ANOTHER IMPORTANT YEAR FOR THE BRAIN COMMUNITY
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Dear Colleagues,

We are delighted to share with you the European Brain Council (EBC) Annual Report for 2023. It has been a monumental and jam-packed year for EBC. When reflecting on the highlights of the last 12 months, it was amazing to identify just how many there were.

As the main voice speaking on behalf of the brain community in Europe, representing scientists, clinicians, patients, industry — encompassing basic neuroscience, neurology, neurosurgery, and psychiatry — EBC certainly has a vast mandate. This wide breadth of focus areas was demonstrated in our variety of initiatives this year, from expanding global partnerships in brain research and building EBC’s international reach, taking a stand for animal research, raising the profile of brain health and the notions of brain capital and brain wealth, carrying out ongoing research and policy projects, all the way to ending the year as main partners within the Coordination and Support Action (CSA) BrainHealth, tasked by the European Commission to help pave the way towards a European Brain Health Partnership.

This year saw the successful continuation of key projects and flagship initiatives as well as the birth of new ones. 2023 immediately began with the launch of the Rethinking Alzheimer’s White Paper, followed soon after by EBC’s largest Brain Awareness Week event ever, focused on Global Partnerships in Brain Research. EBC kept a strong science advocacy profile this year, particularly linked to a recent European Citizens’ Initiative calling for the banning of all animal research in Europe, successfully organising meetings with scientists and 25 different Members of the European Parliament in one day. A “sold-out” event within the Science Summit at the 78th United Nations General Assembly, Fostering Global Partnerships in Brain Research in New York was followed by a bigger-than-ever third edition of the Brain Innovation Days, also featuring the launch of a fourth Rethinking project: Rethinking Schizophrenia. Our reach this year was immense: expanding from our European mandate to the global policy level as well as entering the national stage, with an event under the aegis of the Spanish Presidency of the Council of the European Union, “Our Brains, Our Future”, hosted in the Senate of Spain in Madrid.

It has truly been an outstanding year for EBC, and we certainly could not have done this without the continued support and collaboration of our Members and Partners, who not only fed directly into the content of all the initiatives of the year but also provided additional platforms, such as during their Annual Congresses, celebrations and events, as well as within internal meetings and networks. EBC continued strengthening its alignment and synergy with member societies and organisations, ensuring clear channels of communication and prioritising its role to represent the brain community in a coordinated and synergetic fashion. This brought the introduction of additional forms of communication on top of traditional newsletters, Brainy Insights and congress participation, namely with Secretariat Coordination Meetings and Letters from the President, meeting the needs of member organisations and key stakeholders to receive direct updates about EBC’s current priorities and the motives underpinning the vast array of activities we undertake.

We thank you all for your partnership and continued dedication to work, as a community, to gain recognition of the importance of brain health and that it continues to grow – for the sake of all Europeans – to be recognised as a priority at the political and societal level.

Kind regards,

Prof. Suzanne Dickson  
President

Frédéric Destrebecq  
Executive Director
ABOUT US
ABOUT US

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. A non-profit organisation based in Brussels, its main mission 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.

With the aim to speak with one voice, EBC stands as the platform to foster cooperation between its member organisations and other stakeholders, consistently promoting dialogue between scientists, industry and society. As showcased by its growing portfolio of projects, research and policy papers, as well as events, EBC emphasises the importance of continued interaction with the European Institutions to build strong European health policies, raising awareness and encouraging education on the brain and the repercussions of neurological and mental health conditions on society as a whole.

Our Vision

Our Mission
On 16 March 2023, EBC organised a full-day programme focused around Global Partnerships in Brain Research, showcasing ongoing work to enable dialogue and foster further collaboration within the community. The event was an opportunity for participants from across the global brain space to learn from their peers from all over the world through panel discussions, presentations and networking opportunities.

Organised by EBC in collaboration with FENS, IBRO and with support from Roche and Boehringer Ingelheim — the day brought together key stakeholders representing Europe, North and South America, Africa, Asia and Australia, to reflect on the global burden of brain disease, enhancing brain health and how to approach the challenges together through knowledge and data sharing, capacity building, funding and policy: key areas to forge a path towards stronger international research alliances and, perhaps, a grander, global approach to brain health and research.

Annually, EBC takes part in Brain Awareness Week with activities to promote and communicate around the subject of brain health and research, particularly with the aim to draw more attention towards the space not only from within the wider brain community but also from EU policymakers and the general public.

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Tasked with the forging of global partnerships in brain research during the now completed EBC-coordinated European Brain Research Area (EBRA) project and currently leading global outreach within the Coordination and Support Action (CSA) BrainHealth, EBC has served as a convener over the last years for experts in the brain community to share best practices, exchange ongoing work and align priorities to forge a joint path forward to understand and address the brain rather than in silos across continents.
In collaboration with supporting partners, EBC hosted a Brain Health & Research Day within the Science Summit at the 78th United Nations General Assembly on 18 September 2023 in New York City.

Event brought together over 150 key stakeholder organisations, all committed to the same goal: fostering and enhancing global collaboration in the brain area, with the ultimate goal of improving the lives of people living with brain conditions, neurological and mental alike.

In order to move past discussion and work towards explicit and tangible next steps in solidifying global efforts in brain research, the full day event covered a number of important areas for action and ended with the release of a Call to Action on brain health and the need for global research investment to help guide national, regional and global policymakers towards better addressing brain health in the future, particularly as they prepare for the post-Sustainable Development Goals era (during the Summit of the Future 2024 and the High Level Conference on the UN NCD Strategy 2025).

Tasked with the forging of global partnerships in brain research, EBC has served as a convener over the last years for experts in the brain community to share best practices, exchange ongoing work and align priorities to forge a joint path forward to understand and address the brain rather than in silos across continents.
The European Brain Research Area paved the way towards the EU-funded Coordination and Support Action (CSA) BrainHealth, which kicked off on 7 November 2023. This two year project will prepare for the future European Brain Health Partnership, with EBC leading Work Package (WP) 4 on Global Outreach and WP6 on Communication & Dissemination.

CSA BrainHealth addresses policy makers and funders from European Member States, Associated and Third Countries and other stakeholders, in close interaction with the research community.

The CSA BrainHealth is comprised of like-minded institutions willing to take on the preparation of a European Partnership. Among the tasks of the CSA are to develop a Strategic Research & Innovation Agenda and to gather an extensive circle of potential partners and stakeholders for the future partnership.

A wide ranging and diverse CSA BrainHealth ecosystem has been created including a Funders Forum, a Stakeholders Forum, and a Scientific Advisory Board to enable broad discussions in preparation of a future European partnership on Brain Health.
I. “AFTER EBRA”: PROMOTING THE SHARED EUROPEAN BRAIN RESEARCH AGENDA

Our Brains, Our Future - Spanish Presidency Event in the Senate of Spain

On 28 November 2023, the European Brain Council (EBC), in partnership with the Spanish National Research Council (CSIC) and the Spanish Brain Council, held the event “Our Brains, Our Future: The Value of Brain Research – from Basic to Clinical – to Improve Patient Outcomes in Europe” in the Senate of Spain, Madrid, under the auspices of the Spanish Presidency of the Council of the European Union.

The bilingual conference brought together leading scientists, patients, industry representatives and policymakers to speak with one voice in advocating for a brain healthy future for Europe and beyond.

Building on the strong emphasis placed by the Spanish Presidency on improving health outcomes across the EU, the programme shed light on the steadily growing burden of brain disorders, calling for the urgent prioritisation of brain research in Europe and increased efforts towards the translation of basic neuroscience into clinical practice for the benefit of patients.
II. ENSURING A SUPPORTIVE ENVIRONMENT FOR RESEARCH IN EUROPE

Pledge for Science

The European Brain Council, in collaboration with member and like-minded organisations, has launched a Pledge for Science: Brain Research and Innovation in the EU in response to policy developments, particularly those with possible implications for health and research – including a European Citizens’ Initiative on “Save Cruelty Free Cosmetics – Commit to a Europe Without Animal Testing”, which received over one million signatures, triggering a public hearing in the European Parliament (to take place on 25 May). Alongside a direct statement on this topic directly, EBC launched the Pledge for Science to raise awareness on the importance basic research plays in our lives and the role policy can play in directly impacting the work of scientists.

The pledge, which received over 3000 signatures, called for brain research and innovation to be recognised, more than ever, as a health and research priority in the EU. The scientific community called upon national, EU and international policymakers to support the development of a European Brain Research and Innovation Plan, combining research and public health initiatives to address brain function and disorders in a comprehensive, collaborative and innovative way.

On top of signature collection from like-minded institutions, the Pledge for Science campaign received wide support from Members of the European Parliament and key voices in the neuroscience community, including Nobel Prize winners.

In May 2023, the EBC Animal Research Task Force and additional scientists spent a day in the European Parliament speaking with their country’s MEPs to openly discuss how their research is undertaken, walk them through a day in their life in the lab and answer questions.

"Almost everything we know about mechanisms in the brain rests on research in laboratory animals. Animal research is indispensable if we are to cure and prevent the many devastating diseases that affect this organ."

Edvard Moser
2014 Nobel Prize in Medicine or Physiology

READ MORE
This event, and the community built around it, is the platform to boost interaction, facilitate knowledge exchange and business development, connect the dots with key people, potentiate investments, foster dialogue and showcase ongoing innovation and progress being made in the space, particularly in Europe.

The **3rd edition of the Brain Innovation Days** took place on 26-27 October 2023 at The EGG Brussels (Belgium) under the overarching theme **“The Brain in the 21st Century”**, with a focus on resilience, better brain health and adaptation to an evolving environment.

The event was opened by EBC officials and highlighted the importance of brain research and innovation. MEPs discussed ongoing EU health policy files, including mental health strategy and the European Health Data Space.

The event featured exhibitions, talks, and discussions on topics like gene therapies, dementia, and migraine in the workplace. It emphasized the need for continued investment in brain research and innovation to improve treatments and quality of life for those affected by brain conditions.
A YEAR FULL OF IMPORTANT EVENTS
EBC PROJECTS
I. VALUE OF TREATMENT

The Value of Treatment for Brain Disorders (VoT) is a health economics and outcomes research project coordinated by EBC. EBC conceptualised in 2015 the Value of Treatment research framework with a first VoT study to address current unmet needs in healthcare and the increasing all-age burden of brain disorders – both neurological and mental alike.

The Value of Education: Digital Care Pathways for Rare Brain Diseases: The Case of Phenylketonuria

The COVID-19 pandemic has highlighted the need for effective communication and continuity of care, especially for people with rare brain diseases (RBDs). There’s been a rapid shift to telemedicine services, with many healthcare procedures moving online to maintain care for non-COVID-19 patients. Initially adopted out of necessity, telemedicine could lead to a major shift in post-pandemic care paradigms if implemented correctly. Project kicked off in 2023 with the aim to understand the needs of high-risk populations, specifically patients with Phenylketonuria (PKU), and to identify the best communication channels for engaging with them.

Value of Treatment Chronic Pain

VoT Chronic Pain promotes the Interdisciplinary Multimodal Chronic Pain Management as best practice healthcare intervention for:

- ensuring shorter wait times, earlier diagnosis and guidelines implementation;
- increasing patients’ quality of life, response to treatment and physical function;
- reducing costs, lost of productivity, treatment failure and switching.

The research focused on adults of working age, a pilot country (Germany) and three pain indications (fibromyalgia syndrome, diabetic neuropathic pain and chronic primary low-back pain).

First results were presented at the 13th Congress of the European Pain Federation (EFIC 2023) and final results will be showcased at the 20th World Congress on Pain (IASP 2024) and in a publication.
II. RETHINKING THE MANAGEMENT OF BRAIN DISORDERS

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

Rethinking Alzheimer's Disease

Rethinking Alzheimer’s disease (AD) is a research-driven project offering policy recommendations to make tangible changes with the aim to improve the lives of people living with Alzheimer’s disease across Europe. This year was marked by the launch of the White Paper and two major online events which took place.

On 24 January 2023, EBC in collaboration with the European Federation of Pharmaceutical Industries and Associations (EFPIA), organised a digital event “Rethinking Alzheimer’s disease: Detection and diagnosis”, looking at the need to rethink the way we approach detection and diagnosis of Alzheimer’s disease.

More than 475 people from all over the world registered to attend the event, including many representatives from the NGO sector, government institutions and industry.

The outcomes of the discussions and the results of the pre-event survey conducted among the registrants will feed directly in the policy recommendations of the White Paper “Rethinking Alzheimer’s disease: Detection and diagnosis”, officially released following the event.

On 26 September 2023, EBC in collaboration with the European Federation of Pharmaceutical Industries and Associations (EFPIA), the Swedish Brain Foundation (SBF) and the Swedish Association of the Pharmaceutical Industry (LIF), organised a digital event “Rethinking Alzheimer’s disease: Moving towards a new Alzheimer’s disease detection and diagnosis pathway in Sweden”, exploring the ways we can rethink the Alzheimer’s care pathway, particularly in the Swedish healthcare context.
II. RETHINKING THE MANAGEMENT OF BRAIN DISORDERS

Rethinking Schizophrenia

The 1st phase of the project, “Rethinking Schizophrenia: Beyond the Voices”, aims to offer tangible policy changes to improve the lives of people living with schizophrenia across Europe. It challenges the status quo and refreshes the European policy debate on people living with schizophrenia, recognises the presence of cognitive and emotional aspects in the condition as well as the essential role of social support and encourages multi-stakeholder-driven policy.

The project kicked off at the Brain Innovation Days, organised by EBC, which took place on 26-27 October 2023 in Brussels.

During the third edition of the event, participants had the opportunity to explore the Rethinking Schizophrenia poster exhibition, featuring portraits and quotes of people living with schizophrenia, patient advocates and caregivers. The exhibition fell under the #BeyondTheVoices campaign highlighting the need to rethink the way we deal with schizophrenia.
EBC participation in EU-funded projects aims at optimising brain research and brain health policies and ensuring they are based on evidence, effective and efficient collaboration and cooperation among various scientific projects, the brain research and health community, and EU and national policymakers.

### BRAINTEASER

**Full project name:** “Bringing Artificial Intelligence home for a better care of amyotrophic lateral sclerosis and multiple sclerosis”

BRAINTEASER is a H2020-funded project seeking to exploit the value of big data (large clinical datasets, patient-generated and environmental data) to advance remote monitoring and clinical decision making in Multiple Sclerosis (MS) and Amyotrophic Lateral Sclerosis (ALS).

In 2023, EBC got in touch with 9 related projects and initiatives to present the BRAINTEASER project and identify common interests. BRAINTEASER was also introduced to representatives from Italian MS Society, European Charcot Foundation and Merch Healthcare.

### PRIME

**Full project name:** “Prevention and Remediation of Insulin Multi-morbidity in Europe”

PRIME is a H2020-funded project aiming to unravel the insulin-dependent mechanisms that underly both somatic conditions (i.e. type 2 diabetes, obesity, metabolic syndrome) and brain disorders (i.e. Alzheimer's disease, obsessive-compulsive disorder, autism spectrum disorders) to develop tools for improved diagnosis, clinical care and prevention of insulin-related lifespan multimorbidity. EBC currently supports dissemination activities to increase the project visibility. In 2023, EBC empowered the PRIME consortium with notions about EU policymaking.
THE LANCET NEUROLOGY

Sustainable development demands brain health

The 78th Session of the UN General Assembly (UNGA 78) was gathering in New York City as this issue of The Lancet Neurology was sent to press. The aim of UNGA 78 is to “rebuild trust and reignite global solidarity” by “accelerating action on the 2030 Agenda and its Sustainable Development Goals [SDGs]”. Midway between the introduction of the SDGs in 2015 and their completion in 2030, progress is off track and, for some SDGs, even backsliding. Hence, UN Secretary-General António Guterres’ has appealed for “a renewed impetus and accelerated actions”, which will be the focus of the 2023 SDG Summit that takes place alongside UNGA 78.

EUROPEAN JOURNAL OF NEUROLOGY

From fragmentation to collaboration in European brain research

The early history of the European Brain Council (EBC), an organisation that changed our perspective on advocacy

The European Academy of Neurology (EAN) is a member of the European Brain Council (EBC), a coalition of neurologists, psychiatrists, neurosurgeons, neuroscientists, patient organisations and industry with an interest in the brain and its diseases. It was founded by the present author. Here, its formation, early history and the results of its advocacy are described.
Progressive ataxias are rare and complex neurological disorders that represent a challenge for the clinicians to diagnose and manage them. This study explored the patient pathways of individuals attending specialist ataxia centres (SAC) compared with non-specialist settings. We investigated specifically how diagnosis was reached, the access to healthcare services, treatments, and care satisfaction. The focus of this study was on early intervention, coordination of treatment to understand the care provision in different countries.

Little is known about the costs of treating ataxia and whether treatment at a specialist ataxia centre affects the cost of care. The aim of this study was to investigate whether patients who attended specialist ataxia centres in three European countries reported differences in their health care use and costs compared with patients who did not attend a specialist ataxia centre. We compared mean resource use and health service costs per patient affected by ataxia in the United Kingdom, Italy and Germany over a 12-month period. Data were obtained from a survey distributed to people with ataxia in the three countries. We compared mean resource use for each contact type and costs, stratifying patients by whether they were currently attending a specialist ataxia centre or had never attended one.
**Autism with co-occurring epilepsy care pathway in Europe**

Autism and epilepsy often occur together. Epilepsy and other associated conditions have a substantial impact on the well-being of autistic people and their families, reduce quality of life, and increase premature mortality. Despite this, there is a lack of studies investigating the care pathway of autistic children with co-occurring epilepsy in Europe.

**Economic impact of reducing treatment gaps in depression**

Major depressive disorder (MDD) is highly prevalent across Europe. While evidence-based treatments exist, many people with MDD have their condition undetected and/or untreated. This study aimed to assess the cost-effectiveness of reducing treatment gaps using a modeling approach.

**Viewpoint: Assessing the value of mental health treatments in Europe**

One in eight individuals worldwide lives with a mental health disorder. For many European countries, the prevalence is even higher, with one in four people reporting mental health problems. Three-quarters of all mental health disorders develop before age 25, with many presenting initially in undiagnosed forms already in the mid-teens and eventually manifesting as severe disorders and lasting into old age.

**Autism care pathway in Europe**

Autism is a lifelong complex neurodevelopmental condition that affects brain development and behaviour with significant consequences for everyday life. Despite its personal, familial, and societal impact, Europe-wide harmonised guidelines are still lacking for early detection, diagnosis, and intervention, leading to an overall unsatisfactory autistic person and carer journey.
Care pathways for people with major depressive disorder: A European Brain Council Value of Treatment study

Despite well-established guidelines for managing major depressive disorder, its extensive disability burden persists. This Value of Treatment mission from the European Brain Council aimed to elucidate the nature and extent of “gaps” between best-practice and current-practice care.

The effects of COVID-19 on European healthcare provision for working-age adults with major depressive disorder

Major depressive disorder (MDD) is a leading cause of disability worldwide, and yet delivery of care for this illness is rife with gaps. The COVID-19 pandemic has had far reaching implications for every facet of healthcare, and MDD is no exception. This scoping review aimed to ascertain the impacts of COVID-19 on the delivery of MDD care in Europe, as well as to evaluate any novel MDD care strategies trialled in this period.

Economic analysis of early intervention for autistic children: findings from four case studies in England, Ireland, Italy, and Spain

Many autistic children experience difficulties in their communication and language skills development, with consequences for social development into adulthood, often resulting in challenges over the life-course and high economic impacts for individuals, families, and society. The Preschool Autism Communication Trial (PACT) intervention is effective in terms of improved social communication and some secondary outcomes. A previously published within-trial economic analysis found that results at 13 months did not support its cost-effectiveness. We modeled cost-effectiveness over 6 years and across four European countries.
Economic Evaluation of anti-epileptic Medicines for Autistic Children with Epilepsy

We examine the cost-effectiveness of treating epilepsy with anti-epileptic medicines in autistic children, looking at impacts on healthcare providers (in England, Ireland, Italy and Spain) and children’s families (in Ireland). We find carbamazepine to be the most cost-effective drug to try first in children with newly diagnosed focal seizures. For England and Spain, oxcarbazepine is the most cost-effective treatment when taken as additional treatment for those children whose response to monotherapy is suboptimal. In Ireland and Italy, gabapentin is the most cost-effective option.

Rethinking the detection and diagnosis of Alzheimer’s disease: Outcomes of a European Brain Council project

Alzheimer’s disease (AD), the most common form of dementia, is a progressive and debilitating neurodegenerative condition which robs people of their memory, their independence, their relationships and, ultimately, their lives. It affects close to 7 million people in the European Union (EU) alone.
Global synergistic actions to improve brain health for human development

The global burden of neurological disorders is substantial and increasing, especially in low-resource settings. The current increased global interest in brain health and its impact on population wellbeing and economic growth, highlighted in the World Health Organisation’s new Intersectoral Global Action Plan on Epilepsy and other Neurological Disorders 2022–2031, presents an opportunity to rethink the delivery of neurological services.

EPILEPSY RESEARCH

Shaping the future of European epilepsy research: Final meeting report from EPICLUSTER

Collaboration is essential to the conduct of basic, applied and clinical research and its translation into the technologies and treatments urgently needed to improve the lives of people living with brain diseases and the health professionals who care for them. EPICLUSTER was formed in 2019 by the European Brain Research Area (EBRA) to support the coordination of epilepsy research in Europe.
Beyond forgetfulness: Why we must act on Alzheimer’s disease now

Alzheimer’s disease is a ticking time bomb for individuals, families and health care systems, unless we invest in our future health today.

In the face of an increasingly aging population, today’s reality reveals a harsh truth: health systems in the EU and beyond are ill-equipped to provide a timely diagnosis of Alzheimer’s disease and embrace innovative treatments that could help to preserve memory and, with it, independence.

Global data is key to tackling the rise in brain health conditions

Global efforts to tackle the rise in brain conditions requires data to inform patients, researchers and the medical community and enable them to work together.

Brain health conditions have become a global health emergency. Incidences of Parkinson’s disease and dementia have more than doubled over the past 30 years. More than 15 percent of all health loss (for example through illness, disability or death) around the world is now associated with brain health conditions. In 2021, approximately 406 million disability-adjusted life years were caused by brain health conditions, which is higher than other widely acknowledged health threats such as cancer (260 million DALYs) or cardiovascular disease (402 million DALYs).
Fostering brain research and innovation in the EU

Now is the time for the EU to prioritise research and innovation into brain diseases

Fostering brain research and innovation must, more than ever, be a European priority. Earlier this year, the European Citizens’ Initiative ‘Save cruelty free cosmetics – Commit to a Europe without animal testing’ called for a legislative roadmap to phase-out all animal testing in the EU before the end of the current legislative term. In case this request was accepted, the consequences would be major. Putting a definite stop on animal research within Europe would lead to an exodus of research to regions of the world where animal welfare is less regulated, and of researchers, academics and industry who would move outside of the EU.

No health without brain health

Whilst an estimated 179 million Europeans live with brain conditions, brain disorders still lack the awareness and recognition in the EU

The human brain is an incredibly complex organ, acting as the control centre of our body, in charge of even the smallest function within our bodies.

Brain conditions, neurological and mental alike, are non-communicable diseases that emerge throughout the life course and affect all individuals. These conditions impose a high burden on all affected and represent a major medical, technological and societal challenge.
Stop the epidemic of brain diseases and go for a healthier brain!

More than 50% of the European population suffers from a brain disease today. "A number that will only continue to rise in the coming years and decades," says Frédéric Destrebecq, executive director of the European Brain Council. The prevalence of Parkinson’s disease and dementia has already more than doubled in the past three decades, and the consequences are huge for the patient and those around them. A person with a brain disorder often experiences emotional problems (e.g. anxiety and depression), becomes socially isolated and loses his or her job.

Article available in Dutch

Prioritising brain health in Europe and beyond

With the growing burden of brain disorders, it is more important than ever to ensure the necessary approaches are available; the European Brain Council discusses the priorities for supporting brain health and research in Europe and beyond.
Call to Action: Putting Brain Health on the Global Agenda

On the occasion of the 78th United Nations General Assembly, the European Brain Council and partner organisations (including the Baker Institute) hosted a Brain Health and Research Day as part of the Science Summit, bringing together over 150 key stakeholder organisations all committed to the same goal: fostering and enhancing global collaboration in the brain area, with the ultimate goal of improving the lives of people living with brain conditions, neurological and mental alike. This call to action reflects the urgent calls from the community.
PUTTING BRAIN HEALTH ON THE GLOBAL AGENDA
EBC MEMBERS & PARTNERS
The **European Federation of Associations of Families of People with Mental Illness** (EUFAMI) has an ongoing commitment to improving 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** 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 (NBCs) are independent and multidisciplinary councils that unite scientific organisations of neuroscientists, psychiatrists, neurologists, neurosurgeons, patients’ associations, as well as the pharmaceutical and medical device industry, in order to speak with one strong voice — at the national level — on behalf of the “brain space”.

EBC realizes that the best results are created in close alignment with NBCs in a bottom-up and top-down approach, thereby ensuring optimal key stakeholder management on both national and EU level. It is especially true at the country level, given that the organisation, management and funding of health services, fall within the exclusive competence of the national governments.

Therefore, although independent, NBCs are aligned with the main goals of EBC. These include promoting brain health, raising awareness of brain disorders, addressing stigmatisation, stimulating brain related research, fostering exchange between different disciplines and associations, promoting prevention and lobbying governments for enhanced research and treatments, in order to improve the quality of life of people affected by brain disorders.
The 9th Academy of National Brain Councils (NBCs) took place on 23-24 May 2023 in Brussels, Belgium. The annual meeting brought together NBCs representatives alongside prominent speakers and guests, in-person and remotely, from 15 countries: Austria, Belgium, Croatia, Finland, France, Greece, Italy, Malta, Poland, Portugal, Spain, Switzerland, Serbia, Sweden and Turkey.

**9th National Brain Council**

This year’s meeting was preceded by a campaign of engagement with EU policymakers on the EBC-led “Pledge for Science”, calling for the prioritisation of brain research and innovation in the EU. The Pledge was publicly launched that week in response to recent policy developments, particularly those with possible implications for health and research – including a recent European Citizens’ Initiative on “Save Cruelty Free Cosmetics – Commit to a Europe Without Animal Testing”.

NBC and EBC representatives met with MEPs, advocating for increased support for brain research and discussing the necessity of animal research. They also promoted the Pledge for Science. The following day, the Academy commenced with a session on developing National Brain Plans, featuring presentations on the WHO Intersectoral Global Action Plan for neurological conditions. Speakers addressed the European Health Data Space, highlighting perspectives from patients, policymakers, and researchers, and closed with updates from National Brain Councils and Action Groups on policy developments.

**Participants**

15 Countries
UNITING FOR BRAIN HEALTH
The membership of the EBC consists of patient groups, scientific and professional organisations as well as industrial partners. As per its statutes, the EBC accepts as Full Members pan-European umbrella organisations with an interest in the brain. Any organisation that supports the aims of the EBC can apply to become an observer in order to contribute in an advisory capacity. Organisations or individuals that have contributed in an outstanding fashion to the aims of the EBC can also become honorary members.
The European Federation of Neurological Associations (EFNA) brings together European umbrella organisations of 19 neurological patient advocacy groups, to work with other associations in the field of neurology, including the European Federation of Neurological Societies (EFNS), in what has been termed a “Partnership for Progress”.

In October 2023, EFNA was granted official Non-State Actor status with the WHO Regional Office for Europe (WHO/Europe). This partnership enables EFNA to broaden its reach, benefiting patients, caregivers and patient organisations across the continent particularly with implementation of WHO’s Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (IGAP). EFNA is committed to collaborating with WHO to galvanise European nations into action, ensuring they meet the targets set forth within the Plan. In March 2023 EFNA published its 2023 position paper on targets relating to national plans and awareness campaigns within the IGAP. In November 2023 EFNA held the first Stronger Connected Workshop to address strategic approaches to support the implementation of the WHO’s Intersectoral Global Action Plan on Epilepsy and other Neurological Disorders (IGAP).

In early 2023, the MEP Interest Group on Brain, Mind and Pain announced its rebranding as the MEP Interest Group on Brain Health and Neurological Conditions. This name change reflects the group’s strategic focus and commitment to advocating for people impacted by neurological conditions and the promotion of brain health with European Union.

Up to 36 million people in Europe are living with a rare disease. Up to 75% of rare diseases have neurological manifestations, involving central, peripheral nerve and muscle. Most rare diseases are associated with high unmet needs due to the lack of available and effective diagnosis and treatment measures. For this reason, EFNA led a multi-stakeholder Rare Neurology Working Group in development of the Rare Neurology Charter. This charter has been developed by the patient advocacy community and healthcare professionals to drive open conversations about the unmet needs of people living with rare neurological diseases. It outlines high-impact policy solutions with the potential to transform the lives of patients.

In late 2023 EFNA launched the Brain Health Matters podcast. Through this podcast, EFNA hopes to raise awareness of how precious our brain health is, how many of us will be affected by neurological conditions and how, while many of those conditions are unavoidable, there are ways that all of us can protect and improve our brain health.
GAMIAN-Europe (Global Alliance of Mental Illness Advocacy Networks–Europe), a patient-driven pan-European organisation, represents the interests of persons affected by mental illness. Its main objectives are: advocacy, information and education, anti-stigma and discrimination, patients’ rights, co-operation, partnerships and capacity building.

In 2023, GAMIAN-Europe spearheaded significant advancements in mental health advocacy and policy across Europe. The year began with crucial discussions at the European Parliament, co-hosted with the Coalition for Mental Health and Wellbeing and the MEP Alliance for Mental Health—secretariat managed by GAMIAN-Europe. This event, featuring Health Commissioner Stella Kyriakides, underscored their commitment to mental health priorities.

A detailed report, co-authored with Mental Health Europe, which outlines the proceedings, is available for access here.

Addressing the comorbidity of conditions such as cancer and depression, GAMIAN-Europe launched a report and video on World Cancer Day, advocating for a holistic approach to health care.
This was complemented by their work with the European Migraine and Headache Alliance (EMHA) on the “Migraine and Mental Health in Women: Addressing the Challenge” project, which aimed to unravel the complex relationship between migraines and mental health. The results and report were presented during a widely attended webinar.

Innovation in mental health care was showcased through the Vibrant Mind project, merging art with mental health recovery to explore the therapeutic potential of creativity. Similarly, the peer support project aimed to enhance knowledge exchange across Europe, highlighted by workshops and a dedicated website for sharing best practices in mental health peer support.

The GAMIAN-Europe’s Annual General Meeting in Bucharest set the stage for future efforts, fostering essential collaborations for improving mental health care. The introduction of Coffee Table Sessions and the “The Human Storybook” event on World Mental Health Day further emphasised the value of community and open dialogue in tackling mental health challenges, advocating for societal change and destigmatisation.

GAMIAN-Europe’s engagement in prominent events like the 31st European Congress of Psychiatry, the ECNP Congress, and the Brain Innovation Days demonstrated their ongoing dedication to closing knowledge gaps in mental health.

Last year, GAMIAN-Europe achieved key milestones in its mission to engage patients in European research and enhance public accessibility of research objectives and findings. The organisation launched the Psych-STRATA project website and established the initial phase of the Patient Advisory Board. Furthermore, GAMIAN-Europe actively participated in the inaugural meeting of the TRUSTING project, funded by the EU, serving as a leader in communication and dissemination efforts.

Overall, GAMIAN-Europe’s 2023 activities reflect a strong focus on advocacy, education, and collaboration, significantly contributing to the advancement of mental health care and support across Europe.
The European Academy of Neurology (EAN) is the organisation that unites and supports neurologists across the whole of Europe. Currently, 45 European national neurological societies as well as 800 individuals are registered members of the EAN. Thus the EAN represents more than 21,000 European neurologists.

In 2023, the European Academy of Neurology (EAN) focused efforts on fostering relationships and communication within the neurology sphere and beyond. The EAN National Neurological Societies Forum and the European Brain Health Summit – both now biennial events – exemplified this commitment. The forum, held virtually in March and November, facilitated exchanges among European national neurological societies, emphasising the importance of collaboration for better brain health. Meanwhile, the Brain Health Summits, held in Vienna in May and at the European Parliament in Brussels in November, addressed ‘Precision Neurology and Prevention of Neurological Diseases’ and ‘Brain Disorders: The Neglected Burden in Non-Communicable Diseases’ respectively, featuring speakers from various European organisations.

The May event also saw the launch of the Brain Health Mission to advocate for national strategies to boost brain research and improve care for mental and neurological disorders. This initiative aims to address the societal impact of brain disorders and promote the development of national brain plans across Europe.
The year also saw the launch of four new initiatives. The EAN Masterclass, launched in January, provides opportunities for in-depth face-to-face discussions on neurological topics selected from the previous congress. The EAN Leadership Programme, introduced during the EAN Congress in Budapest, aims to cultivate leadership skills among neurology professionals. The EAN Advocacy Training for Neurology and Brain Health, launched in October, was introduced to empower members with the specific communication skills required to effectively advocate for neurology and its patients. Lastly, the development of the EAN Strategic Neurological Research Agenda for Europe was an ongoing project throughout the year, culminating in the drafting of a position paper to be published in the European Journal of Neurology in early 2024. The initial study aimed to identify current gaps in neurological research across the continent, with the resulting agenda then setting new priority areas for clinically relevant research.

As always, the annual congress – held this time in Budapest – served as the centrepiece of the year, attracting a record number of abstracts for an in-person EAN congress, and drawing an audience of almost 6,000 onsite and 2,000 virtual participants with an engaging and entertaining programme. Finally, as 2023 came to an end, preparations were underway for both the 10th anniversary of the EAN (including the 10th EAN Congress, in Helsinki) and the 30th anniversary of the European Journal of Neurology, with numerous events and activities taking place throughout 2024 to mark both milestones.
The European Association of Neurosurgical Societies (EANS) is a fast-growing, independent association, both of European neurosurgical societies and of individual neurosurgeons all over the world. Its aim is to enable members to enhance the care they deliver to their patients by facilitating the exchange of scientific information at the highest level.

Reflecting on EANS activities in 2023 and having concluded what was probably the busiest-ever EANS educational portfolio, it is evident that the organisation answered the call for more neurosurgical training and education across Europe. In the same context, the EANS webinar series, organised by the EANS Sections, Committees and Task Forces, provided hundreds of educational hours for free to the global neurosurgical community. In addition to that, 2023 marked the very first EANS Congress organised entirely by the EANS Office. The internalisation of the congress was a long-discussed goal that was finally achieved, and the result was excellent in every aspect. The EANS2023 Barcelona Congress was the largest ever, having been attended for the first time by more than 2000 participants, accompanied also by the biggest exhibition ever in an EANS Congress, with 55 industry partners.
In the past year, the association exceeded 3000 individual members and took important steps towards further strengthening its connections with its National Member Societies, by organising the first National Societies Meeting. Furthermore, the association achieved to enhance its status at the European level, by joining the Health Technology Assessment Stakeholder Network (HTA), a European Commission policy-making body. On the other hand, the EANS and EUROSPINE Journal, Brain & Spine, achieved several milestones in 2023 and is now moving forward towards having an impact factor in the next few years. A new year is ahead, with a solid plan and new goals aiming towards the constant growth and development of the organisation. The EANS Annual Meeting remains within the EANS Office mandate and now goes to Sofia for another successful edition.

Last but not least, this year’s AGM was particularly significant as it marked the election of a new Board of Officers. With a history of continuing excellence in neurosurgical care, research, and education, the EANS reaffirms its commitment to the pursuit of knowledge and innovation through its new Board. Torstein Meling is the new EANS President and Francesco Sala, the new EANS President Elect.
The European College of Neuropsychopharmacology (ECNP) is an organisation committed to ensuring that advances in the understanding of brain function and human behaviour are translated into better treatments and enhanced public health.

The year began with ECNP’s annual suite of meetings in Nice, France, including the ECNP Workshop for 100 early career translational neuroscientists and the New Frontiers Meeting, focused this year on psychedelics, with 120 research leaders, industry representatives and regulators in Nice, and a further 300 participants online. Both meetings are built around ECNP’s core mission of exploring brain mechanisms to open up new treatment horizons. In June two ECNP Courses were launched, on Anxiety and ADHD, spearheading a programme to broaden the ECNP educational footprint to include more distributed online audiences and carry the mission into clinical training. Parallel to this, the ECNP Early Career Academy was launched to help formalise a career trajectory for early career applied neuroscience researchers and clinicians and provide a pathway through ECNP’s array of learning and career development opportunities.

At the senior researcher end of this spectrum, the ECNP Networks were expanded to 24, with the addition of a Depression Meta-Network, bringing expertise together from across the Networks programme to tackle this especially complex and intractable disease, and the Public-Private Partnership Roundtable was launched to provide a dynamic new platform for forming and co-ordinating multi-stakeholder research collaborations. In October these themes came together at the 36th ECNP Congress in Barcelona, which attracted 6,450 participants from nearly 100 countries, including nearly 800 online.
Further highlights included the ongoing strengthening of the ECNP journal European Neuropsychopharmacology (impact factor of 5.6) and the consolidation of ECNP’s new open-access title, Neuroscience Applied, both targeting the intersection between human biology, neuropsychiatric disorders, and treatment science; the ninth ECNP Workshop on Clinical Research Methods in Barcelona in November; the 120,000th download of the Neuroscience-based Nomenclature (NbN) app; the full return to pre-Corona levels of the ECNP Research Internship programme; and the conferral of 100 awards and prizes, including the ECNP Neuropsychopharmacology Award, given to Oscar Marín, United Kingdom, and the ECNP Lifetime Achievement Award, given to Aleksander Mathé, Sweden.

Plans were also begun on the 2024 New Frontiers Meeting, ‘A consensus roadmap for a new diagnostic framework for mental disorders’, which will further develop the theme of precision psychiatry and linking neuropsychiatric disorders to brain biology might lead to better diagnostic and treatment possibilities for patients.
The European Psychiatric Association (EPA) is the main association representing psychiatry in Europe. EPA’s activities address the interests of psychiatrists in academia, research and practice throughout all stages of career development.

With active individual members in as many as 88 countries and 44 National Psychiatric Association Members who represent more than 78000 European psychiatrists, the European Psychiatric Association is the main association representing psychiatry in Europe.

In 2023, the EPA served as a forum for the exchange of knowledge on mental health-related subjects, by actively advocating and engaging in EU-level activities for enhanced mental health prevention and treatment across Europe. As part of its EU Advocacy activities, the EPA organised an event in the EU Parliament on 6 December 2023, to celebrate its 40th Anniversary and to gather mental health experts and institutions’ representatives to discuss the future landscape of mental health care in Europe. On this occasion, the EPA launched its EU Manifesto in preparation for the 2024 EU Elections.

Throughout the year, the EPA engaged in numerous joint initiatives, webinars, and projects with European partners to raise awareness of the importance of mental health care and its intersection with other disciplines and domains.

Continuing its series of Ambassadors Surveys, the EPA launched its fourth edition questionnaire, aimed at understanding the experience and viewpoint of mental health care professionals on treating Schizophrenia Spectrum Disorders.

The annual EPA Summer School took place in Strasbourg in September 2023 on the topic “Focus on Suicidal Behaviours – One Step Beyond”, welcoming 30 participants from all over Europe.
The EPA also launched the 2023 edition of the Gaining Experience Programme, offering participants the opportunity to undertake observerships in various psychiatric institutions across Europe to enhance their clinical, research, and teaching competencies and become familiar with different mental health care systems in Europe.

Additionally, a few “Online Talks with Experts” were organised in 2023, to allow Early Career Psychiatrists (ECPs) to meet with worldwide renowned experts and discuss specific psychiatry-related topics. In July, the EPA Committee on Ethical Issues organised a webinar on “Implementing alternatives to coercion in psychiatric practice”, bringing together interested participants and experts to deliberate on strategies for preventing coercion in psychiatry.

The 31st European Congress of Psychiatry took place on 25–28 March 2023, welcoming more than 4,000 participants from over 100 countries in Paris and Online. The EPA Congress was preceded by the EPA Policy Forum, which gathered experts and EU and international institutions’ representatives to discuss the mental health effects of some of the main societal challenges in terms of migration, climate change and emergencies.
The **European Paediatric Neurology Society (EPNS)** is an international, independent non-profit making Society for physicians, health professionals, scientists, and students with research and/or clinical interest in Paediatric Neurology. The Society’s mission is to promote excellence in patient care, research, and education to improve the neurological outcome of children and young people in Europe and across the world.

2023 has been another outstanding year with the EPNS membership base increasing and strengthening the Society’s voice in advocating for paediatric neurology at the highest level.

The EPNS has continued to nurture national, multidisciplinary, and international collaborations. For example, as a EBC full member the EPNS networks with the key players in the ‘brain field’ adding focus to childhood brain health. In 2023, the EPNS started to build a framework focusing on the Intersectoral Global Action Plan on Epilepsy & Neurological Disorders (IGAP), with the goal to implement across Europe with specific reference to paediatric neurology.

In June 2023, the EPNS Congress in Prague welcomed approx. 2,000 participants and presented a scientifically stimulating programme with an outstanding Aicardi Award Lecture, three full days of educational sessions, networking, and interaction.

The first EPNS Exam successfully took place on 20 June 2023 in Prague, assessing the basic knowledge needed to underpin Paediatric Neurology training. In addition, 2023 saw the EPNS Moodle roll-out, a learning platform for EPNS members. Many other EPNS educational activities have taken place in 2023, including the well-established EPNS webinars every 2 weeks.
The EPNS Central Eurasia Workshop took place in Almaty, Kazakhstan on 12–14 April 2023 covering assessment tools in neonates and young children. This was followed on 24–27 April 2023 by 2 EPNS training courses in Riga, Latvia covering the topics of Neurometabolics and Epilepsy. With pleasure the EPNS continues to award EPNS Fellowships and EPNS Visiting Teachers to selected EPNS members who benefit from these unique opportunities.

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 the EPNS Guidelines Committee, a committee created for promoting high-quality and homogenous patients care (diagnosis, treatment) based on existent evidence all over Europe.

The European Journal of Paediatric Neurology, the official EPNS journal, is available to members. Published 6 times a year, it accepts high-quality papers primarily of a clinical research nature on the whole spectrum of paediatric neurological disease.
The **Federation of European Neuroscience Societies (FENS)** is the voice of European neuroscience. FENS currently represents 44 European national and single discipline neuroscience societies with more than 20,000 member scientists from 33 European countries. FENS’ mission is to advance research and education in neuroscience within and outside Europe.

In 2023 the Federation of European Neuroscience Societies (FENS) continued to pursue its mission to support and promote neuroscience in Europe and beyond with numerous impactful activities. The FENS Regional Meeting (FRM) held in Portugal from 3–5 May, by the Portuguese Society for Neuroscience in collaboration with the Mediterranean Neuroscience Society drew in 890 participants in the city of Albufeira for three days of enriching discussions and exchanges.

The FENS Committee on Animals in Research (CARE) intensified its efforts to advocate for the importance of animal research. Notably, it contributed to the drafting of the EBC statement on Animal Research in response to the European Citizens’ Initiative, ‘Save cruelty free cosmetics’, and the organisation of the policy webinar “Animals in Research and a Pledge for Science”.
Moreover, during FRM 2023, CARE together with EARA organised a special symposium titled “Animal Research: Time to Talk!” on how to communicate effectively on the subject of animal research.

Through the efforts of the Committee of Higher Education and Training, FENS championed several initiatives to boost the careers of European neuroscientists. The FENS–IBRO PERC Exchange Fellowship Programme was inaugurated in 2023 and allowed 22 Early Career Researchers to spend four weeks in a host institute in Europe, fostering interlaboratory exchanges. Two Brain Conferences were held, bringing together hundreds of researchers and dozens of top scientists as speakers in Denmark. The first FENS–Chen Institute – NeuroLéman Summer School took place in Lausanne, Switzerland, on “Motor control: from thought to action”. This school, together with the annual FENS – Hertie Winter School, represents an invaluable opportunity for young scientists to directly engage with some leading researchers in neuroscience.

FENS also supported The European Neuroscience Conference by Doctoral Students, organised by and for PhD students as a satellite event at FRM 2023.

The European Journal of Neuroscience, FENS’ official journal, collaborated with the FENS–Kavli Network of Excellence to curate a series of editorials focusing on career models in neuroscience and strategies to bridge interdisciplinary gaps within the field.

In 2024, FENS, the Austrian Neuroscience Association and the Hungarian Neuroscience Society are looking forward to welcoming the global neuroscience community to the FENS Forum 2024, from 25–29 June, in Vienna. As Europe’s premier neuroscience meeting, the FENS Forum will cover all aspects of neuroscience and represent an incredible opportunity for the entire community to come together and share their latest advancements and achievements.
The **International Brain Research Organisation (IBRO)** is the global association of neuroscience societies aiming to promote and support neuroscience around the world through training, education, research, and outreach and engagement activities. The IBRO Pan–Europe Regional Committee (IBRO–PERC), is an IBRO Regional Committee supporting IBRO’s mission and helping to plan and implement IBRO activities in Europe.

IBRO continues to focus on strengthening its commitment to providing equitable, diverse, and inclusive opportunities for the global neuroscience community.

In this context, IBRO has been supporting early-career neuroscientists through funds such as the Early career and Rising star awards, offering support for equipment and other research costs linked to the establishment of their labs. In addition, Parenthood grants have been targeted to assist scientists approaching parental leave.

IBRO has also been providing global support for schools, conferences, and meetings, including events dedicated to increasing diversity in neuroscience.

Additionally, IBRO has also supported the attendance of PhD students and early-career researchers at conferences and lab internships through travel grants and exchange fellowships. Recognizing the importance of science education beyond academia, IBRO has also supported outreach and engagement projects, including events taking place during Brain Awareness Week.
In September 2023, the IBRO World Congress, held in Granada, Spain and hosted by the Spanish Society of Neuroscience (SENC), provided an excellent platform for ample scientific and cultural exchanges among the diverse audience that attended the World Congress in Granada. Close to 2,800 scientists from 83 different countries enjoyed a festive and inspiring IBRO World Congress.

In 2023–2024, IBRO looks forward to continuing its efforts to ensure impactful outcomes for its initiatives that ultimately aim to elevate neuroscience research and education around the world. IBRO will continue to offer support for individuals and organisers at all career stages.

We are excited to report that a new team of Chief Editors has been appointed to steer IBRO’s flagship journal Neuroscience from 2024 onwards. Drs Francesca Cirulli (Italy), Chen Zhang (China) and Sarah Spencer (Australia) have taken up the reigns after Juan Lerma who ended his term in 2023. The energy and attitude of this diverse group are quite inspiring and IBRO is excited to embark on this journey with them.

IBRO Neuroscience Reports is IBRO’s fully open access journal that serves as a venue for the publication of original research on any aspect of the scientific study of the nervous system.

IBRO will be present at many different events around the world, including the FENS Forum 2024 (Vienna, Austria), the NEURO2024 (Fukuoka, Japan), and the SfN Neuroscience 2024 meeting (Chicago, US), and will welcome attendees interested in exploring IBRO’s opportunities and interacting with IBRO members at its dedicated booth.

Finally, during the IBRO 2023 World Congress in Granada, Spain, IBRO announced that the next World Congress taking place in 2027, will be held in the continent of Africa for the first time. During 2024, the country and venue will be announced following a competitive selection process.
FINANCIAL REPORT*

*Official figures will be disclosed in Q2 2024.
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ANOTHER IMPORTANT YEAR FOR THE BRAIN COMMUNITY