Europe", the gala will focus on the importance of the healthy brain and the vital impact this has on society. With this event the EBF hopes to unite all relevant stakeholders, including policymakers and people living with and/or affected by brain disorders, to strive together for brain health.







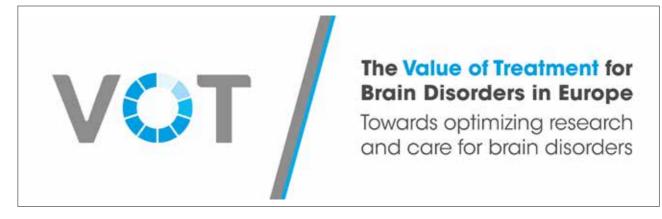




Projects & Initiatives



EBC PROJECTS > VALUE OF TREATMENT



Delivering high quality patient-centered care, promoting equitable access to healthcare services everywhere in Europe independently from the place where the patients live, promoting efficient use of resources favoring the economic sustainability of the healthcare systems, are some of the main targets of the European Commission's healthcare policy and of the separate or individual national healthcare systems in Europe. There are some organizational barriers and crucial issues to manage in the achievement of these objectives in particular for rare disease patients or people affected by a mental disorder. The lack of coordination of care, the lack of communication among health care providers, healthcare professionals and patients, the duplication of many services that are provided to the patients, represent some paradigmatic examples. The organization of care has a deep impact on the variability in the quality of care provided to patients and on the equity of care access. The patients care pathways can be defined as "a methodology for the mutual decision making and organization of care for a well-defined group of patients during a well-defined period". Patient care pathways (PCPs) are a useful tool for the (re)design and the (re)definition of the provision of the healthcare services to the patients.

The <u>Value of Treatment for Brain Disorders (VOT)</u> is a health economics and outcomes research project coordinated by the EBC. The study addresses current unmet needs in healthcare and the increasing all-age burden of brain disorders by answering three questions from a clinical, economic, and patient-centered outcomes perspective: what impact do care pathways have on outcomes; what is the cost of optimized care pathways and how to make policy recommendations grounded in relevant and solid scientific knowledge? A second round (2019-2021) focused on The Value of Early Diagnosis and Coordinated Care for Rare Brain Diseases (Ataxia, Dystonia and Phenylketonuria); and The Value of Early Intervention and Continuity of Care for Mental Disorders (Anorexia Nervosa, Autism Spectrum Disorder and Major Depressive Disorder).

► Value of Treatment for Rare Brain Diseases

Over 30 million people in the EU live with a rare disease. 75% of rare diseases have neurological symptoms, seriously compromising the health and quality of life of people living with a rare disease. A multiplier effect of comorbidities on the impact of rare diseases requires innovative care and treatment pathways for society to cope. The case study results released in 2022 highlights the value of coordinated care and specialist centers to address the challenges faced by people living with a rare neurological disease (Ataxia, Dystonia) or a neurometabolic disorder (Phenylketonuria). Scientific publications will be released in the European Journal of Neurology.

EBC together with its members, academic partners and the involved European Reference Networks (ERN-RND and MetabERN) launched in 2022 (Brain Awareness Week) a <u>call</u> for the prioritization of brain health, efficient care pathways and seamless, coordinated care for people living with rare brain diseases.

▶ Value of Treatment for Mental Disorders

An estimated one in four people in Europe experience a mental health condition at some point in their lifetime. Like any other mental disorders, anorexia nervosa, autism, and major depressive disorder all share similar challenges. People with mental health issues face complex biological, psychosocial, and healthcare needs with clear implications in terms of quality of life and costing. According to the VOT case study results on autism, more than 60% of parents say they do not get the support they need for their child. The duration of untreated illness for adolescents with anorexia nervosa can be high. Many young adults with major depressive disorder are not receiving treatment at any one time and it is known that both duration of untreated illness and the number of ineffective treatments trialed are risk factors for poorer long-term outcomes. The study looked at early intervention and explored 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 provided in 2022 insight on the value of early intervention to improve children and young people's mental health and the causes of mental ill-health. Scientific publications will be released.

EBC together with its members and academic partners launched in 2022 (Brain Awareness Week) a <u>campaign</u> calling for early detection, continuity of care, prioritising brain health and efficient care pathways for youth with mental health issues.

► 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 lowback 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 modeling/cost effectiveness analysis are expected at the end of 2023.

EBC PROJECTS > 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.

The aim of the <u>RETHINKING Projects</u> 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 > RETHINKING PROJECTS

RETHINKING Multiple Sclerosis in times of COVID-19

RETHINKINGMS IN TIMES OF COVID-19



On the occasion of Multiple Sclerosis Awareness Week 2022, the national extension of the virtual exhibition <u>"Living with MS during COVID-19: A case for rethinking MS care in the EU"</u> brought light to the impact of the COVID-19 pandemic on multiple sclerosis at country level.

Impact of the COVID-19 pandemic on multiple sclerosis at national level

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 disruption in their care pathways, and, as a consequence, have dealt and will continue to deal with long-term physical and emotional implications of not receiving optimal care.

National stakeholders across Europe wanted to make a difference in how MS care and treatment are delivered. They called for 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. In the extended exhibition, experts from Belgium, the Czech Republic, France, Germany and the United Kingdom shared unique insights on MS care during the COVID-19 pandemic.

RETHINKING MS in Europe

The virtual exhibition "Living with MS during COVID-19: A case for rethinking MS care in the EU", initially launched on the World MS Day 2021, is part of the research project RETHINKING MS in Europe, coordinated by EBC. The aim of the project is to create greater visibility for the unmet needs experienced by people with MS, with a particular focus



on three key areas: timely diagnosis and personalised treatment; interdisciplinary and coordinated care; and adaptable support in daily life, including rehabilitation and social protection.

EBC PROJECTS > RETHINKING PROJECTS

RETHINKING Migraine



On the occasion of Migraine & Headache Awareness Month, the European Brain Council launched "Migraine, my brain" campaign to highlight the need to rethink migraine care. The campaign fell under "RETHINKING Migraine in times of COVID-19", a research-driven project offering tangible policy changes to improve the lives of people living with migraine across Europe.

About RETHINKING Migraine in times of COVID-19

The management of chronic neurological disorders such as migraine can be challenging under "normal circumstances", not to mention the global pandemic that the world has been facing since 2020. It is undeniable that COVID-19 has disrupted every sphere of society, but the repercussions for people living with migraine, overshadowed by the COVID-19 outbreak, should not be overlooked. What were the challenges faced by people with migraine before and during the coronavirus pandemic and what lessons can be learnt from this unprecedented experience? What strategies can be put in place to make them sustainable in the long term?

The objective of the policy report <u>"RETHINKING Migraine in times of COVID-19"</u> was to respond to these questions by a comprehensive literature review of the recent publications and by providing concrete and tangible testimonies of all relevant stakeholders. Clinicians, migraine patients, patient and family advocates, health insurance providers 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.

We shed light on how people living with migraine have been impacted by the pandemic, which good practices have been put in place and what lessons can be learnt from this experience. The report provided insight into why we need to rethink migraine to provide and ensure access to optimal care for all.

EBC PROJECTS > RETHINKING PROJECTS

RETHINKING Migraine

RETHINKING Migraine poster exhibition at the Brain Innovation Days 2022

During the second edition of the Brain Innovation Days, participants had the opportunity to explore the <u>"RETHINKING Migraine in times of COVID-19"</u> poster exhibition, featuring portraits and quotes of people living with migraine, patient advocates and policy makers. The exhibition fell under the #MigraineMyBrain campaign highlighting the need to rethink the way we deal with migraine.



RETHINKING Migraine: The Economic Value of Preventive Treatments for Episodic & Chronic Migraine

Started end of 2022, aim of the study on The Economic Value of Preventive Treatments for Episodic & Chronic Migraine is to conduct an economic evaluation of preventing treatments for episodic and chronic migraine. The focus will be on working age adults and the analyses will be conducted in two countries. We will build on expertise from clinicians and populate model with economic data sourced from the literature.

EBC PROJECTS > RETHINKING PROJECTS

RETHINKING Alzheimer's disease



Through <u>RETHINKING Alzheimer's disease (AD)</u>, the European Brain Council and the European Federation of Pharmaceutical Industries and Associations (EFPIA) joined forces with the ambition of improving Alzheimer's disease care pathway and the lives of people living with it.

Officially launched on 29 April 2022, the project kicked off its operational activities with the aim to call for change in how Alzheimer's disease care and support are organised in Europe.

About RETHINKING Alzheimer's disease

EBC and EFPIA will collaborate with experts from different European countries to build an interdisciplinary consensus around practical and sustainable policy responses to Alzheimer's disease that will aim to improve the lives of people living with it.

As different countries face specific challenges, it is important to consider the national context when advocating for policy change. For this reason, RETHINKING AD will take a closer look at the national context in **5 European countries** (Czech Republic, Germany, Italy, the Netherlands, Sweden) with the aim to provide tailored solutions and policy recommendations to create a new patient pathway and care journey.

Building on the outcomes of the paper on <u>"Alzheimer's Disease Health System Readiness - The Time to Act is Now"</u>, launched by EFPIA in 2020, the recommendations will focus on 2 areas in 2022: detection and diagnosis. The project will continue in 2023 with a focus on AD interventions and treatment, and monitoring.

EBC PROJECTS > RETHINKING PROJECTS

RETHINKING Alzheimer's disease

Alzheimer Europe Conference: Symposium on rethinking the early detection and diagnosis of Alzheimer's disease

The speakers of the evening symposium <u>"Rethinking the early detection and diagnosis of Alzheimer's disease"</u>, held on **18 October 2022** at the **Alzheimer Europe Conference** in Bucharest (Romania), presented RETHINKING Alzheimer's disease. The panel discussion, moderated by Lydia Lanman (Roche) on behalf of EFPIA's Alzheimer's Disease Platform (Roche, Eisai, Eli Lilly, Novo Nordisk and Biogen), featured Kevin Quaid (European Working Group of People with Dementia), Wiesje van der Flier (Alzheimer Centre Amsterdam) and Lenka Krajčovičová (Masaryk University). The speakers of the symposium explored how to rethink the way we approach Alzheimer's.



EU-FUNDED PROJECTS > EBRA

European Brain Research Area (EBRA)



More than one out of two Europeans currently live with a brain disorder, neurological and mental alike. Despite enormous effort from the scientific and clinical community over the last decades, the challenges in the brain space remain tremendous, spurred by the high prevalence and increasing disease burden. This showcases the immensity of the problem, and it makes clear that brain health and brain research

need to be promoted and recognized as a priority by European society. The EU has already undertaken some important steps to boost brain research initiatives with partners around the world, including the EU-funded project "the European Brain Research Area (EBRA)" (2018-2022), led by the European Brain Council (EBC), in partnership with the EU Joint Programme on Neurodegenerative Diseases (JPND), the Network of European Funding for Neuroscience Research (ERA-NET NEURON) and the Human Brain Project (HBP).

Tackling the challenge posed by the complexity of the brain is possible only through close collaboration and cooperation within the community. The involvement of all relevant stakeholders in the brain area is required, including basic, translational, and clinical scientists, neurologists, neurosurgeons, psychiatrists, industry, regulators, funders, and policymakers. The role of people with brain disorders, their families and citizens cannot be underestimated here and is of utter importance. Building networks and matchmaking with key experts in the field (e.g., the Brain Innovation Days - BIDs) should be a priority for all the stakeholders, including policymakers. This will reduce fragmentation in the brain space, contribute to a better understanding of the brain, and will eventually improve the lives of persons with brain disorders, their families and society as a whole.

EU-FUNDED PROJECTS > EBRA

European Brain Research Area (EBRA)

The European Research Inventory and Mapping Report shows brain research activities funded at the European level over the last decades, examining the past and current state of brain research in Europe. The statistics demonstrate that annual fundings in Europe can reach significant levels to support highly competitive research projects reaching €550 million in 2014-2018. As the challenges posed by brain disorders remain high, continued funding of research consortia is key for a lasting impact on collaboration and innovation in the European and global brain research area. It evidences that continuous support is still needed in all areas of brain research in the EU, particularly to support initiatives that reduce fragmentation and increase collaboration. Attention should be given to the importance of animal models, increasing public patient engagement and encouraging and enabling data sharing.

Through EBRA, recommendations on future areas for excellent, innovative, and translational research in the brain space were provided. To identify the gaps in currently existing brain research and set the priorities for the future, EBRA, working with experts in the brain space (neuroscientists, neurologists, psychiatrists, and persons with brain disorders) has developed the Shared European Brain Research Agenda (SEBRA). Representatives from the EBC systematically presented the SEBRA at several international conferences and global meetings like the IBRO World Congress, the United Nations General Assembly Side Sessions: "Science Digital @ UNGA75", Science Summit at the 77th UN General Assembly to foster the global brain research agenda.



To promote cooperation and exchange in all areas of brain research, the EBRA project regularly had a "Call for Clusters" to promote cooperation and exchange among specific brain research projects, and to boost international collaboration in these areas. Up to date, six clusters have been selected: BRAINFOOD, EPICLUSTER, PSMD (Prevention of Severe Mental Disorders), PREMOS (Predictive Model Systems), TRISO-MY21 (Down Syndrome) and ECIB. The 6 clusters organised 18 consensus meetings, workshops, and policy conferences. All relevant stakeholders were systematically involved in those meetings including large research initiatives, infrastructures as well as relevant public, private and philanthropy funding bodies and regulatory authorities, in order to ensure effective implementation and impact of this coordination action. Importantly, by highlighting the importance of communication and dissemination of the cluster activities and outcomes on the EBRA website and social media, the visibility of the cluster coordinator, community and research field increased enormously and made other researchers aware of the importance of joining such initiatives in the future.



To enable and accelerate the translation of breakthroughs in brain research into relevant clinical applications, EBC created the BIDs in 2020. The BIDs serve as an instrument to bring together the wider brain community, raising awareness on the importance of brain research and brain innovation. The event brings together both key stakeholders and the broader public through these accessible materials. After three digital sessions during the COVID-19 pandemic, a first in-person event took place in October 2021, under the auspices of the EBC and EBRA and a second in-person event took place in October 2022 in conjunction with the EBRA final conference. The BIDs are now an annual event and will be organised again in October 24-25, 2023.

Crucial stakeholders in the EBRA project were the experts by experience¹ and patient representatives². The EBRA patient involvement strategy was fully embedded and implemented in all EBRA activities. Based on this experience, EBC wrote "the recommendations for patient involvement best practice".

Impact was reached at 3 levels:

- 1. Scientifically, the EBRA project raised awareness on the brain research landscape and on the ongoing societal challenges for researchers, health professionals and scientific global organizations. The visibility of the cluster coordinator, community and research field made other researchers aware of the importance of being involved in research networks and of joining coordination initiatives in the future. In addition, with many of the brain-related flagship projects ending in 2023 including JPND, NEURON and the Human Brain Project the need for continued prioritisation of European-led, coordinated collaborations is clear. The challenge of getting Member States and national funding councils to commit to long-term partnerships remains. Unification in the brain space is now more important than ever and a coordinated partnership is the only answer to avoid fragmentation in the field and move forward together.
- 2. At the societal level, awareness was raised on brain diseases and research for patients and civil society through online material shared via the website and social media, including publications, interviews, webinars, podcasts and videos with leaders from the EBRA community. Patients and their caregivers will also have access to the recommendations on patient involvement best practice. This will contribute to an improvement of Quality of Life in patients and their families.
- 3. At the economic level, the launch of the BIDs and the involvement of SMEs and start-ups in brain research, will lead to the development of novel tools and approaches to advance our understanding of unknown basic brain functions, as well as opportunities to generate novel therapeutic approaches. Such delivery of new health interventions in brain disorders will eventually result in a reduction in the burden of brain diseases in Europe and tackle this major societal challenge in Europe and worldwide.
- in ebra-eu
- o ebra.eu

^{1.} Experts by experience refer to all persons with a brain disorder, mental and neurological alike.

^{2.} Patient representatives refer to all persons representing a patient organisation (e.g., EFNA, GAMIAN-Europe and/or their member organisations).

EU-FUNDED PROJECTS > BRAINTEASER

Brainteaser



Officially started on the 1st of January 2021, the EU-funded project <u>BRAINTEASER</u> 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 setor 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.

BRAINTEASER took part in the Brain Innovation Days 2022

The second edition of the Brain Innovation Days featured BRAINTEASER as one of the exhibitors in the Innovation Hall. Not less than 15 companies showcased their work in the Innovation Hall via an Innovation Showcase stand or poster presentation, with impressive work and tools. On behalf of the BRAINTEASER project, Vladimir Urošević, Research & Development Manager at Belit Ltd. Belgrade, presented the novel interactive BRAINTEASER Tools for Amyotrophic Lateral Sclerosis and Multiple Sclerosis Management in the Innovation Hall. He explained how the BRAINTEASER project integrates detailed clinical datasets with novel personal health, activity, lifestyle, habitual/behavioral, and environmental data collected using commonly available sensing/loT devices and the demonstrated first release of developed interactive tools for disease monitoring and management.

- @brainteaser2020
- in **BRAINTEASER** Project
- brainteaser.health

EU-FUNDED PROJECTS > PRIME

PRIME (Prevention and Remediation of Insulin Multi-morbidity in Europe)



The Prevention and Remediation of Insulin Multimorbidity in Europe (PRIME) project (2020 – 2024) was designed to respond to the Horizon 2020 call, SC1-BHC-01-2019 entitled "Understanding causative mechanisms in co- and multimorbidities combining

mental and non-mental disorders". PRIME addresses insulin-related signaling. Dysfunctional insulin signaling is a key modulator of mental and non-mental chronic diseases. However, until now scientific studies have overlooked these insulin-related "co-occurring diseases". PRIME aims to generate innovative diagnostic and treatment strategies to improve the monitoring and clinical outcomes of patients. In addition, we aim to identify and specify the molecular mechanisms underlying insulin multimorbidities.

Within the PRIME project, EBC is responsible for the organisation of a public/policy event in 2024. This event frames into the communication and outreach task and aims to reach all relevant stakeholders including researchers, clinicians and patients but especially policy makers. This event will allow to:

- 1. Liaise with the relevant stakeholders in the "PRIME research space"
- 2. Raise awareness about the PRIME research results
- 3. Increase the impact of the PRIME research field
- 4. Create connections between science, industry, and society

To prepare for this policy event, EBC in collaboration with Concentris organised a "world café type" training event during which the members of the PRIME consortium - junior and senior alike - brainstormed about:

- 1. The societal impacts of the research performed in PRIME
- 2. The needs, priorities and gaps in the broader PRIME research field and community
- 3. The enabling actions on how the identified needs, priorities and gaps should be addressed
- 4. The audience that should address the needs, priorities and gaps in their research field and community

The consortium was divided in 5 groups and had to brainstorm about the 4 overarching topics. To align the different visions and perspectives in each group, a member of the PRIME communication and dissemination team (i.e., Angela Bradshaw, Christiana Krammer, Kristien Aarts, Elke De Witte, Jeanette Mostert and Rosanne Ausems) as well as the project coordinator, Prof. Barbara Franke, moderated the discussions. After the brainstorming, each group shared their main consensus points (max. 3 per topic) back to the whole consortium. During the Innovation and Impact Board, the next steps were discussed.

- in PRIME Horizon2020
- o prime-study.eu



Advocacy & Outreach



ADVOCACY & OUTREACH

EBC call to European Commission for Thematic **Network on Brain Health**

At the end of August 2022, EBC responded to the European Commission's Call for Proposals on 2022 Thematic Networks, which invited health stakeholders to submit proposals for a new cycle of Thematic Networks, organised under the framework of the EU Health Policy Platform. The purpose of a Thematic Network is to produce a Joint Statement within six to nine months, summarising the common position and action of a group of stakeholder organisations on selected public health areas — with this particular round having proposed three new areas of focus, including "Mental Health in all policies".

EBC, on behalf of its Members and like-minded partners, reiterated its support and appreciation for the spotlight on mental health, however, called for the European Commission to take it a step further, urging for the expansion of the proposed topic to 'Brain Health', covering both mental and neurological disorders. To amplify the call, the response was shared publicly and the community was called to pledge their support to the letter in order to show the European Commission the importance of addressing the brain (preventive health and ill-health) as a whole.

Unfortunately, in September, EBC received word from the European Commission Directorate-General for Health and Food Safety (DG SANTE) that the proposal to expand the mental health thematic network to encompass brain health as a whole was not selected among the top four that will be launched in the EU Health Policy Platform. Though we are still encouraged by the fact that Mental Health will receive a dedicated network, "Mental health in all policies", EBC was firmly convinced by the large-scale backing from the wider EBC community, including mental health experts and representatives, that recognising and prioritising the brain as a whole is crucial. We will continue to work towards this recognition.

ADVOCACY & OUTREACH > VISIBILITY

Brain Awareness Week

Brain Awareness Week 2022 was a busy time period for EBC this year, with a series of virtual launches taking place, namely the release of the 2nd Round of the Value of Treatment project results and Calls to Action.

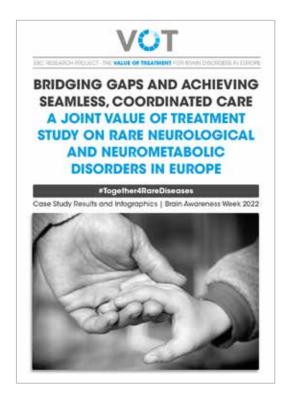
On 14 March, the <u>Value of Early Diagnosis and Coordinated Care for Rare Brain Diseases</u> results summary was launched, with case studies focused on rare neurological diseases and neurometabolic disorders Ataxia, Dystonia and Phenylketonuria. The results were accompanied by a Call to Action for a renewed EU Action Plan on Rare Diseases, calling on the European Commission and EU countries to renew a European action plan on rare diseases, which would bring together existing efforts across different legislation and EU programmes under a coherent framework to spearhead change and align EU countries towards the same measurable goals to ultimately improve survival, quality of life and clinical guidelines harmonization.

On 16 March, the <u>Value of Early Intervention and Continuity of Care for Mental Disorders</u> results summary followed, with case studies on mental disorders Anorexia Nervosa, Autism Spectrum Disorder and Major Depressive Disorder. Just like for rare brain diseases, the results of the mental disorders cases studies were accompanied by a Call to Action for an updated European framework for action on mental health, particularly focused on young people. Study results showed that there is an urgent need to prioritise early detection, continuity of care, prioritizing brain health and efficient care pathways for youth with mental disorders.

Around these major releases, further attention was also brought to ongoing work, such as the release of the <u>EBRA Mapping Report</u> and the announcements of the 2022 Brain Innovation Days and the EBRA Final Conference.

ADVOCACY & OUTREACH > VISIBILITY





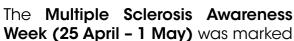




ADVOCACY & OUTREACH > VISIBILITY

Awareness raising days

Every year a number of awarenessraising 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.



by the launch of the national extension of the virtual exhibition <u>"Living with MS during COVID-19: A case for rethinking MS care in the EU"</u>, bringing light to the impact of the COVID-19 pandemic on multiple sclerosis at country level.

European Brain Council

#MentalHealth care in Europe?

disorders.

Dbit.ly/2UQydo5

11:35 am - 10 Oct 2022

Have you read the EBC Call to Action on improving

The call, falling under #ValueOfTreatment, highlights

A CALL TO ACTION

MPROVING

HEALTH CARE

IN EUROPE

MENTAL

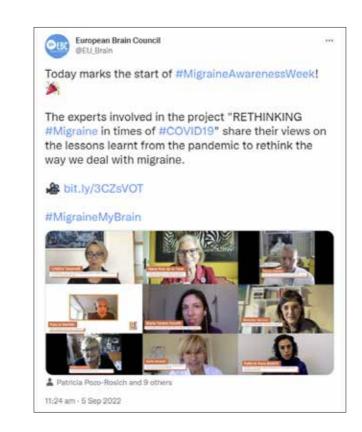
the need for early detection, continuity of care &

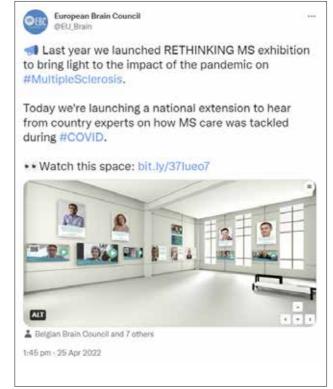
efficient care pathways for youth with mental

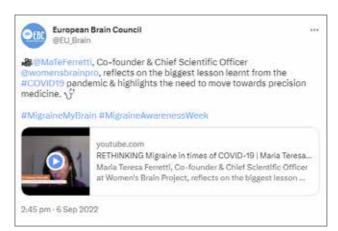
On the **Migraine Awareness Week (5-11 September)**, the experts involved in the project "<u>RETHINKING Migraine in times of COVID-19</u>" shared their views on the lessons learnt from the pandemic to rethink the way we deal with migraine.

EBC joined the world brain community on **World Mental Health Day (10 October)** which took place around the theme of "Making Mental Health & Well-Being for All a Global Priority". The EBC Call to Action on improving mental health carein Europe, falling under the <u>Value of Treatment</u> project, was highlighted on this occasion.

ADVOCACY & OUTREACH > VISIBILITY







EBC Collaboration



SCIENTIFIC CONGRESSES

EUROPEAN MULTIPLE SCLEROSIS PLATFORM (EMSP) ANNUAL CONFERENCE

The EMSP Annual Conference 2022 took place on 29-30 April 2022 in hybrid format, virtually and in person in Madrid, Spain.

The theme of this year's conference was "A Holistic Approach for Personalised MS Care". The personalised care model seeks to deliver whole-population approaches to support people of all ages and their carers to manage their physical and mental health and well-being, build community resilience, and make informed decisions and choices when their health changes.

EBC was delighted to be invited as a contributor this year, with EBC Executive Director, Frédéric Destrebecq, to take part in the session "MS in Europe: the value of integrated and personalized health and social care approaches" on the 29th of April.



14TH EUROPEAN PAEDIATRIC NEUROLOGY SOCIETY CONGRESS (EPNS)

The 14th European Paediatric Neurology Society Congress was held from 28 April - 2 May 2022 in Glasgow, United Kingdom, under the overarching theme "Precision in Child Neurology" and virtually, providing an opportunity to learn about the latest developments in the rapidly evolving field of child neurology including basic science, diagnostic methods and novel treatments. The congress theme explored how networks, systems and technology can help deliver precision care and better outcomes.

A few EBC activities relating to child neurology and broader advocacy work were featured during the Conress as well as in a virtual booth. The Value of Treatment project case studies on ataxia and phenylketonuria (PKU) were presented and Frédéric Destrebecq, EBC's Executive Director, spoke on EBC's advocacy and policy activities and promoting child neurology in Europe.





SCIENTIFIC CONGRESSES

2ND INTERNATIONAL CONFERENCE ON NEUROLOGICAL DISORDERS AND NEURORESTORATION

Professor Wolfgang Oertel, EBC President in 2022, was invited to speak at the Opening Ceremony of the International Conference on Neurological Disorders and Neurorestoration, held in Dubrovnik, Croatia on 19-22 May 2022. His talk focused on how to identify and characterize prodromal Parkinson's disease.

The conference is a meeting dedicated to all major areas of neurology, neuroscience and neurorestoration, which previously gathered 150 renowned experts from 26 countries and 3 continents, prefering quality over quantity, up to date and often provocative key-note talks, interdisciplinary cross-fertilization of approaches and solutions and major results published in dedicated journals.



30TH EUROPEAN CONGRESS OF PSYCHIATRY

The <u>30th European Congress of Psychiatry</u>, organised by the largest association of psychiatrists in Europe – EBC Member, the European Psychiatric Association (EPA) – took place virtually on **4-7 June 2022**.

"Linking Clinical Practice and Research for Better Mental Health Care in Europe" was the guiding motto for this edition of the EPA Congress, an opportunity to engage with state-of-the-art clinical tools, to expand the frontiers of research, explore innovative ideas for mental health care and prevention with a community of global professionals and stakeholders in the field of psychiatry and mental health care.

EBC took part in the congress again in 2022, first with a presentation of its project, the <u>European Brain Research Area (EBRA) at the 8th EPA Forum</u> and with a symposium on the <u>Value of Treatment (VOT) in Mental Health</u> as well as the <u>Autism Care Pathway in Europe</u>. EBC also presented its projects through a virtual exhibition stand.



SCIENTIFIC CONGRESSES

8TH CONGRESS OF THE EUROPEAN ACADEMY OF NEUROLOGY

EBC was pleased to be part of this year's <u>Congress of the European Academy of Neurology</u>, which took place in person on 25-28 June 2022 in Vienna, Austria. The overarching theme of the 2022 EAN congress was "Getting Evidence Into Practice".

Alongside an Exhibition Stand in the EAN Neurohood, EBC had a Special Session take place on 28 June at 13:00-14:30 (Room Berlin), celebrating 20 Years of Advocacy for the Brain. Additionally, EBC projects such as the European Brain Research Area (EBRA) and the Value of Treatment were showcased at the congress in the Scientific Theatre and through ePosters.







FENS FORUM 2022

EBC was pleased to be back to another in-person FENS Forum on 9-13 July in Paris, France with a <u>series of events</u> throughout the five days, including a permanent stand in the Exhibition Hall, which brought a lot of interest and saw many EBC materials and giveaways distributed to the 8000+ congress attendees, with plenty of interest shown towards the European Brain Research Area (EBRA) project and the Brain Innovation Days.

EBC held a few Special Interest **Events** during the Forum, including a joint hands-on advocacy training workshop with organisers Fed-<u>eration of European Neuroscience</u> Societies (FENS) focused at the national level for FENS national societies and National Brain Councils. a session on The European Brain Research area: Building a Brain **Health Partnership** with the four EBRA partners and a session on Building youth brain capital for a better European future, which featured representatives from the WHO, OECD and work presented from the Value of Treatment project.





SCIENTIFIC CONGRESSES

35TH EUROPEAN COLLEGE OF NEUROPSYCHOPHARMACOLOGY CONGRESS

The annual European College of Neuropsychopharmacology (ECNP) Congress is Europe's premier scientific meeting for disease-oriented brain research, annually attracting more than 5,000 psychiatrists, neuroscientists, neurologists and psychologists from around the world.



EBC was pleased to take part in the ECNP Congress which took place on 15-18 October 2022 in Vienna, Austria and virtually. Alongside an Exhibition Stand in the exhibition area, EBC had a campfire session "The value of early intervention and continuity of care for mental disorders" take place on 17 October.

Additionally, the EBC project, the European Brain Research Area (EBRA) was showcased at the congress through a poster.



EUROPEAN CONGRESS OF NEUROSURGERY 2022

The <u>European Congress of Neurosurgery 2022</u> took place on 16-20 October in Belgrade, Serbia. The European Association of Neurosurgical Societies (EANS) is both an independent federation of European national neurosurgical societies and a fast-developing association of individual neurosurgeons from around the world.

The Congress theme – Trends, Insights, Innovations: Neurosurgery beyond Technology – addressed the complex relation between technological advances and human ingenuity in the field of neurosurgery. The age of rapid technological progress, artificial intelligence, machine learning and virtual reality in the 21st century has brought many benefits to neurosurgery, but also many challenges.

EBC President, Prof. Wolfgang Oertel, was pleased to take part in the congress and present "EBC and the Brain Policies in Europe" during a plenary "Brain & Spine, The Official Journal of EANS & EUROSPINE" on 19 October 2022.



SCIENTIFIC CONGRESSES

13TH INTERNATIONAL AUTISM-EUROPE CONGRESS

The <u>13th International Autism-Europe Congress</u> was a hybrid congress held on 7-9 October 2022 both online and in Krakow, Poland. The Congress brings expertise from around the world to promote a positive vision for autistic people and their families.

"Happy Journey through Life" was the theme of the 2022 Congress – to highlight the importance of taking a lifespan perspective on autism research and practice, with the promotion of wellbeing for all being the focal point. EBC was happy to take part in the congress to present outcomes from the Value of Treatment project, including an oral session on the Autism Care Pathway in Europe and a poster presentation on Autism with associated epilepsy care pathway in Europe.



SCIENTIFIC CONGRESSES

NEURO, DIGITAL & A.I. INNOVATION SUMMIT

EBC Executive Director, Frédéric Destrebecq, was invited to speak at the Neuro, Digital & A.I. Innovation Summit on 4-5 October 2022, to present our work, including major projects such as the Brain Innovation Days, the Rethinking series and how we are working to further brain research to improve the lives of those living with brain conditions through awareness raising, advocacy and policy work.

The in-person Summit took place at the Champalimaud Foundation in Lisbon, Portugal and brought together neuroscience, psychiatry and digital health innovation-leaders, decision-makers & KOLs, from all stakeholder groups in an open format, high-engagement, interactive, cross industry, multi-disciplinary summit of roundtable discussions on meeting both the challenges and the opportunities in brain health innovation. The summit is organised by Broadreach Global and EBC was happy to be a partner for this year's event.



OTHER COLLABORATIONS

PSYCHEDELIC ACCESS AND RESEARCH EUROPEAN ALLIANCE (PAREA)

The <u>Psychedelic Access and Research European Alliance – PAREA</u> is a non-profit, multistakeholder and multidisciplinary partnership bringing together 15 members spanning patient organizations, professional associations, umbrella organizations, psychedelic foundations, and for-profit sector. The organisation aims to change perceptions about psychedelic-assisted therapies, raise awareness of the scientific advances, scale-up and accelerate action and, ultimately, bring better health to European citizens.

PAREA was officially launched in June 2022 in <u>a virtual event</u>, featuring high-level speakers from the European Parliament, European Commission, European Medicines Agency, patients/patient organisations as well as PAREA members. A Keynote Address was delivered by Dr Thomas Insel, former Director of the US National Institute of Mental Health (2002 – 2015). The launch event brought together multiple stakeholders to discuss the scientific advances in the area of psychedelic medicines, bridging the gap between patients and innovation and improving the regulatory context for studies on psychedelic-assisted treatments. A <u>Call to Action</u> to European decision-makers was launched.

EBC was pleased to welcome Prof David Nutt, EBC Past President and current Chair of PAREA, at the 2022 Brain Innovation Days, where he gave an inspiring Brain Talk on how psychedelics will revolutionise the treatment of some brain disorders.

Furthermore, in December 2022, PAREA held its first policy meeting in the European Parliament, looking at the basic ingredients of psychedelic novel treatments captured in the event's title: "Psychedelic-assisted therapies in the treatment of brain disorders". Over 400 people registered for online and in-person attendance, including many EU and government officials – a clear sign that Europeans start looking for evidence-based education on psychedelic medicines. An appeal to the European Union institutions and Member States was launched on the day.





EBC is a founding partner of PAREA, with its Executive Director – Frédéric Destrebecq – sitting in the organisation as Vice-Chair.

OTHER COLLABORATIONS

ONE NEUROLOGY

The <u>OneNeurology Initiative</u> – in which EBC is a partner – 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.

In 2022, members of the OneNeurology partnership celebrated a major milestone for all those affected by neurological disorders, with the <u>adoption of the Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders</u>, announced at the 75th World Health Assembly in May. The group fully endorsed the aims of the Action Plan, will support its implementation, and celebrated the positive impact it should have for those living with neurological disorders, their carers, the medical professionals who support them, and those researching scientific breakthroughs in prevention, diagnosis and treatment.

The Global Action Plan will address the worldwide challenges and gaps in providing care and services for people with epilepsy and other neurological disorders and ensure a comprehensive, coordinated response.

Additional episodes were also added to the <u>One Voice for Neurology podcast</u>, a series of podcasts exploring why it's time to make neurology a global priority, how that can be achieved and what that could mean for those living with a neurological disorder.

OTHER COLLABORATIONS

EUROPEAN STAKEHOLDER GROUP STATEMENT ON MAINTAINING THE EXCHANGE OF CRITICAL HEALTH DATA

EBC was happy to support a statement released by the Standing Committee of European Doctors (CPME), on behalf of the European Health Stakeholder Group, to call for a formal association of the UK to the Horizon Europe research programme. The European Health Stakeholder Group aims to raise awareness of the implications that Brexit could have for patients and the public at large and make sure that patients' interests are put first. Read the full statement online.

OTHER COLLABORATIONS

CARE4AUTISM ERASMUS+ PROJECT

EBC was invited to speak at the <u>Care4Autism</u> Kick-off Meeting as an Associate Partner of the Belgian Brain Council-coordinated Erasmus+ project, which aims to reduce stigma and discrimination of people with autism through awareness, highlight effective practices in digital health care services and provide support for carers. EBC Executive Director, Frédéric Destrebecq, introduced the work EBC does at the EU policy level, particularly in awareness raising and advocacy.

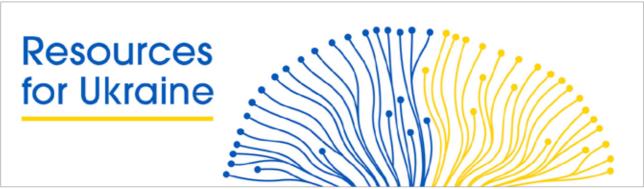




OTHER COLLABORATIONS

SHARING RESOURCES FOR ACTION IN UKRAINE

Since the war in Ukraine began, the European Brain Council followed the situation closely to identify ways it could provide support. The situation on the ground has had- and will continue to have – tremendous impact on the mental wellbeing of people, as well as immense disruption on regular, life-saving care needs for people living with chronic conditions. Our members have mobilised multiple response efforts, which EBC wanted (and wants) to amplify. A <u>dedicated page</u> was set up on the website in order to spotlight all ongoing initiatives for Ukraine – and remains active.



OTHER COLLABORATIONS

PATIENT INVOLVEMENT IN BRAIN HEALTH: SAFEGUAR-DING THE FUTURE OF BRAIN HEALTH FOR PATIENTS

EBC took part in a meeting on "Patient involvement in Brain Health: Safeguarding the future of Brain Health for patients", organised by three leading European patient organizations in the field, Alzheimer Europe, the European Federation of Neurological Associations (EFNA) and GAMIAN-Europe, to underline to the brain health community why engaging patients in the discussion on brain health is crucial.

The meeting presented a call for action in anticipation of a possible brain health summit and – later – a brain health partnership and emphasised the importance of engaging the patient community in the discussions on brain health, with the overall goal of bringing people from the entire community together, outlining what our organisations hope to achieve, and most of all raising awareness of this important matter.





Media report



OPEN ACCESS GOVERNMENT

EBC invited to prepare a few editorial pieces in 2022, all centred around its core advocacy work around brain research in Europe. Below an overview of the various publications:

2022 began with a piece on prioritising brain research in Europe in the January edition of Open Access Government by EBC Executive Director, Frédéric Destrebecq, who outlined the core evidence behind the need for increased investment in brain research, a vital call for innovation in the space and an overview of the challenges currently faced.



https://www.openaccessgovernment.org/brain-research-in-europe/124261/

OPEN ACCESS GOVERNMENT

Following on the Open Access Government article calling for the prioritisation of brain research in Europe, an article by European Brain Research Area (EBRA) Coordinator and EBC Past President, Prof. Monica Di Luca, was published in April 2022 examining the current state of brain research in Europe and analysing the past and looking towards the future. The publication expanded on the outcomes of the EBRA European Research Analysis and Mapping Report, which provided a concrete examination and data of all brain-related research funded by the European Union over the last decade. Using this analysis of the past and present, the article was able to provide recommendations and calls to action for the current and future state of brain research in Europe.



https://edition.pagesuite-professional.co.uk/html5/reader/production/default.aspx?pubname=&edid=f2355726-b86d-4a5b-879e-c528c1881551&pnum=126

FORTUNE ITALIA

In May 2022, EBC Executive Director, Frédéric Destrebecq, was interviewed for an article in Fortune Italia - Health, highlighting the advocacy work that EBC does for the brain space at the European level since its establishment 20 years ago. (published in Italian)

FORTUNE HEALTH



HEALTH, RICERCA

Ricerca e neuroscienze: è il momento di politiche europee

By **Eduardo Pisani** Maggio 16, 2022



https://www.fortuneita.com/2022/05/16/ ricerca-e-neuroscienze-e-il-momento-dipolitiche-europee/

OPEN ACCESS GOVERNMENT

EBC and the European Brain Research Area project were again featured in Open Access Government in their July 2022 edition, focused on improving the lives of people with brain disorders and exploring the future of excellence in European brain research, translating research into reality, tackling the burden and quest to understand the brain through collaboration in the field and continuing and strengthening the efforts to have the brain recognised as a priority at the European level.



https://edition.pagesuite-professional.co.uk/html5/reader/production/default.aspx?pubname=&edid=85f0d134-d2ec-4b73-b1ac-c5001c395a2a&pnum=110

ECONOMIST IMPACT

In October 2022, EBC was part of the a publication in Economist Impact focused on **The value of action: mitigating the global impact of neurological disorders**, which examined the global burden of neurological conditions and called for the need for urgent action to drive prevention, improve care effectiveness and leverage policymaking and funding to reach achievable advances in outcomes. The paper covered the need for economic prioritisation (looking also at the difference between impact in low- and middle-income countries as well as wealthier regions) and targeted policies. The paper built a detailed economic picture spanning ten disorders, finding that 50% the total cost of neurological disorders is due to these indirect costs.



https://impact.economist.com/perspectives/perspectives/health/mitigating-global-impact-neurological-disorders



EBC Members & Partners



Full Members



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

www.efna.net @EUneurology



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

o www.gamian.eu 9 @GamianE



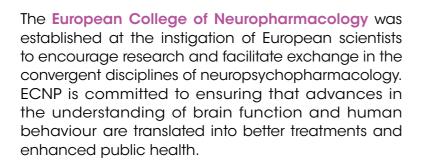
The European Academy of Neurology (EAN) is a nonprofit organisation that unites and supports neurologists across the whole of Europe. EAN is a society of national neurological societies and at the same time a society of individual members. The purpose of EAN is to promote "Excellence in Neurology in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

www.ean.org @EANeurology

Full Members



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



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 @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.

Full Members



INTERNATIONAL BRAIN

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

www.fens.org
@FENSorg

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
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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.



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.



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.



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.

National Brain Councils









Belgium

Bulgaria

Croatia

Czech Republic









The Netherlands

Finland

France

Germany









Hungary

Ireland

Luxembourg

Norway









Poland

Portugal

Serbia

Slovenia





Spain

Sweden

National Brain Councils

8th Academy of National Brain Councils

The 8th Academy of National Brain Councils was held on 10th May 2022 in Brussels, Belgium, hosted at the Representation of the Free State of Bavaria to the European Union.

This year's Academy hosted the launch of the German Brain Plan, led by the German Brain Council, including a presentation on how the plan was formed and plans for its implementation. Furthermore, updates and sharing of good practices in developing National Brain Plans were presented by the Norwegian, German, Belgian, Dutch and Polish Brain Councils.

The meeting took place from 10:00-16:00, including both closed and public programmes, also including presentations on the future plans of the European Commission for brain disorders: the EU "HealthierTogether" Initiative and the presentation of EBC's Strategy and National Brain Plans to decision-makers.





Industry Partners





















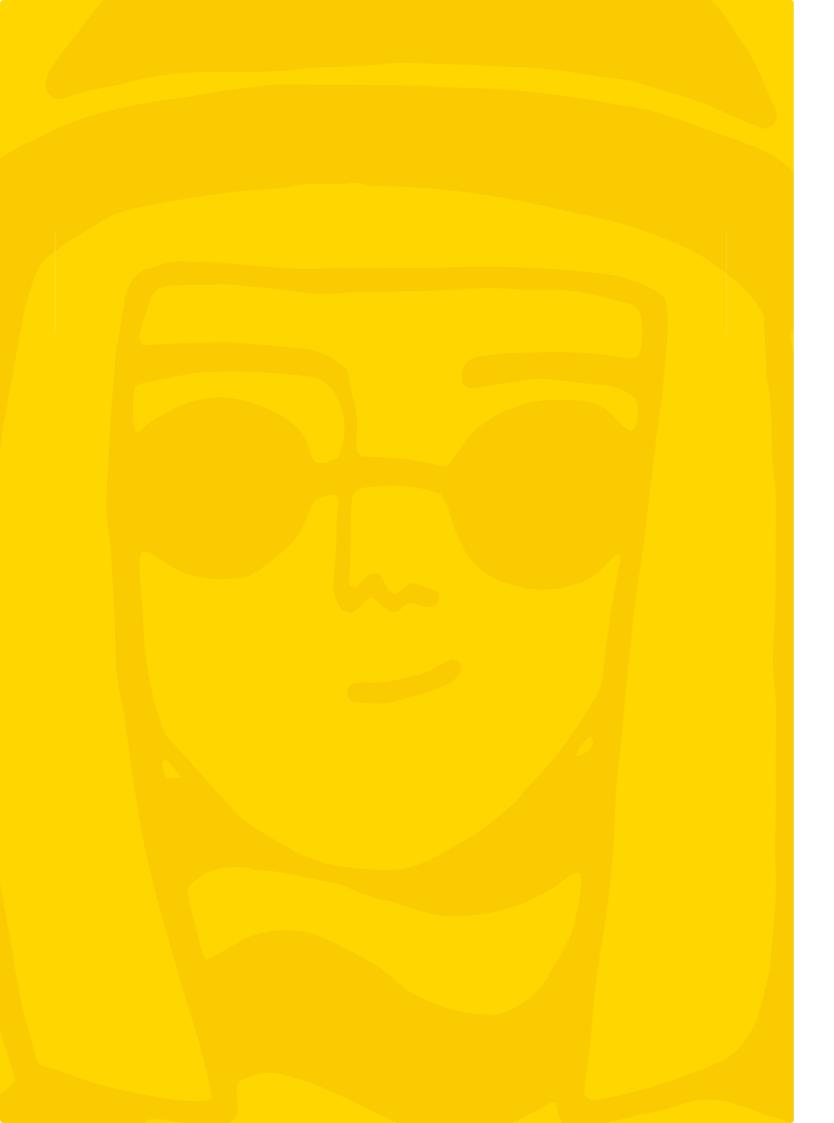




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Members Highlights



European Federation of Neurological Associations (EFNA)



The European Federation of Neurological Associations (EFNA) is an umbrella group representing 20 pan-European neurology patient groups. In 2022 we celebrated 21 years of empowering and integrating the neurology patient voice in Europe.

EFNA embraces the concept of Partnership for Progress – working at a high level with relevant stakeholders across policy, medicine, science/research, industry, patient partners and other key opinion leaders.

The brain health momentum across Europe and indeed the globe provides an opportunity to address many public health issues and to encourage research for both neurology and mental health. For this reason, EFNA organised two events on the topic.

On May 12th, a webinar on 'Patient involvement in Brain Health: Safeguarding the future of Brain Health for patients' was held, jointly organised with Alzheimer Europe and the Global Alliance of Mental Illness Advocacy Networks(GAMIAN)-Europe. The meeting portrayed to all brain health stakeholders why engaging patients in the discussion on brain health is crucial.

In December, EFNA brought together members, partners and other key stakeholders for a roundtable discussion on 'Brain Health for Neurology: Opportunities and Risks'. The event featured presentations from the European Academy of Neurology (EAN), Prof. Mayowa Owolabi (OneNeurology), Tadeusz Hawrot (EFNA) and a statement from MEP Katerina Konecná, followed by open discussion.

EFNA conducted a survey on 'Assessing diagnosis and care pathways of people living with neurological disorders in Europe' to identify, report and begin to address the varied challenges facing all affected by neurological conditions, either as patients or caregivers, from diagnosis to care pathway.

The key finding of the survey was that only 1 in 5 living with a neurological condition have access to affordable therapeutic interventions that satisfactorily manage their condition.

Results also suggest nuances to gender equity in neurology, most notably that females are less encouraged to visit a doctor, while being more aware of their symptoms and more engaged in research. EFNA looked more deeply into these gender differences during a webinar in early October, 'Addressing Gender Equity in Neurological Care'.

The topic was also addressed during November's meeting of the MEP Interest Group on Brain Mind and Pain, held under the patronage of the Czech Presidency of the Council of the EU, entitled 'Addressing Gender related issues and bias in the Prevention and Treatment of Neurological Conditions'. The event's main objective was to discuss how the Interest Group can advance meaningful policies and interventions to address the drivers of gender health inequity.

In 2022, EFNA continued in its role as secretariat of the OneNeurology partnership, of which it is a co-founder.

In May, the partnership celebrated a major milestone for all those affected by neurological disorders, with the adoption of the Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders at the 75th World Health Assembly. EFNA fully endorses its aims, supports its implementation in Europe, and celebrates the positive impact it should have for those living with neurological disorders, their carers, the medical professionals who support them, and those researching scientific breakthroughs in prevention, diagnosis and treatment.



EFNA President Joke Jaarsma with MEP Sirpa Pietikäinen at the MEP Interest Group on Brain, Mind and Pain meeting, November 2022.



The EFNA team meets with the WHO Brain Health Unit, May 2022

- efna.net
- facebook.com/European-Federation-of-Neurological-Associtions-173781099807815/
- instagram.com/euneurology/
- in <u>linkedin.com/company/11281270/</u>
- youtube.com/channel/UCY3r6AoeWnCUZNOmWIFgwGg

GAMIAN-Europe



GAMIAN-Europe has been involved in many different projects and activities throughout 2022. As well as our own projects we have also been involved in several EU projects as well as being asked to attend different events related to mental health throughout the year. We are developing a **peer support network website** to bring together all the different ways of setting up, running and managing peer support groups. **#Breaking-SuicideStigma** was a successful awareness campaign focused

on suicide prevention in young men. It involved workshops carried out with young men and culminated in the creation of a suicide prevention toolkit for young men and a testimony video. We held our inaugural mental health art contest called My HeArt: Exploring Mental Health through Visual Art in which more than 50 people living with different mental health conditions submitted their artworks with their explanations of what it meant to them and how art affects their lives. The competition was capped off by a webinar where a panel discussion around mental health and art was undertaken. In May we released a COVID-19 Survey Report that was a survey aimed at assessing whether mental health needs were being met by services. On the topic of comorbidities, we created two ongoing projects looking at the comorbidities of cancer and depression and migraine and mental health in women. Different surveys and workshops were run for both with reports due in early 2023.

Concerning Horizon 2020 EU Research Projects, GAMIAN-Europe was involved in 5 different projects that took place or continued in 2022. IT4Anxiety is a project based on supporting innovative strategies and solutions through start-ups that reduce patients' anxiety. EBRA is a project that looks to reduce the fragmentation and duplication of research efforts via enhanced coordination. PSY-PGX is the first initiative that involves a non-industry-sponsored clinical trial around the benefits of pharmacogenetics for psychiatric patients. Psych-strata aims to combine data collection through different sources and through an evidence-based approach to identify patients at risk of treatment resistance. REALMENT looks to optimise the treatment of mental health conditions through precision medicine involving AI and machine learning to develop prediction and stratification tools.

Finally, GAMIAN-Europe was involved in different advocacy work throughout 2022. We attended various EU-level meetings related to mental health such as the **Resilient Mental Health** event organised by the Czech Presidency where our President Péter Keri was invited to speak in the panel discussion along with other speakers. We also organised a hybrid **MEP Alliance for Mental Health** (for which GAMIAN-Europe runs the secretariat) meeting in the European Parliament with several MEPs from the alliance as well as other speakers from the Commission and other relevant NGOs. The meeting was used as an opportunity to discuss the upcoming EU initiative for mental health and how patients must be at the heart of this.

- gamian.eu
- witter.com/GAMIAN Europe
- facebook.com/GAMIANadvocacyNetworksEurope
- instagram.com/gamian europe/

European Academy of Neurology (EAN)

As always, the centrepiece of the year for the European Academy of Neurology (EAN) was the annual congress, this time held as a hybrid event on June 25-28 in Vienna, Austria and online. The overarching theme for the 8th Congress of the European Academy of Neurology was 'Getting evidence into practice' which was built into numerous sessions throughout the programme. Key questions surrounding issues of transferring clinical evidence into practical settings, covering topics such as clinical trial design, diagnostic testing, and guideline implementation, were addressed by leading specialists in numerous workshops and symposia. More than 8,000 people from around the world took part in the congress, 5,300 of whom were onsite in Vienna. In the second half of 2022, focus switched to preparations for EAN 2023, which will be held in Budapest, Hungary, on July 1-4.

In terms of scientific activity, the EAN made some significant strides in 2022. The largest scientific project was development of the <u>EAN Strategic Research Agenda</u>. Following a survey of EAN Scientific Panel members and a scientific study of the responses, preliminary results were presented at the EBRA Final Conference in October. This project will be one of the EAN's major focuses during 2023. Guidelines were also a key area of progress, including the launch of both a <u>new guideline protocol template</u> and a <u>new guideline prioritisation procedure</u>. In addition, the first <u>EAN Science School</u> was held in April and two new Coordinating Panels (<u>Diversity, Equity and Inclusion in Neurology</u> and <u>Neuroscience/Translational Neurology</u>) were established.

The EAN increased its strong commitment to supporting the neurology community through education in 2022, launching the new EAN eLearning platform <u>eanCampus</u>, and the podcast <u>eanCast: Weekly Neurology</u>. With eanCampus offering learning opportunities for all levels of expertise and eanCast providing a regular forum for review, discussion, and debate via a totally new medium for the EAN, the spectrum of resources offered by the academy has undergone a great expansion. In addition, the first mentors and mentees matched by the <u>EAN Mentorship Programme</u> began journeys together; the first <u>EAN Student Teaser Fellowships</u> took place; and there was a welcome return to in-person events throughout the range of EAN educational events.

Advocacy activity increased in 2022, with EAN putting on two key events. First was the European Brain Health Summit, held on 31 May, in connection with the launch of the new EAN Brain Health Strategy. The summit featured a full-day programme of talks and discussions from leading experts on brain health and its status and future in Europe, watched by 3,000 participants via livestream. Second was an event on the Future of Brain Health at the European Parliament, on clinically informed and patient-centred brain research, which aimed to outline the main priorities and gaps within neurology in the EU and highlight the importance and need for research. Both events were extremely productive and well received, and the EAN Board is eager to continue working with all partners to bring brain health to the forefront of policy decisions.





- ean.org
- facebook.com/eaneurology/
- instagram.com/eaneurology/
- <u>twitter.com/eaneurology</u>
- in linkedin.com/company/european-academy-of-neurology/

The European Association of Neurosurgical Societies (EANS)

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 2500 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.

Following two pandemic years, 2022 signaled the return to normality. In 2022 the EANS educational portfolio grew larger and more diverse, as more educational events were organised than ever, while touching a range of new topics that were taught by elite scientists of European Neurosurgery. The EANS Training Courses & Exams, the Hands-on Courses, the Accredited Events, and the Webinars consist the backbone of the Society's educational portfolio, while the annual EANS Congress remains the highlight of the EANS activities.

The EANS 2022 Belgrade Congress will remain in the EANS history as a legacy event. The programme included 11 plenary and 13 parallel sessions, 20 masterclasses, and 10 pre-congress symposia. The EANS family welcomed 1400 delegates from 83 countries, 42 exhibitors, 423 faculty speakers and oral abstract presenters and 658 e-Poster presenters who delivered lectures of outstanding quality and interest. Having set extremely high standards after a spectacular Congress in Belgrade, the EANS2023 Congress will take place from 24 to 28 September in Barcelona.



A few months ago, Brain & Spine, the official journal of EANS and EUROSPINE celebrated its one-year birthday. What began as an exciting project has evolved into a truly revolutionary endeavor, aiming to make a huge impact in the neurosurgical and spine community. The Journal was recently indexed in PubMed, and therefore all articles published in Brain and Spine are now automatically uploaded to the journal's website and to the PMC database.

This year at the EANS 2022 Congress in Belgrade, the EANS Foundation for Research in Neurological Surgery was officially introduced to the global neurosurgical community. This new foundation has the strict goal to provide a legally viable and transparent way for potential donators to support research activities in any



neurosurgical domain, to support specific educational activities, and to fund initiatives for the improvement of care in a pre-defined context.

At the Congress, the Young Neurosurgeons Network was also launched. A community where people from all levels of training, ranging from medical students and up to board-certified neurosurgeons, can have their base for sharing ideas, questions, experiences, and ultimately - their common passion for Neurosurgery.

All projects that lie under the EANS umbrella are worked with a common goal – Better Education, better Training, better European Neurosurgery.

The European Association of Neurosurgical Societies is excited about what is next and invites those interested to become part of the EANS family.

- eans.org
- facebook.com/EANSonline
- instagram.com/eansonline
- witter.com/eansonline50
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- youtube.com/user/EANSonline
- flickr.com/photos/136732519@N06/albums

European College of Neuropsychopharmacology (ECNP)

To execute its mission to support European applied and translational neuroscience, the European College of Neuropsychopharmacology (ECNP) performs a number of activities annually, focusing especially on stimulating research, sponsoring education and raising awareness. The College's more than 50 meetings every year – across all aspects of scientific exchange, education, and regulatory dialogue – bring together some 6,000 neuroscientists, psychiatrists, neurologists, psychologists and neurobiologists and train more than 400 early career scientists.

Education

In 2022, amongst the suite of educational meetings delivered, covering preclinical and translational education, methods training and clinical instruction, were the ECNP Seminar Virtual (12-13 May) for eastern European clinicians, the ECNP Workshop for early career translational neuroscientists (17-20 March), the ECNP School of Child and Adolescent Neuropsychopharmacology (27 March-1 April), and the ECNP Workshop on Clinical Research Methods (9-11 November).

Science

The **35th ECNP Congress** Hybrid was held in Vienna, Austria (15-18 October), attracting over 5,000 participants (in-person and online). The fourth iteration of the ECNP New Frontiers in Digital Health Meeting was held in Nice (20-21 March), to map out the research horizons and regulatory implications of this critical area. To complement the College's journal **European Neuropsychopharmacology** (IF 5.414), a new fully open access title, **Neuroscience Applied**, was launched, focusing especially on novel research that applies mechanism-based neuroscientific approaches to brain disorders. The ECNP Networks programme of multicentre European research clusters grew to 22 Networks, bringing together several hundred of Europe's leading researchers in applied and translational neuroscience. The ECNP Neuropsychopharmacology Award for research excellence was awarded to Marie Åsberg, Sweden, the ECNP Citation Prize for the most-cited research paper in European Neuropsychopharmacology to Martin Madsen et al., and the ECNP Rising Star Award for up-and-coming early career researchers to Liubov Kalinichenko, Germany, and Nils Opel, Germany. The Neuroscience-based Nomenclature project to develop a new nomenclature for psychotropic medications grounded in the latest advances in brain science passed 100,000 downloads of its landmark NbN app.



ECNP team at the 35th ECNP Congress 2022 in Vienna.

Outreach

The **ECNP Co-morbidity Study** to quantify the coincidence of disorders of the brain coincide with somatic illnesses was launched in collaboration with the London School of Economics (LSE) and Medical University of Vienna (MUV). ECNP also continued to provide communication, dissemination and outreach support for a range of major European Union scientific research projects, including PRISM 2, AIMS-2-TRIALS, conect4children, EBRA, SEROTONIN and BEYOND, REALMENT and PRIME.

- ecnp.eu
- facebook.com/myECNP
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- **y** <u>twitter.com/ECNPtweets</u>
- in linkedin.com/company/european-college-of-neuropsychopharmacology-ecnp-/

European Psychiatric Association (EPA)

With active individual members in as many as 88 countries and 44 National Psychiatric Association Members who represent more than 78,000 European psychiatrists, the European Psychiatric Association (EPA) is the main association representing psychiatry in Europe.

In 2022, the EPA made a concerted effort to support mental healthcare professionals and patients in Ukraine, who faced extreme conditions because of the War. As soon as the War started, the EPA issued statements to express its position and to outline the activities undertaken to support Ukraine. The EPA developed the "Trauma Resource Centre", a webpage containing relevant publications and initiatives on trauma and PTSD, and it organised three "Help for Helpers" Webinars addressed to first-line helpers. The EPA also established a "Fund for Ukraine" and, thanks to the support of its members and the Bavarian Parliament, it was able to purchase and deliver needed medications and equipment to hospitals in Ukraine.

As part of its Advocacy activities, the EPA joined the European Medicines Agency (EMA) Healthcare Professionals' Working Party (HCPWP) in May 2022, and also contributed to the discussions led by the World Health Organisation (WHO) in the frame of the Pan-European Mental Health Coalition. Within its Ambassadors Programme, the EPA launched the third Ambassadors Survey (following the surveys launched in 2020 and 2021), to gather the experience and viewpoint of mental healthcare professionals on trauma-related treatment and diagnosis.

For its return to Strasbourg, the EPA Summer School focused on the brand-new topic "Focus on Suicidal Behaviours – One Step Beyond". From 29 September to 2 October 2022, the EPA was pleased to welcome 21 brilliant young psychiatrists from across Europe for an immersive three-day training programme featuring the expertise of Prof. Emilie Olié, Prof. Jorge López-Castromán and Prof. Carla Gramaglia. Organised as a blended-learning event in combination with the EPA Online Course "Focus on Suicidal Behaviours", available on the EPA e-Learning platform, scholars were able to engage in discussions on a variety of topics, including the management of suicidal crises, therapeutic innovations, and prevention strategies.



The EPA organised the 30th European Congress of Psychiatry, which took place as a virtual meeting from 4 to 7 June 2022. Delegates were able to participate, learn and engage with experts and colleagues through a dedicated congress platform. Despite the unpredictable times, the EPA community came together to share good practices, as well as the latest developments in psychiatry. The event, guided by the motto "Linking Clinical Practice and Research for Better Mental Health Care in Europe", welcomed more than 2,800 participants from more than 90 different countries. The EPA Congress 2022 was preceded by the EPA Policy Forum on 4 June, which was focused on "Mental Health in Europe: Care, research and response in times of crisis".

For its 31st Congress, the EPA community will get together in Paris from 25 to 28 March. The Congress' opening will be preceded by the 9th EPA Forum on "Mental Health in the context of challenging ecosystems" on 25 March. More information can be found on the EPA and Congress websites.



EPA 2023 Congress

- europsy.net/
- epa-congress.org/
- twitter.com/euro psychiatry
- www.facebook.com/europsy/
- in fr.linkedin.com/company/european-psychiatric-association
- www.instagram.com/euro psychiatry/

European Paediatric Neurology Society (EPNS)

The European Paediatric Neurology Society (EPNS) is a society for physicians, health professionals, scientists and students with a research or clinical interest in Child Neurology. The core goal is to improve the lives of children and adolescents with neurological disorders.

First, the EPNS stands united in solidarity and expresses concern for the safety and support of the children, their families who care for them and colleagues in Ukraine.

2022 started with a newly elected EPNS Board for a four-year term and Professor Kevin Rostasy was appointed as the EPNS President.

With more than 600 new members joining, 2022 has been a busy time at the EPNS including the official Society journal, European Journal of Paediatric Neurology (EJPN), Impact Factor increasing to 3.692.

A new EPNS Advocacy and Collaboration committee formed in 2022 and is already making a positive difference, for example, by contributing to the Global Action Plan on Epilepsy & Neurological Disorders which was recently approved at the World Health Assembly. One focus of this committee is the European Brain Council (EBC) which gives the EPNS an opportunity to network with the key players in the 'brain field', collaborate in research and add



focus to childhood brain health. The EPNS congratulates Professor Sameer Zuberi who was elected as an EBC board member in 2022, giving the EPNS more opportunity to raise the voice of child neurology.

The EPNS Congress in Glasgow in April 2022 welcomed more than 1,000 in-person and approx. 600 via virtual participants. The event was successful both in terms of the exchange of clinical and scientific knowledge on the latest developments in paediatric neurology and in reuniting healthcare professionals from across the world. The next EPNS Congress will take place in Prague on 20-24 June 2023 with the



main theme "From genome and connectome to cure" and the EPNS looks forward to welcoming delegates to participate in this forum to develop new collaborations and exchange scientific ideas of the highest standard.

The EPNS has undertaken many educational and training activities in 2022, including the virtual events such as the webinars and the two March 2022 EPNS training courses on Acute Paediatric Neurological Diseases and Immune Mediated Diseases & Infections. As the Covid-19 pandemic evolved the EPNS was once again able to host in-person and hybrid educational events such as the special EPNS Masterclass and the hybrid Caucasus Teaching Course.

With pleasure the EPNS continues to award EPNS Fellowships and EPNS Visiting Teachers to selected EPNS members who benefit from these unique opportunities. In 2022 the EPNS was pleased to roll-out the EPNS Training Guide and, following this guide, in Prague in 2023 the first summative EPNS Exam will take place, which is a great achievement for the EPNS.

The Young EPNS (YEPNS) is a motivated group bringing together younger EPNS members to learn, collaborate and network who have made a significant contribution to EPNS activities, for example contributing to a project to develop a library of EPNS approved Guidelines in the field of Paediatric Neurology.



- www.epns.info/
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- young epns
- **f** YEPNS

Federation of European Neuroscience Societies (FENS)

The Federation of European Neuroscience Societies (FENS) carried out its mission this year in supporting the neuroscience community in several impactful ways. We organised the largest neuroscience meeting in Europe, the 13th FENS Forum 2022, in collaboration with the Société des Neurosciences, which took place in Paris, France on 9-13 July. The event welcomed 7,890 participants from 92 countries and hosted more than 400 speakers, 22 plenary and special lectures, 56 scientific symposia, 22 satellite and networking events and 19 special interest events covering all aspects in modern brain research. It also provided exclusive learning and networking opportunities, as researchers from all around the world were able to meet, share knowledge and celebrate excellence in neuroscience.





Addressing the importance of animal research

During Brain Awareness Week, the FENS Committee on Animals in Research (CARE) issued a 'Commentary on calls to phase out animal experiments' following the European Parliament's Motion for Resolution in 2021. It clarified the need for animal research and described how a ban would have a negative impact on progress in brain research and the development of better medical treatments, European Health innovations, the economy and even on animal welfare in global research.

Supporting early- and mid-career researchers

The FENS Committee for Higher Education and Training (CHET) organised a number of webinars to support the professional development of early career neuroscientists. It also supported the European Neuroscience Conference by Doctoral Students (ENCODS) in Paris, France, organised by and for PhD neuroscience students. The Network of European Neuroscience Schools (NENS) offered Exchange Grants to Master's and PhD students who were able to learn new techniques in labs outside of their home countries. FENS was also able to relaunch its Summer School in Bertinoro, Italy in May. It provided a broad perspective on 'Artificial and natural computations for sensory perception' through lectures given by 13 top scientists from around the world. The FENS-Kavli Network of Excellence (FKNE) supported scientific exchanges and a number of key discussions and editorials (in the official journal of FENS, the European Journal of Neuroscience) on diversity, mentorship, sustainability and the future of neuroscience.

Advancing advocacy and outreach

FENS took part in the European Brain Research Area (EBRA) Final Conference, which celebrated the end of the project, its partnerships and highlights during the Brain Innovation Days in Brussels, Belgium. The initiative managed to stimulate European brain research collaborations, proving that neuroscience can be better streamlined and coordinated while fostering global initiatives. FENS also supported the Dana Foundation in organising the annual Brain Awareness Week (BAW), the global campaign that aims to increase public awareness about the benefits and developments in brain research, and also the treatment and prevention of brain disorders. In 2022, 33 projects from 19 European countries received support grants.

- fens.org
- @FENSorg
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- fens_org

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, supported by the publication of its two journals, *Neuroscience* and *IBRO Neuroscience Reports*.

In 2022, IBRO has strengthened its commitment to providing equitable, diverse, and inclusive opportunities for the global neuroscience community, supporting 250 grantees and 30 schools, with over 700 participants, around the globe. IBRO's support has facilitated a broad spectrum of activities, ranging from collaborative research projects to conferences and meetings, including events dedicated to increasing diversity in neuroscience. Early-career scientists have also benefited from IBRO opportunities, including early career and rising star awards, that fund dedicated projects and the establishment of labs, as well as parenthood grants that assisted scientists approaching parental leave.

The IBRO Pan-Europe Regional Committee (PERC), through which IBRO is a member of EBC, funded two schools in 2022, in Romania and Northern Ireland. While the Romanian Summer School focused on modern optical and electrophysiological methods to investigate neuronal circuits, the Northern Irish School covered topics related to computational neuroscience, neurotechnology, and neuro-inspired artificial intelligence. Additionally, the committee awarded 60 grants, including grants to foster collaborative research and support projects and events promoting diversity in neuroscience, as well as awards and exchange fellowships focused on the career development of early career neuroscientists. In addition, IBRO supported 8 meetings and sponsored 5 conferences that happened in the Pan-European region. Finally for the first time, two parental leaves were awarded to male recipients, from a total of 5 awardees.

In 2023, IBRO-PERC will maintain its efforts to ensure the highest impact for its initiatives with the aim of elevating neuroscience research and education within the Pan-European region. The committee will fund schools in Romania and Portugal, and will support 9 scientific meetings, taking place in France, Portugal, Germany, Georgia, Slovenia, and Serbia. PERC will also offer support for soft skills training and collaborative research grants, as well as partnering with the Federation of European Neuroscience Societies (FENS) to support exchange programs within the region.

Finally, 2023 will be a particularly exciting year for PERC, with the IBRO World Congress, hosted by the Spanish Society for Neuroscience (SENC), taking place in Granada, Spain, from 9-13 September. With a very diverse scientific program, the congress will bring together neuroscientists from around the world, with many opportunities for support, such as travel grants, available for early career scientists. The Congress promises to be a stimulating opportunity to hear from leading international neuroscientists, discover the latest research from the global neuroscience community, and establish new scientific connections within the IBRO community.



- ibro.org
- @ibroSecretariat
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WHO'S WHO?

EBC Executive & Brussels Office



EBC EXECUTIVE

Professor Wolfgang Oertel
President



Professor Juan Lerma
Vice-President



Professor Wolfgang GaebelVice-President



Joke JaarsmaTreasurer



EBC INCOMING EXECUTIVE 2023

Professor Suzanne DicksonPresident



Professor Claudio Bassetti Vice-President



Professor Juan Lerma Vice-President





Dr. Orla GalvinTreasurer



EBC BRUSSELS OFFICE

Executive Director

Frédéric Destrebecq
Executive Director



Finance & Administration Team

Cécile Grebet

Head of Finance & Administration *Until June 2022



Latifah Irakiza

Office Manager



Anissa Bajja

Finance ¢ Administrative Manager



Monika Hoang

Assistant to the Director



EBC BRUSSELS OFFICE

Communications, Advocacy & Policy Team

Stephanie Kramer
Head of Communications,
Advocacy & Policy







Domenico lannone Communications & Advocacy Officer *Until August 2022



Annette DumasSenior Policy Advisor



Eleonora Varntoumian
Communications & Policy Officer
*Joined in March 2023



EBC BRUSSELS OFFICE

Projects Team

Elke De Witte

Head of Project Development



Kristien Aarts
Project Manager



Vinciane Quoidbach
Public Health & Policy,
Research Project Manager



Françoise van Hemelryck Senior Project Manager *Until February 2022



Carla Finocchiaro
Senior Project Manager



Cécile Grebet, Domenico Iannone and Françoise van Hemelryck moved on from EBC in 2022. We thank them all for their successful years and work within the team!

QΛ



Meetings attended



• 20 January 2022:

Social Media Trends 2022: Hot Takes

26 January 2022:

PRIME webinar by Prof. Monica Bullo: Obesity & Mental Health

• 27-28 January 2022:

BRAINTEASER Plenary Meeting

• 28 January 2022:

EBRA-PSMD Cluster: Ethics in Precision and Preventive Psychiatry Strategy Planning Meeting

• 3-4 February 2022:

PRIME 3rd General Assembly meeting

• 3 February 2022:

Stakeholder meeting: Healthier together - EU Non-Communicable Diseases Initiative

• 16 February 2022:

PRIME Webinar by Henrik Larson - TIMESPAN: Background, early achievements, and potential links to PRIME

• 3 March 2022:

BRAINTEASER Review Meeting

17 March 2022:

Stakeholder meeting: Healthier together - EU Non-Communicable Diseases Initiative

29 March 2022:

GoToWebinar - IMI impact on SMEs in health data management & health IT sectors

• 1 April 2022:

PREDICTIVE MODEL SYSTEMS (PREMOS) stakeholder meeting

• 1 April 2022:

13th ANNUAL LECTURE - Science Communication, Health Literacy and Public Confidence

7-8 April 2022:

EBRA-ECIB activity: Consensus meeting on sharing brain imaging data in online repositories

• 27 April 2022:

Webinar: Healthier Together - EU NCD Initiative

28 April 2022:

JPND/JPco-fuND/JPco-fuND2 Midterm symposium (Brussels, Belgium)

28 April 2022:

Exercice in Brain Health and Disease

• 10 May 2022:

8th Academy of National Brain Councils (Brussels, Belgium)

12 May 2022:

EBC: Patient engagement in brain health: Safeguarding the future of brain health for patients

19 May 2022:

GAMIAN/EUPHA: No health without mental health

31 May 2022:

European Academy of Neurology (EAN) European Brain Health Summit

3 June 2022:

Webinar: Healthier Together - EU NCD Initiative

14 June 2022:

Alzheimer Europe European Parliament Lunch Debate (Brussels, Belgium)

22 June 2022:

Webinar: Healthier Together - EU Non-communicable diseases initiative

25-28 June 2022:

8th European Academy of Neurology Congress (Vienna, Austria)

1 July 2022:

EBRA PREMOS Cluster Consensus Meeting: Improving the translational value of animal models

• 9-13 July 2022:

FENS Forum 2022 (Paris, France)

• 13-15 July 2022:

BRAINTEASER plenary meeting (Madrid, Spain)

27 July 2022:

Eurocare: Alcohol policy coordination platform meeting

24 August 2022:

Eurocare: Awareness Week on Alcohol Related Harm (AWARH) meeting

6-8 September 2022:

PRIME 4th GA - 6th extended Scientific Committee meeting

21 September 2022:

EBRA - Prevention of Severe Mental Disorders event: Implementing precision and preventive psychiatry in Europe (Brussels, Belgium)

26-27 September 2022:

Science Summit at the 77th United Nations General Assembly (New York, USA)

• 22 September 2022:

EBRA - BRAINFOOD event: "What actions improve nutrition for brain health for European citizens?"

• 29 September 2022:

EBRA - EPICLUSTER: Shaping the future of epilepsy research in Europe

4-5 October 2022:

Neuro, Digital & A.I. Innovation Summit (Lisbon, Portugal)

• 10 October 2022:

EBRA - TRISOMY21 meeting: Patient Involvement in European Down Syndrome research

11 October 2022:

TRISOMY21 meeting: Patient Involvement in European Down Syndrome research

• 11-12 October 2022:

Brain Innovation Days: Connecting Brains (Brussels, Belgium)

• 15-18 October 2022:

European College of Neuropsychopharmacology (ECNP) congress

• 17-19 October 2022:

Alzheimer Europe Conference (Bucharest, Romania)

• 25 October 2022:

EPC meeting - Health in all policies

• 7-8 November 2022:

University of Texas Systemwide Brain Research Summit (Austin, Texas)

• 8 November 2022:

Legacy of Conferences

9 November 2022:

Le sommeil, un pillier essentiel à la santé

14 November 2022:

Czech Presidency Event on Resilient Mental Health in the EU (Brussels, Belgium)

• 15 November 2022:

EU Health Summit (Brussels, Belgium)

17 November 2022:

European Patient Advocacy Summit 2022

• 22-23 November 2022:

Patient Engagement Open Forum 2022

25 November 2022:

Meeting with John Ryan, Acting Deputy Director General, DG SANTE (Health and Food safety), European Commission

28 November 2022:

Stakeholder meeting: Healthier together - EU Non-Communicable Diseases Initiative

• 28 November 2022:

Friends of Europe - pre Health Innovation Summit dinner

29 November 2022:

Friends of Europe - Health innovation summit - 'Reimagining health systems: green, agile, and citizen-centred'

• 1 December 2022:

EU Big Data Stakeholder Forum

• 5 December 2022:

Launch of Health at a Glance - Europe 2022

• 5 December 2022:

Brain Health for Neurology: Opportunities and Risks

• 6 December 2022:

Psychedelic-assisted therapies in the treatment of brain disorders

• 6 December 2022:

EPC - Task Force on the European Health Union

7 December 2022:

NMOSD/rare neurological disease roundtable event in European Parliament (Brussels, Belgium)

• 8 December 2022:

The Future of Brain Health: Clinically Informed & Patient-Centred Brain Research, European Parliament (Brussels, Belgium)

12 December 2022:

POLITICO - The incoming Swedish presidency of the Council of the EU

• 13 December 2022:

EARA General Assembly

13 December 2022:

EU-US Long COVID Conference

• 12-14 December 2022:

Innovative Health Initiative (IHI) Call Days

• 15 December 2022:

Health Council Briefing and EU Presidency priorities

Credits

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

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

Please email your comments to: info@braincouncil.eu



THE FUTURE BELONGS TO THOSE WHO GIVE THE NEXT GENERATION HOPE!



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