



EBC PROJECTS 2020-2021

Bringing science and society together

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

EBC aims to:

FOSTER COOPERATION

between its member organizations and other stakeholders.

PROMOTE DIALOGUE

between scientists, industry and society.

EMPHASISE THE IMPORTANCE

of continued interaction with European Institutions to build strong European health policy

RAISE AWARENESS

and encourage education on the brain.

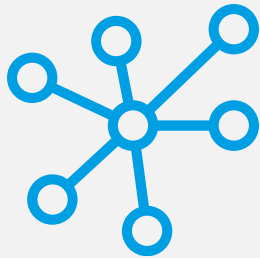
To **improve the lives of those living with brain disorders**, we **advance the understanding of the healthy and diseased brain** by **bringing science and society together**.

EBC works towards this **mission** through:

Advocating for
brain research



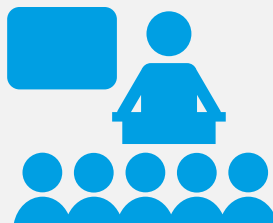
Demonstrating
the societal
impact of brain
disorders



**ADVANCING
BRAIN
KNOWLEDGE
AND DRIVING
ADVOCACY**



Building
consensus
within the brain
community



Raising
awareness and
promoting
education on
the brain

1

Full Industry Partnership

Become a full Industry Partner of EBC for access to all activities and a seat on the Industry Board to bring forward ideas and be part of strategic planning. *(See next page)*

2

Project-based Sponsorship

Be part of EBC projects and/or activities on an individual project-by-project basis (i.e. support of VOT case study or funding of white paper).

3

Industry Partnership & Project Support

Be part of the Industry Board for a voice in all EBC activities and provide support to any additional projects of interest to your company.

Industry Partner Benefits



Access and be part of a broad network of key players in the brain space, including representatives from all main fields.



Opportunities to initiate and/or join key research projects, political advocacy activities and awareness-raising initiatives.



Representation of your company on the EBC Industry Board, which represents the voice of the industry and private sector within EBC



Support evidence-based policy recommendations in the context of the current EU research and health policy.



Contribute to multi-stakeholder consultations and take part in multi-stakeholder projects and activities.



Stay up-to-date with the latest in the brain ecosystem and be part of community reactions and activities in real time.



EBC & PARTNER- FUNDED PROJECTS

The European Brain Council has been involved in many projects ever since its creation. All projects, either EBC-led or involving EBC, result from concerted discussions with its members and partner organisations.

In addition, members of project groups are appointed by the EBC leadership in order to find the best-suited experts throughout Europe be they doctors, basic scientists or expert patients.



2nd ROUND 2018-2021
**BRIDGING THE GAPS &
ACHIEVING SEAMLESS,
COORDINATED CARE**

EBC RESEARCH PROJECT - THE **VALUE OF TREATMENT** FOR BRAIN DISORDERS IN EUROPE

www.braincouncil.eu/projects/the-value-of-treatment/

VOT PROJECT OBJECTIVES:

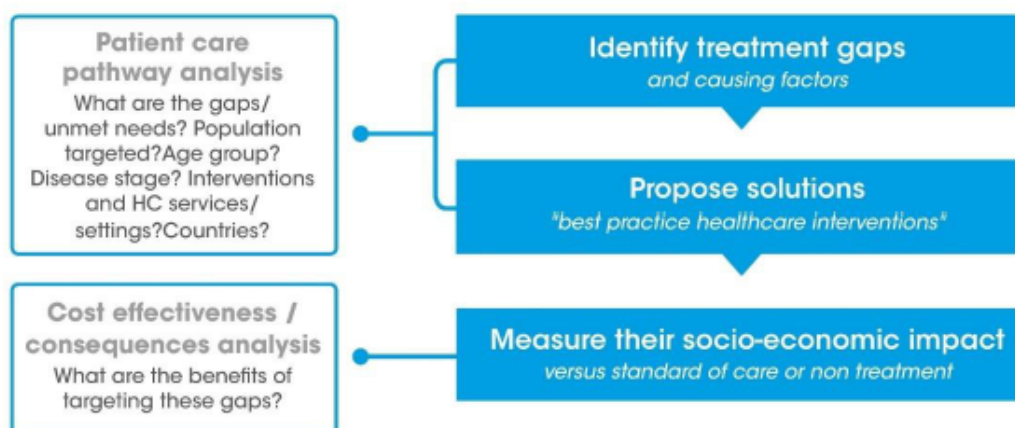
- I. Identify treatment gaps (or barriers to care) and causing factors along the patient care pathway and propose solutions to address them;
- II. Assess health gains and socio-economic impacts resulting from best practice healthcare interventions, in comparison with current care or no treatment;
- III. Converge data evidence to policy recommendations on how to improve the care pathways.

Case studies are conducted in collaboration with experts from the EBC network and with the support of academic partners, applying empirical evidence from different European countries.

RESEARCH METHOD

The method is similar for all case studies. It is important to harmonize datasets for the case studies– a standardised and homogenous approach, which facilitates interpretation and comparison, for the Final Paper.

Case studies analysis aims to:





www.braincouncil.eu/projects/rethinkingms/

The "RETHINKING" Concept and Aim: Building on the findings from the 'Value of Treatment (VOT)' studies, the 'Rethinking' studies as a health systems and policy research aim to create greater visibility for the unmet [medical, psychosocial, health care] needs experienced by people with brain disorders at country level.

Approach: Standardised methods on the measurement and valuation of services in the health and social care sector that are applicable across countries were used (SWOT analysis as a tool for prioritization and strategy development)

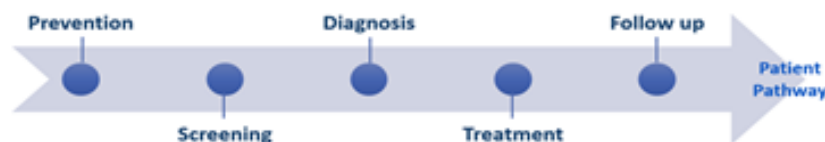
Multiple Sclerosis (MS) was the first case study (2018-2020) developed by EBC using the 'RETHINKING' concept. Focus was on three key areas: timely diagnosis and personalised treatment; interdisciplinary and coordinated care; and adaptable support in daily life, including rehabilitation and social protection.



Launched respectively at the European Parliament on 6th November 2019 and during the Brain Awareness Week in March 2020

New projects in the pipeline:

- RETHINKING MS in times of COVID-19
- RETHINKING Migraine
- RETHINKING Alzheimer's disease





Brain Innovation Days

Disrupt and rewire: how brain innovation is changing Europe

www.braininnovationdays.eu

European Brain Council and **beLean.net** launched the first **Brain Innovation Days** virtually on 13 October 2020, kicking-off one full year of a packed brain innovation agenda leading up to the Brussels on-site event on 12-13 October 2021 and a series of annual events.

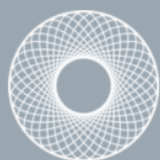
Brain treatments remain insufficient and research is disproportionately underfunded compared to other disease areas. At the same time, we have inspiring innovators in the brain space paving their way to building solutions for patients with brain disorders. In order to connect all parties involved, enhanced multi-stakeholder engagement in the brain ecosystem is needed to foster dialogue, exchange knowledge, accelerate investment in research and innovation, facilitate business development and showcase on-going work.

This is what the Brain Innovation Days are about: a platform bringing together science and society and an annual event where leaders in the brain ecosystem, researchers, industry, start-ups, innovators, policymakers, investors, health care professionals and patients are invited to discover the potential for innovation and build strong matchmaking opportunities.

EBC works with sponsors and other partners to power the Brain Innovation Days. Further details on how to get involved can be found [here](#).



Virtual launch event,
exploring how brain
innovation is changing
Europe



Online panels, interviews
and more with prominent
speakers in their fields



"My Start-up in 180
seconds" Pitching
Competition with an
award for the 'Best Pitch'



Matchmaking and
networking opportunities



Online content streams
with regular updates on
the latest in brain
innovation

THE VALUE OF INNOVATION

Aim: A multi-stakeholder effort to determine how to create an enabling environment to foster investment and policy engagement in innovation in brain disorders in Europe and propose concrete avenues to remove existing barriers.

Outcome: consensus-driven policy paper

Start – end date: June 2020 – Spring 2021

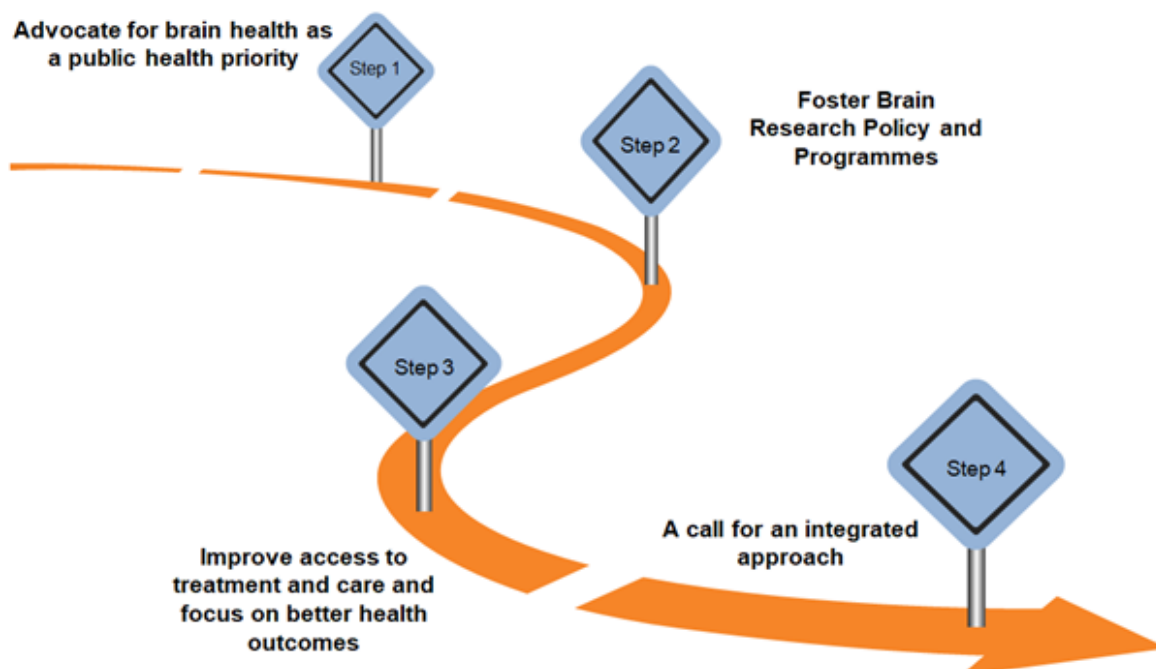
Phase 1:

- A draft policy paper identifying challenges and enablers to creating an innovation-friendly ecosystem for brain disorders in Europe, including case studies and recommendations
- A concise plan on how to best engage policy audiences around the recommendations of the paper

Phase 2:

- A fully implemented communications and dissemination plan and materials
- Bilateral outreach to policymakers and a policy event (targeted high-level roundtable dedicated to innovation)
- An op-ed (or more), potentially followed by a peer-reviewed publication based on the policy paper at a later stage

EBC Policy priorities and Actionable Items:



The European Brain Council is producing a series of videos covering key messages for use across social media, the wider internet, during events and more. These videos tackle complex issues in accessible, lay language, with topics varying from:

- Brain disorders and their diagnosis, symptoms and treatment
- Simplified explanations of the brain and its underlying mechanisms
- Showcasing how basic neuroscience has led to discoveries of brain disease mechanisms that help feed into treatment generation and improved care for patients

These videos are produced and shared with the idea to improve the knowledge and understanding of the general public of these various, seemingly complex topics.

EBC would like to take advantage of the knowledge-spreading power of the internet and circulate powerful yet understandable videos involving both science and those living with the conditions themselves. This series of videos will inform a wide audience on brain research and patient lives in a factual, captivating manner and will feed into EBC's mission and objectives of promoting brain research with the goal of making a difference in the lives of those living with brain conditions.

Patient Advocacy


One of EBC's key drivers is to raise awareness of brain disorders and for those living with these conditions. The videos dedicate part of the focus on patients living with different brain disorders, using patient testimonials to create patient perspective videos that not only help the general public understand what the disease is, but give them a personal connection to what it is like to live with it.

Brain Research

Addressing EBC's call for continued support of fundamental research, the videos explore the underlying causes for different brain disorders as well as the research that is conducted to gain insights on basic brain mechanisms. These videos link research to disorders by scientifically explaining the conditions from a "mechanism" point of view, and discuss the research that continues to explore ways to improve understanding, treatment and/or cures.



The first Science & Society video focused on Parkinson's Disease. Watch it [here](#).



EU-FUNDED PROJECTS

EU support for brain research spans across the various European Commission funding mechanisms, from Horizon 2020 and the industry co-supported Innovative Medicines Initiative (IMI), to the European Research Council (ERC) and the Future and Emerging Technologies (FET) programme.

EBC is involved in projects in the brain space that are in line with the mission and vision of EBC. EBC is either a coordinator or a partner in an international consortium, typically including various stakeholders such as academics, clinicians, SMEs and patient organizations.



Coordinating European brain research and developing global initiatives

www.ebra.eu

CHALLENGE: The highly diversified nature of European public research represents a considerable obstacle in the European Research Area, especially in the field of brain research. The complexity of the brain imposes a coordinated research effort to advance the understanding of brain and its disorders. The EU and its Member States have already made considerable investments in brain research, leading to a significant increase of initiatives in this area, particularly under Horizon 2020. Although these initiatives have generated considerable amounts of knowledge and innovative approaches, more coordinated efforts to identify gaps and highlight priorities are needed, to combat the complexity of the challenge.

Aim: The European Brain Research Area project — EBRA — was created as a catalyzing initiative for brain research stakeholders (researchers, clinicians, patients, governments, funders and public institutions) to streamline and better co-ordinate brain research across Europe while fostering global initiatives.

Start – end date: 1 November 2018 – 30 April 2022

Partnership: EBRA is coordinated by the European Brain Council, in partnership with the [Human Brain Project](#), [ERA-NET NEURON](#) and the [EU Joint Programme – Neurodegenerative Disease Research \(JPND\)](#).

EBC's role: As a coordinator of this project, EBC works together with its partners as well as its third parties (EFNA, GAMIAN, IBRO, FENS, EPA, EAN, ECNP, IFCN) on a strategic and operational level:

Strategic: Foster alignment and better co-ordinate research strategies across European brain initiatives.

Operational: Support research communities in specific brain research areas.

Expected project outcomes: European Brain research landscape; Shared European Brain Research Agenda (SEBRA); activities with international brain research initiatives; six EBRA clusters: PSMD, EPICLUSTER, BRAINFOOD, TRISOMY21, two others to be defined.

Project video: <https://youtu.be/MCcgBrcNhHI>



A Collective Research Impact Framework to foster the true engagement of actors and stakeholders in Health Research and Innovation

www.multiact.eu

Rationale: the future of healthcare sustainability requires new multi stakeholder and multidisciplinary managerial models of cooperation that guarantee a long term return on investment, not only economic

Aim: to increase the impact of health research on people with brain diseases

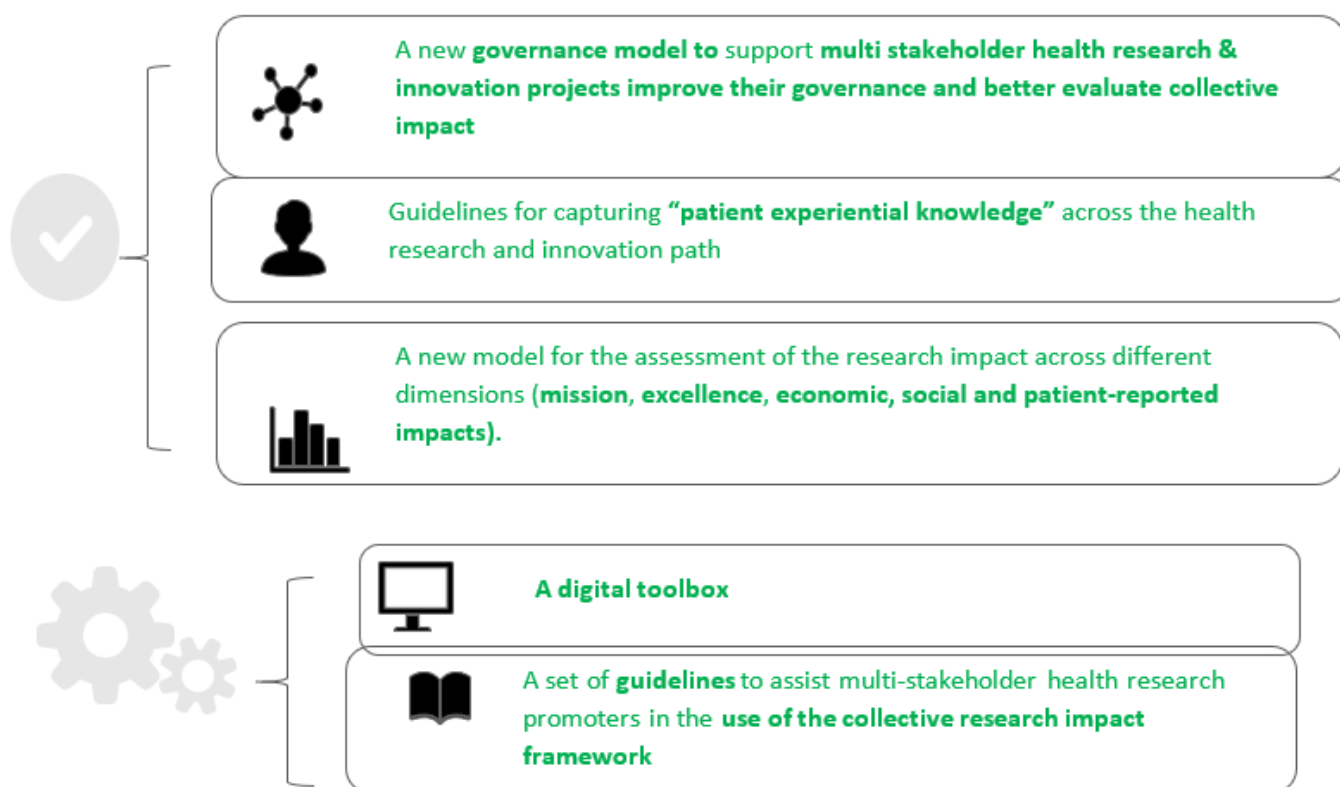
Start – end date: May 2018 – April 2021

Target audience: The framework is intended for multi-stakeholder research initiatives, promoted by Health Research Funding & Performing organizations (RFPOs), that are already grouped in a multi-stakeholder initiative (e.g. Alliance) or that are willing to start conducting their R&I with a multi-stakeholder and co-accountable approach.

Partnership: Coordinated by Italian Multiple Sclerosis Society Foundation (FISM), MULTI-ACT brings together leading European societies, patients, patient organizations, research/ academic institutions, governmental organizations, and technological organizations.

EBC's role: communication and dissemination; MULTI-ACT framework test, transfer and exploitation

Outcomes: A collective research impact framework (CRIF)



PROJECT VIDEO:
<https://youtu.be/rmWo62IBQOc>



An innovative EU-funded project developing a robust digital tool that enables the early detection of Alzheimer's disease

www.addp.eu

Aim: The project aims to develop an innovative digital tool for improving the early detection of Alzheimer's disease (AD). This healthcare solution will also offer personalized intervention programmes in order to address risk factors connected to Alzheimer's dementia.

Start – end date: November 2018 – October 2021

Target audience: The digital tool is intended for patients and healthcare professionals.

Partnership: Coordinated by Brain+, the ADDP consortium brings together leading research/academic institutions (e.g. University of Oxford, University of Nottingham, Aarhus University), European societies (EBC), patients, patient organizations (Alzheimer Europe), and technological organizations (Brain+).

EBC's role: Communication and dissemination, e.g. coordination of webinar, conferences and social media/online content.

Ongoing studies:



Study 1: University of Oxford & Brain+ | 4 groups (AD high risk group, Mild Cognitive Impairment patients, AD patients and healthy controls) (total 180) will take part in the study where they perform a standard neuropsychological test and tests in the AD Detect & Prevent detection tool.



Study 2: Aarhus University | The AD detection tool will be validated by AD hallmarks (amyloid build-up and tau protein plaques) using PET and hippocampal volume using MRI. The integrity of brain connectivity will be measured with diffusion-weighted MRI (DW-MRI).



Study 3: University of Nottingham | The immediate and prolonged impact of AD Detect & Prevent training will be examined, particularly for transfer effect to other real-world tasks, using a mixture of a) longitudinal user studies, and b) qualitative Public & Patient Involvement Workshops.

For more information on the above studies, click [here](#).

Project videos: https://youtu.be/iFsJRKwHn_Q



Training on Advanced Stem Cell Technologies in Neurology

www.asctn-training.net

Aim: ASCTN-Training is addressing existing gaps within Human Stem Cell-based Neuronal disorders (NDs) Modelling (NDM) for research to develop new medicines for the treatment of neurological disorders (e.g. Parkinson's (PD), Huntington's (HD) and Demyelination's (DM) diseases), which occur as a result of acute or progressive loss of cells, glial or neuronal, and structures and function in the brain.

Start – end date: 2018 - 2022

Partnership: Coordinated by University of Barcelona, ASCTN-Training gathers 9 academic and industrial beneficiaries and 2 partner organizations.

EBC's role: Training on Advocacy: Bridging Science, Policy and Society

Target audience: Early stage researchers working on Advanced Stem Cell Technologies in Neurology.



Objectives of EBC Trainings

- Build the strategic capacity of participants to be effectively involved in advocacy activities supported by research evidence and focused on influencing policy decisions in the brain research area
- to empower participants with ways to become a voice for neuroscience research throughout their careers



Expected Learning Outcomes

- The role of science in European policy making
- The European policy making process
- The EU research funding mechanisms and the institutions involved
- Tools and techniques for effective science communication and advocacy
- The challenges of advocacy activities and resources needed to effectively perform advocacy activities in brain research
- Patient engagement in research and advocacy activities
- Career opportunities in science policy and advocacy



Prevention and Remediation of Insulin Multimorbidity in Europe

www.prime-study.eu

Aim: PRIME aims to unravel the insulin-dependent mechanisms that underlie 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). Therefore, through PRIME, we aim to develop tools for improved diagnosis, clinical care and prevention of insulin-related lifespan multimorbidity.

Start – end date: January 2020 – December 2025

Partnership: Coordinated by Radboud University Medical Center. A multidisciplinary team of 17 European Institutions including leading players in their disciplines (from internal medicine to psychiatry), SMEs, societal partners (including EBC and its member ECNP).

EBC's role: Organization of a multi-stakeholder public event in Brussels in 2024




SOCIETAL & ECONOMIC IMPACT | PRIME addresses two of the most pressing epidemics of the industrialized world: 1) the trio of type 2 diabetes, obesity, metabolic syndrome and 2) the dementias including Alzheimer's disease. These conditions are already among the most common and disabling conditions in Europe, with both diabetes and dementia being among the top-10 most burdensome conditions (according to WHO).



CLINICAL IMPACT | Delivering new approaches to treatment and prevention of insulin co-occurring diseases from young to old age will substantially alleviate the burden for patients. It also impacts on broader issues, such as the burden of these co-occurring diseases on the healthcare system and society.



SCIENTIFIC IMPACT | The highly multidisciplinary team of PRIME is the key to the success of our work and ensures its impact. Having opinion leaders from multiple disciplines in our consortium, we ensure broad dissemination of scientific findings. This allows us to work on the edge of science and implement interdisciplinary scientific approaches that will maximize scientific impact.

The background of the slide is a grayscale photograph of a person's hands writing in a notebook. The person is wearing a patterned shirt. The image is partially obscured by a large blue vertical bar on the right side, which contains the text.

EBC OUTREACH & AWARENESS ACTIVITIES

Alongside major projects, EBC also takes charge or takes part in a number of awareness raising initiatives across the year, particularly in the political advocacy realm.

These activities can involve disease-specific awareness raising at the policymaker and/or public level or the release of project outcomes at the political level.

These take place throughout the year but key dates include Brain Awareness Week and other international days, such as World Mental Health Day.



EBC has created the #ILoveMyBrain logo as a communication tool for promoting and connecting all the work being done to promote brain health and prevent and treat brain disorders in Europe.

Different organisations, researchers, patients and carers are working on different conditions – Stroke, Multiple Sclerosis, Traumatic Brain Injury, Epilepsy, Mental Illness are only a few examples. We believe that by bringing together the very diverse activities which are all considered brain disorders, we can all benefit. Using a common logo, which is repeatedly seen in public and in the media, will help to gain more attention for brain disorders from EU policy makers, and ensure that more resources are channeled towards research on the brain and for patients of brain disorders.

We invite everyone to use the logo for any activity that is connected to brain health – conferences, outreach events, online campaigns, etc. We are open to collaborating with organisations to get involved in such awareness and/or advocacy-related events or activities. We hope that over the next few years it becomes as recognizable as the other symbols which have been so effective in attracting resources to specific diseases – the pink ribbon for breast cancer, the red ribbon for HIV.

EBC 'I Love My Brain' Events

Under the **I Love My Brain** branding, EBC has run a number of awareness raising and advocacy-related events across the years, including Brain Awareness Week events in the European Parliament. A list of past activities can be found [here](#).



One of EBC's biggest annual events is a public awareness event in the European Parliament during Brain Awareness Week.

Brain Awareness Week, founded by Dana Alliance for Brain Initiatives (DABI) and the European Dana Alliance for the Brain (EDAB), is a global campaign to foster public enthusiasm and support for brain science.

The annual event of EBC is planned directly in partnership with the European Dana Alliance for the Brain (EDAB) and the Federation of European Neuroscience Societies (FENS), to raise awareness on the importance of brain research - but with differing focus each year - in an audience of policymakers and the general public.

The events always feature key experts in the given field and a number of supportive Members of the European Parliament (MEPs).

Previous events have focused on subjects like 'expanding brain research in Europe - a societal need?', 'education, behaviour and brain development' and 'mood and food - exploring the gut-brain connection'.



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