

# **EBC ANNUAL REPORT 2015**

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IMPROVING  
BRAIN KNOWLEDGE  
AND ADVOCACY



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# INTRODUCTION

By David Nutt & Frédéric Destrebecq



A handwritten signature in black ink, appearing to read "David Nutt".

Prof. David Nutt  
*President*



A handwritten signature in black ink, appearing to read "Frédéric Destrebecq".

Frédéric Destrebecq  
*Executive Director*

Dear Colleague,

We are pleased to present to you this Annual Report of the EBC.

A number of key milestones were set in the course of 2015, all designed to contribute to fulfilling EBC's objectives of our becoming recognised and increasingly respected as the reference when it comes to issues relating to the Brain at the EU level.

Specifically this has materialised with the launch of our Call to Action for the development of national and European Brain Plans, whereby we build on our previous initiatives and the many partners we have been able to reach out to in the past years. In particular, EBC's Year of the Brain provided many opportunities for developing our very active advocacy role and also for meaningful engagement with the EU Institutions and stakeholders. In this regard, the active role of our Ambassadors and the EBC President 2011-2013 Mary Baker needs to be acknowledged. We are thankful for their contribution to the cause of EBC and this is showcased as an integral part of this report.

EBC's Call to Action encapsulates our common vision for an holistic approach to the brain. Other therapeutic areas, such as cancer for instance, are providing us with successful examples of how they have have developed and flourished using this overarching approach. It is clear that, when it comes to brain disorders, their high prevalence, their burden to patients and their families, the associated stigma and the enormous cost to our societies alltogether justify the need to act.

Besides these though, another key element that we ought to address in our journey is: Identity. Recognising brain disorders as belonging to one « family » and therefore acting in a coordinated fashion are prerequisites to success. This is notably why EBC is highly appreciative of EFNA's campaign « Together Under the Umbrella » that has just started. EBC was delighted to provide its full support to it, particularly given the way the campaign synergises with our Call to Action.

Two other landmarks initiated last year are also supporting and paving the way to our objective. These are EBC's Consensus Paper on Brain Research in Europe and EBC's Research Project on the Value of Treatment for Brain Disorders. It is of particular importance to us that we emphasise the new impetus that these initiatives have provided amongst members and partners within EBC's constituency. Never in the past has such a healthy and enthusiastic collaboration demonstrated tangible and meaningful outcomes for the organisation.

Collaboration with National Brain Councils (NBCs) and Action Groups also received particular attention with the establishment of our Academy, aiming to contribute to NBCs capacity building and increased influence. This initiative is receiving a lot of positive feedback and support but will need to be repeated in a sustained fashion in order to bring the expected achievements and see interactions come to fruition.

We are proud of the achievements presented in this report on behalf of EBC. Even more importantly, we trust that the positive spirit within the organisation and the continuous striving for the collective interest of EBC will be key success factors in the months to come. John Forbes Nash, Jr.-mathematician and Nobel Prize Winner in 1994, lived with schizophrenia for more than 50 years. His example is one we can consider as one of the leading examples of the cause that we defend. This is particularly relevant as he demonstrated through his theories, the shared benefit that cooperation brings if members of a group act together for their collective interests. We now look forward to continuing these efforts on that path to the collective future successes of EBC.



# **EBC MISSION & VISION**

Brain disorders are likely to affect **179 million individuals in Europe** and they will affect one in three Europeans during their lifetime.

## Key Facts & Figures

ANNUAL EUROPEAN BUDGET DEDICATED TO TREATING DISEASES AFFECTING THE NERVOUS SYSTEM



€ 800 BILLION



**45%**  
of total annual  
Health budget

EUROPEANS CURRENTLY AFFECTED BY BRAIN DISORDERS



  
127 MILLION INDIVIDUALS



**35%**  
of the burden  
of all diseases  
in Europe

EU FUNDING DEDICATED TO BRAIN-RELATED RESEARCH SINCE 2007 (FP7)



€ 3.1 BILLION (€ 300 MILLION/YEAR)

NUMBER OF EU PROJECTS FUNDED SINCE 2007 (FP7)



1,931

THE EBC, ESTABLISHED IN 2002, REPRESENTS THE MAIN EUROPEAN STAKEHOLDERS IN BRAIN SCIENCES



FENS, EAN, EPA, ECNP, EFNA, IBRO PERC  
Gamian-Europe & EANS



# MAIN ACHIEVEMENTS

## Main Achievements

- **Reshaping strategic planning**

We reset our main goals and objectives while reconnecting with our constituency, along the lines drawn in our Operational Plan for 2015-2016.

- **Bringing added value to the brain space**

We focused on obtaining concrete outcomes from our ongoing projects, while launching new flagship initiatives that respond both to the needs of our constituency and also to the expectations of major health stakeholders.

- **Maintaining influence in health and research policy**

We brought European brain space priorities at the 'high table' of EU policy and we forged successful partnerships with the potential to decisively influence decision-makers.

- **Enhancing collaboration with members**

In 2015 we boosted our membership, exchanged best practice, joined our voice in support of various brain-related advocacy campaigns and built towards a solid organisational structure.

- **Improving communications**

We invested in our communications capacity in order to enhance our organisational profile both off and online.

# BREAKDOWN OF ACHIEVEMENTS



# BREAKDOWN OF ACHIEVEMENTS

## Reshaping strategic planning

Our Strategic Plan discussions - during board meetings and member workshops - allowed us to refine the three main pillars that sum up EBC's priorities:

**AWARENESS  
RAISING  
EDUCATION**

**IMPROVED  
TREATMENT  
PREVENTION**

**STRENGTHENED  
RESEARCH**

According to the 'three pillars', we outlined a transformational vision for EBC, and identified a fitting motto:

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

This refreshed focus enabled us to set a number of priorities for the road ahead. Key among them:

- Support **meaningful collaboration between EBC members and partners**
- **Work with our strengths** (stakeholder recognition, wide network, track record) and address our weaknesses (financial management, resources and internal communications)
- **Focus on project outcomes**, improve membership outreach and expand influence.

# BREAKDOWN OF ACHIEVEMENTS

## Bringing added value to the brain space

2015's summit provided us with the opportunity to mark the successful conclusion of our extended **Year of the Brain campaign**. Started in the spring of 2014, this multi-stakeholder, cross-border campaign focused on empowering brain advocacy and its main actors.

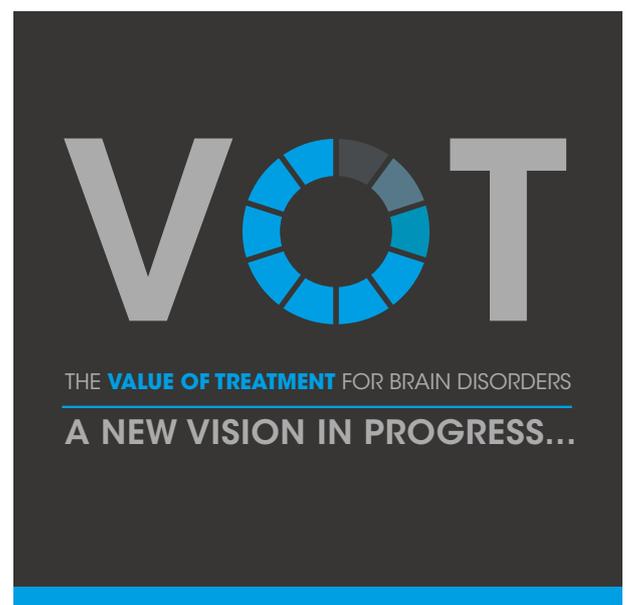


During the same busy period, EBC has been looking into developing a valid solution to European stakeholders involved in addressing the significant treatment gap challenge: we launched our two-year Value of Treatment project.

**To protect, preserve, develop and nurture our most vital asset: The Brain**



▲ **Year Of The Brain** event - 9.12.2015



# BREAKDOWN OF ACHIEVEMENTS

## Maintaining influence in health and research policy

By efficiently employing one of our main strengths (stakeholder recognition) we were able to hold strategic meetings with and win support from top EU decision-makers.

An EBC team met in Brussels with the EU Commissioners for Health and for Research - **Vytenis Andriukaitis** and **Carlos Moedas**, respectively.

As reported by EBC's Vice President **Prof. Patrice Boyer**, during the meeting with Commissioner Andriukaitis 'we underlined our priorities as underpinning the "4 Ps" program that the Commission is currently promoting to the Member States: prevention, protection, promotion and participation.'

Another important outcome was the continuous involvement in the brain space of former EU Parliament President **Jerzy Buzek**, who in his most recent show of support for EBC chaired the launch of our **Call to Action for EU and national plans** 'to tackle brain health in a collaborative, integrated and comprehensive manner.'



Meeting with EU Health Commissioner Vytenis Andriukaitis - 26.05.2015

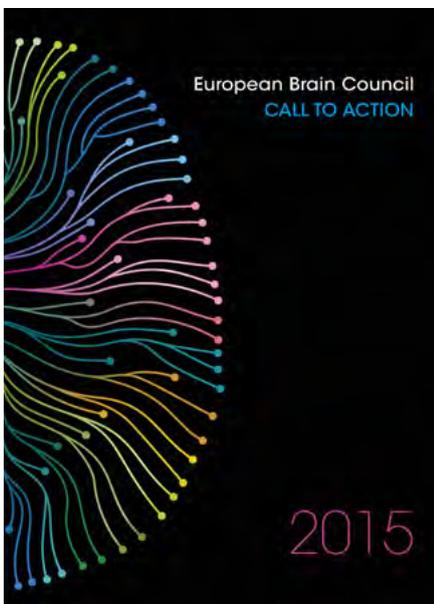
# BREAKDOWN OF ACHIEVEMENTS

## Enhancing collaboration with members

Our **Call to Action for brain plans** launched in 2015 is one example of engaging with our members' and national brain councils' network in an effort to transfer national level best practice onto the European stage.

EBC's Call was inspired by the **Polish Brain Plan**, a national strategy to address brain disorders devised following the European Commission's 2013 Month of the Brain recommendations 'for countries to develop, or refine, national strategies on brain research and healthcare within an overarching European context.' For this purpose, EBC worked closely with the **Polish Brain Council and Foundation "Neuropozytywni"**.

In 2015, EBC also welcomed a new member: the **PanEuropean Regional Committee (PERC) of the International Brain Research Organization (IBRO)**. PERC-IBRO encompasses 37 neuroscience societies and associations.



**The brain is a true wonder that needs to be nurtured, protected and cared for.**

The human brain is the most complex living structure known in the universe. The single organ controls every aspect of our bodies, ranging from heart rate to emotion, learning and memory. The brain has enabled humans to achieve breathtaking milestones: walking on the moon, mapping the human genome, or composing masterpieces of literature, art and music. It is the home of our personalities, thoughts, feelings and other human characteristics. It is the ability of the brain to perform all these functions that makes us human. The brain is a true wonder that needs to be nurtured, protected and cared for.

At the same time, the human brain is also the origin of many chronic and disabling diseases that have a huge impact on the lives of people affected by them, as well as the healthcare systems that support them, and European societies as a whole. Brain disorders – including developmental, psychiatric, neurodegenerative and pain-related disease – represent an enormous disease burden in terms of both human suffering and economic cost.

Brain disorders pose one of the greatest societal challenges for Europe:

- Brain disorders affect at least one in three people during their lifetime – currently 165 million people in Europe!
- Brain disorders cost Europe around € 800 billion every year\*. This cost far exceeds that of cardiovascular diseases, cancer and diabetes combined! As the population in European countries ages, these numbers are increasing.
- WHO concluded that brain disorders account for 35% of the burden of all diseases in Europe and are predicted to become the major medical need of the 21st century\*\*.

Facing the most pressing societal challenges is the key objective of the Europe 2020 Strategy, designed to turn Europe into "a smart, sustainable and socially inclusive market economy". While economic progress comes first in the current environment, healthy brain capacity needs to be put right at the heart of Europe 2020 Strategy. It is only with healthy brains that we will have any hope of the challenges that face modern societies. Advancing understanding and improving the health of the brain has a positive ripple effect – improved health of the brain leads to better overall health, which leads to better productivity among the working population, which thus contributes to increasing Europe's economic competitiveness.

It is crucial that the huge challenges posed by brain disorders are addressed through integrated, coordinated and co-operative efforts, both at the European and national level. These efforts should focus on implementing action-oriented strategies for prevention, early detection and diagnosis, and care, while health care and research, in order to meet the needs of patients, carers, doctors, researchers and industry. Above all, patients should be put at the centre of the entire process, in order to provide the right treatment to the right patient at the right time.

In this and the closing conference of the European Month of the Brain in May 2013, organized by the European Commission together with the Irish EU Presidency, delivered a call for EU Member States and associated countries to develop or refine national strategies on brain research and healthcare within an overarching European context, noting that successful examples of national strategies in other research areas, such as cancer, already exist in Europe!

**While great progress has been made thus far, advancing our understanding of the brain is more essential now than ever before.**

This will be achieved through the enhancement of and collaboration among all researchers and the Member States in transferring research findings into law for people's health, patient care and for society as a whole.

The study on the functioning of the European Union, available from a high level of human health protection, will be aimed at the definition and implementation of all European Union policies and activities (Art. 168).

In recognition of the principles and in light of the above, we call on the European institutions to put support for healthy brains at the top of the European agenda in a strategic manner.

**• We call upon the European Commission to come forward with a European strategy to tackle brain health in a collaborative, integrated and comprehensive manner, as well as to further support European Union Member States and associated countries in their efforts to combat the impact of brain disorders.**

**• We call upon European Union member states and associated countries to implement public health programmes addressing brain health in a systematic way, making the best possible use of available resources in order to stimulate more and better co-ordinated brain research, and to foster strategies for prevention, early detection, diagnosis and adequate treatment.**

Chair of Directors of the Brain in Europe, European Council of Neuroscientists, Vol. 35, pp. 158-174, 2011, 16-18.

\*For work associated with other disease areas see: Economic burden of chronic diseases: the European Union's population ageing and health (COST & Horizon, Cardiovascular Disease Statistics of the European Council of Diabetes Group, Eur J Neurol 2012; 15(10):1417-7.

# BREAKDOWN OF ACHIEVEMENTS

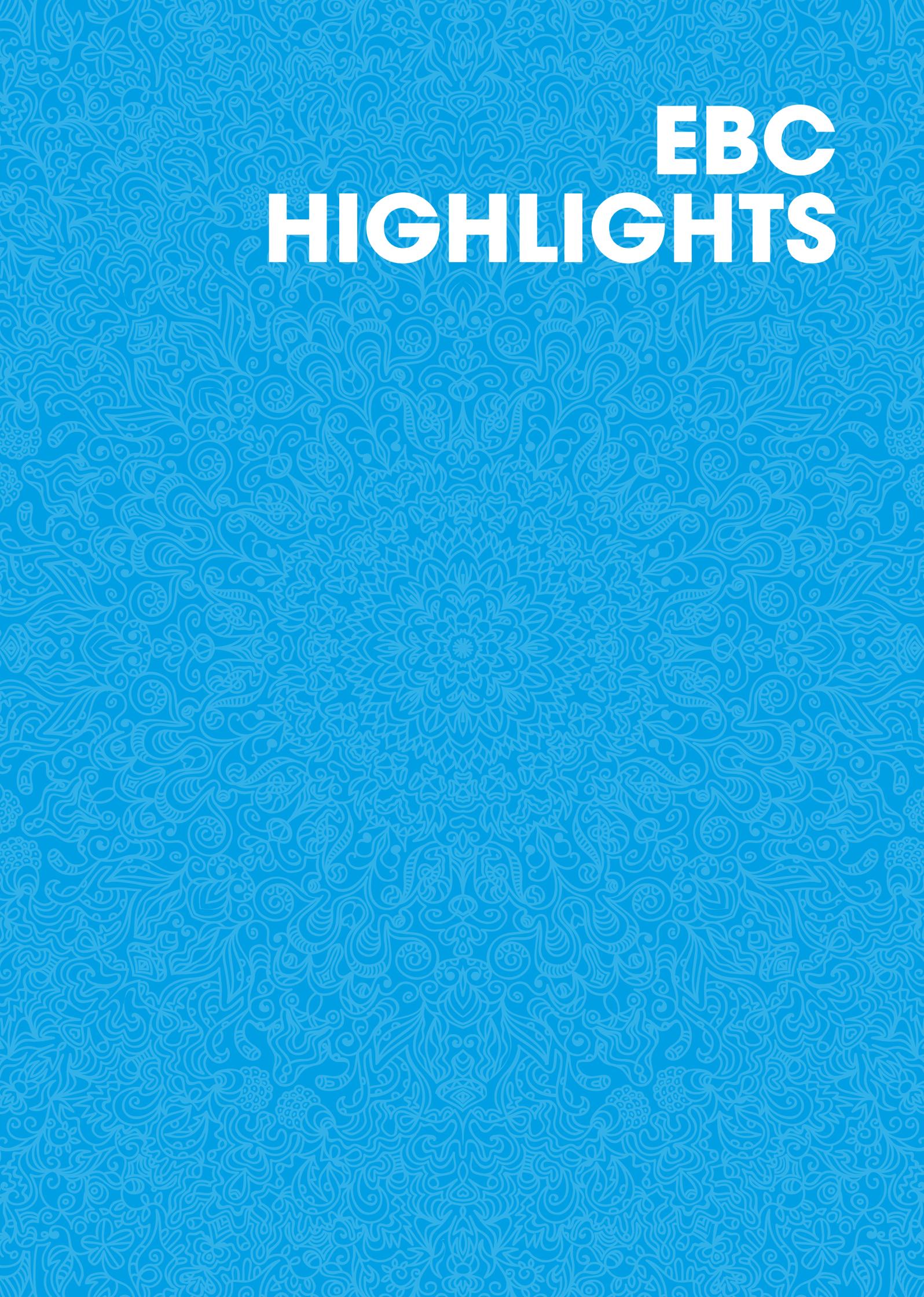
## Improving our communication

Communication was one of EBC's fastest-growing areas in 2015, and the outputs were significant.

We relaunched our website, making it more in tune with members' needs and stakeholders' requirements. We refreshed our visual identity, thus strengthening the EBC brand both off and online. And we continued to improve our outreach, attracting important coverage in Brussels-based media, as well as boosting our influence in social media.

Not least, we built towards ensuring a permanent Communications role within EBC's Brussels Office - a move to enhance internal and external stakeholder engagement.





# EBC HIGHLIGHTS

2015 was a very eventful year for EBC. In the next four pages you will find our Top 5 events, in accordance with our Strategic plan and constituency priorities. All our activities are highlighted on our website [www.braincouncil.eu](http://www.braincouncil.eu).

## Call to Action for brain plans

EBC's Call to Action for the establishment of a European plan, as well as separate national plans to address brain health was positively met by a mixed audience of policymakers, patient advocates and industry partners present at the related launch event organised on 17 November 2015, in Brussels, Belgium.

EBC also provided proof that such a venture can succeed by presenting the only existing national brain strategy in Europe: the **Polish Brain Plan** that is currently being developed.

**MEP Jerzy Buzek, an EBC Honorary Member**, stated that tackling brain disorders requires strategic thinking, model solutions and exchange of good practices:

*"I agree with the recommendation of EBC – each member state should develop a comprehensive strategy for brain diseases. It would also be very important to have a general European strategy."*

Comprehensive was also the term used by one of the main architects behind the Polish Brain Plan, **multiple sclerosis (MS) patient Izabela Czarnecka**.

She mentioned that 13 million people out of a total population of nearly 40 million living in Poland will be affected by a brain disorder at some point in their lives:

*"The Polish Brain Plan exists because we need a comprehensive strategy looking at every aspect of our lives – not only reimbursement, but also aspects such as social inclusion and raising social awareness."*



## The Value of Treatment

Further to a successful feasibility analysis for the study (Phase 1) run over 2015, EBC held a kick-off meeting for its project on the **Value of Treatment for Brain Disorders (VoT)** on 27 January 2016, at the University Foundation in Brussels, Belgium.

EBC's President **Prof. David Nutt** pointed out that EBC's VoT project proposed **"an in depth analysis on why we are not optimising treatment. This project will explore the effectiveness and efficiency of coordinated healthcare models."**

Prof. David Nutt also stressed that the indirect costs of brain disorders make up for 40 percent of the total costs – which EBC estimated at around 800 billion euros per year in Europe.

This is why – Prof. David Nutt argued – continuing to raise the funding for brain research is essential.

**Not succeeding in this goal could mean that people diagnosed in their 20s with a brain disorder will lose 10 years of their life,** warned Prof. David Nutt.

**The Value of Treatment project proposes a model of integrated care for brain disorders to close the treatment gap in Europe as well as the development of a workable care model and case studies analysis.**



VOT

THE **VALUE OF TREATMENT** FOR BRAIN DISORDERS  
A NEW VISION IN PROGRESS...

## YotB: How to reduce depression in the workplace

EBC concluded its **Year of the Brain** campaign with a multi-stakeholder conference on 9 December 2015 titled “**Lifting the Dark Clouds: What can Europe do to Reduce the Burden of Depression in the Workplace.**”

**Ms Mary Baker** EBC President 2011-2013 kicked off the Conference by drawing attention to the fact that “very shortly, the biggest worldwide disease will be depression.”

“We now know that one in ten people across Europe will have a bout of depression in their lifetime”, Mary Baker said.

At least 350 million people live with depression worldwide, said **Prof. Gabriel Ivbijaro**, President of World Federation of Mental Health.

“Stigma is a problem – at workplace, at home, everywhere. Half of those affected by depression are not treated. Women are more vulnerable”, added Prof. Ivbijaro.

**Prof. Norman Sartorius**, the former Director for Mental Health of the World Health Organisation (WHO) mentioned that one paradox of depression is ‘doing better but feeling worse’.

*“The presence of depressive disorders increases the probability of falling ill with other diseases.”*



### Year of the Brain (YotB)

**Duration:** May 2014 – December 2015

**Activities:** Around 70 events hosted around Europe

**Supporters:** Over 80 YotB ambassadors

**Main goals:** Improve education, research and access to treatment

# EBC HIGHLIGHTS

## Future of collaborative brain research conference

As part of its **Year of the Brain** campaign contributing to brain research advocacy, EBC organised a multi-stakeholder seminar “Criteria for success: The future of collaborative brain research”. The event took place on 3 March 2015, in Brussels, Belgium, with the support of EBC’s industry partner Biogen.

The lively presentations and ensuing discussion produced three ‘wish list’ items:

- Develop advanced IT solution for big data management;
- Strengthen the role of patients in decision-making;
- Bolster outreach to policy-makers – in order to improve access to treatment for brain disorders.

## European Population Neuroscience Strategy

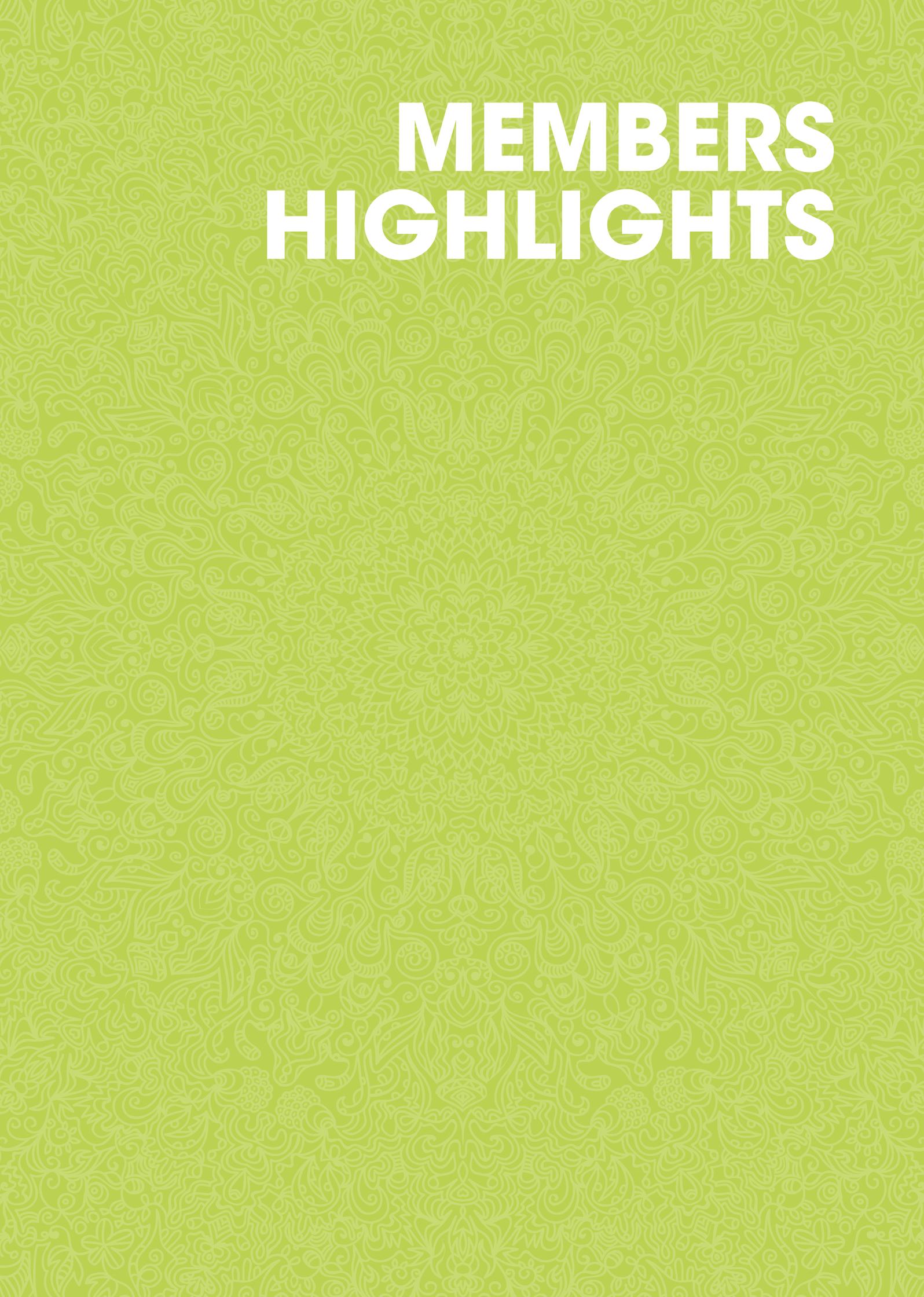
EBC and its partners are building momentum towards a European Population Neuroscience Strategy (EPNS) which would go a long way to understanding the predispositions to mental illness. The implications and possible implementation of such a strategy were debated in a workshop organised on 20 November 2015, in Brussels, Belgium.

**Prof. Thomas Werge** from the University of Copenhagen provided the rationale behind the EPNS initiative:

*"165 million Europeans will be affected by brain disorders during their lifetime. How can we change the course of an individual through life so that we can avoid such disorders? By developing population neuroscience. The time is right!"*



# MEMBERS HIGHLIGHTS



The work of our members is also an integral part of our work. In the next four pages you will find a Top 5 of member events. All members related activities are highlighted on our website [www.braincouncil.eu](http://www.braincouncil.eu)

## First EAN Congress

EBC took part between 20 and 23 June 2015 at **the first ever Congress of the newly established European Academy of Neurology (EAN)**.

The high level event took was organised in Berlin, Germany and was attended by over 6,000 stakeholders from across the world.

The EAN was created in 2014 following the merging of the Federation of Neurological Societies (EFNS) and the European Neurological Society (ENS).



### EAN

- Network: 47 European national neurological societies
- Membership: 800 individual members
- Goal: Supporting the development of neurological education and research in Europe

# MEMBERS HIGHLIGHTS

## EFNA Advocacy Awards

**The inaugural EFNA Advocacy Awards took place on 13 October 2015 in Brussels, Belgium.** The Awards provided an opportunity to recognise some of the excellent efforts made by particular individuals to improve the lives of many living with neurological disorders in Europe.



The first award of the evening - for Policymaker - went to former **MEP Gay Mitchell**.

He launched the first European Epilepsy Day in the European Parliament in 2011 and hosted the event until retirement from politics.



The second award - for Health Professional - was won by **Prof. Cristina Tassorelli**.

She served voluntarily as Medical Advisor for 9 years to the European Headache Alliance. Throughout all these years her clinical and research work has benefited countless people affected by headache disorders.



The third award - for Media - was allocated to **Jeroen de Schepper**.

He raised awareness of a very serious neurological disorder: Huntington's disease. His "crosscountry4huntington" initiative was profiled by national and international media. He travelled throughout the continent by bike, cycling over 12,000km in four months.



Finally, the fourth award, for Patient Advocate, went to **Shana Pezaro**.

Shana is 36 and has Intermittent Relapsing MS. She was diagnosed eight years ago but has had MS since childhood. She is involved in initiatives both with the UK MS Society and with the European MS Platform to support disabled people to maintain paid employment.

# MEMBERS HIGHLIGHTS

## Belgian Brain Ambassadors Day

In April 2015, the Belgian Brain Council marked its 10th anniversary with a conference supported by EBC.

There were four main messages delivered during the conference:

- Interdisciplinary collaboration between medical and non-medical fields is essential and needs to be fostered;
- Funding for brain research needs to be improved at both national and international level;
- Basic and clinical research need further investment;
- Brain research activities need better communications and enhanced support from civil society.

**The event generated a plea for political decision-makers to increase public resources for neuroscience research, initially by € 2 million per year.**

These funds would be used for the following deliverables:

- A "National Institute for Brain Research" - whose principal objective would be to fund and coordinate multi-regional research projects;
- A "Brain Research observatory" - which will create a database of current public and private projects in clinical and basic neuroscience in the country, including clinical trials;
- A "Foundation for Brain Research" - whose primary mission would be to raise private funds for research, possibly in cooperation with other charities.

# MEMBERS HIGHLIGHTS

## Launch of the Luxembourg Brain Council

The Luxembourg Brain Council was officially launched on the occasion of the EU Presidency's High-Level Conference on "Making access to personalized medicine a reality for patients", organised on 8 July 2015.

The aim of the Conference was to formulate a **patient-centered strategy** involving EU decision makers and regulators in the arena of public health in order to enable EU Member States to contribute to integrating personalised medicines into clinical practices while enabling much-greater access for patients.

The launch of the Luxembourg Brain Council echoed the National Brain Councils' Academy meeting that was organised in June by the EBC in Brussels.



▲ **Launch of the Luxembourg Brain Council - 8.07.2015**

## ▼ **1st NBC Academy Meeting - 17.06.2015**



# MEMBERS HIGHLIGHTS

## New centre for rare diseases opened in Germany

On 4 February 2015, EBC attended the launch of the new Centre for Rare Diseases within the "Dr. Horst Schmidt Kliniken" (HSK Clinic) in Wiesbaden, Germany.

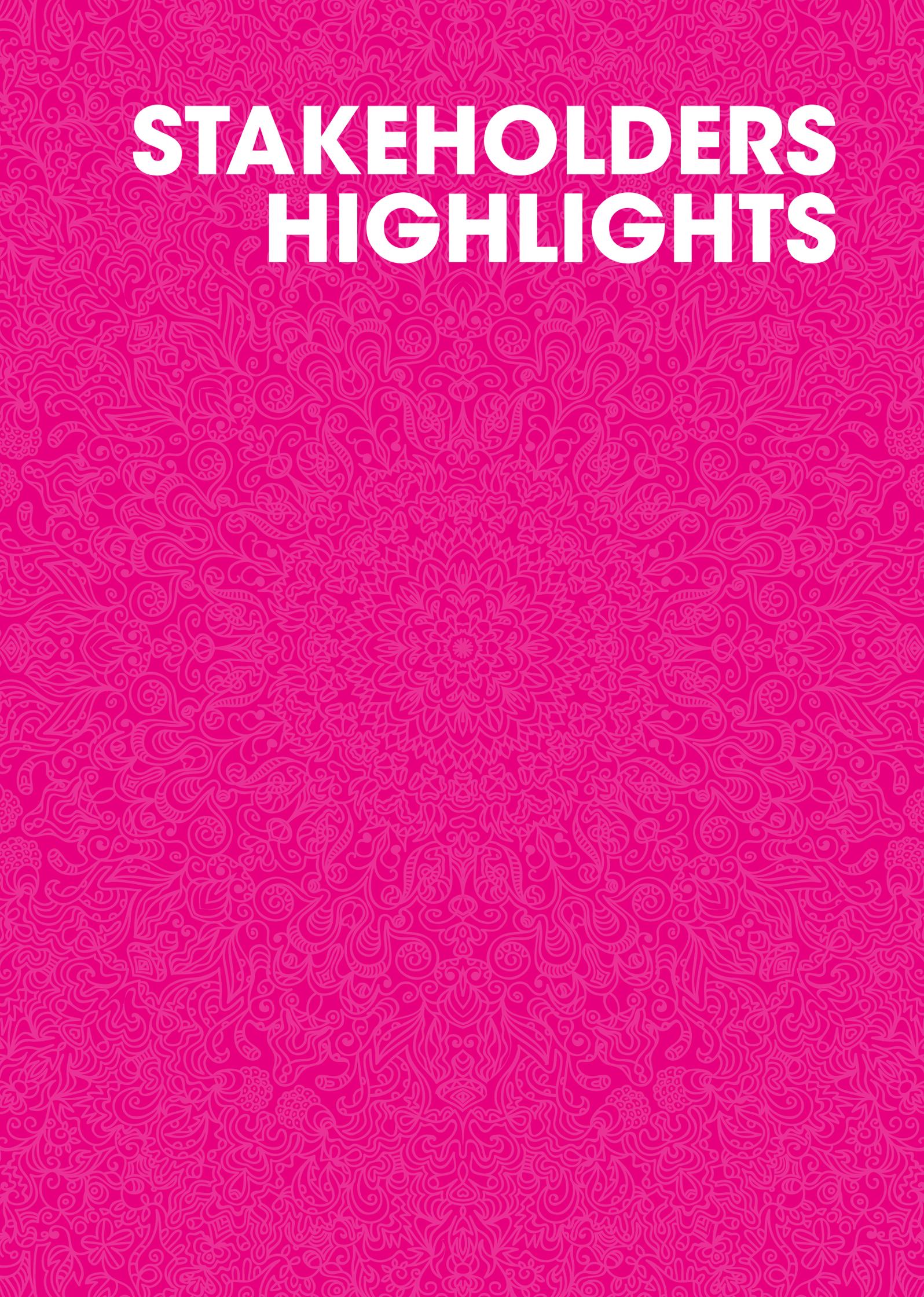
This set a landmark for the region and Germany as a whole in the fight against rare conditions.

The centre will be run by **Prof. Maurizio Scarpa**, President of EBC's Associate Member Brains for Brain.

In his introductory address, Prof. Markus Knuf, HSK Director Department of Paediatric and Adolescent Medicine, pointed to **the need to address rare diseases through an interdisciplinary approach**, which is at the core of the new centre's philosophy.



# STAKEHOLDERS HIGHLIGHTS



EBC's activities are run in a particular EU context amidst a number of initiatives from other stakeholders or institutions. Here is a focus of the Top 5 events of this kind. Further information can also be found on our website [www.braincouncil.eu](http://www.braincouncil.eu)

## New health-related MEP Interest Groups

2015 marked an eventful year for European Parliament Interest Groups. EBC supported three new launches, while continuing its work with established Interest Groups.

### Brain, Mind and Pain

EBC's member the European Federation of Neurological Associations (EFNA) together with the Pain Alliance have launched on 24 February 2015 the Interest Group on Brain, Mind and Pain. **Currently, 1 in 3 Europeans are affected by a brain disorder and 1 in 5 by chronic pain.** These figures are rising due to an ageing EU population.

### Mental Health, Wellbeing and Brain Disorders

EBC continued to provide input for the Mental Health, Wellbeing and Brain Disorders Interest Group, coordinated by our members from the Global alliance of Mental Illness advocacy Networks (GAMIAN). EBC notably reported on its involvement in the ROAMER project as well as on its advocacy for sustained innovation in mental health and neurological research.

### Access to Healthcare & Carers

MEPs launched on 27 January the Access to Healthcare Interest Group, focused **on ensuring more commitment from EU institutions for the patients' cause.** EBC also contributed to the meetings of this Interest Group as well as the one on Carers, coordinated by Eurocarers.

### European Patients' Rights and Cross-Border Healthcare

A group of MEPs have launched on 2 December 2015 an MEP Interest Group on "European Patients' Rights and Cross-Border Healthcare" following the request of around 100 civic and patient organisations to recognise the importance of citizens' initiatives in policy-making.

### What is an Interest Group?

Interest Groups are informal cross-party, cross-country groups, providing a forum for debate and initiating policy action. They bring together MEPs with a common interest in a specific issue/policy field to discuss European policy development and take initiatives that can lead to or influence policy initiatives.



# STAKEHOLDERS HIGHLIGHTS

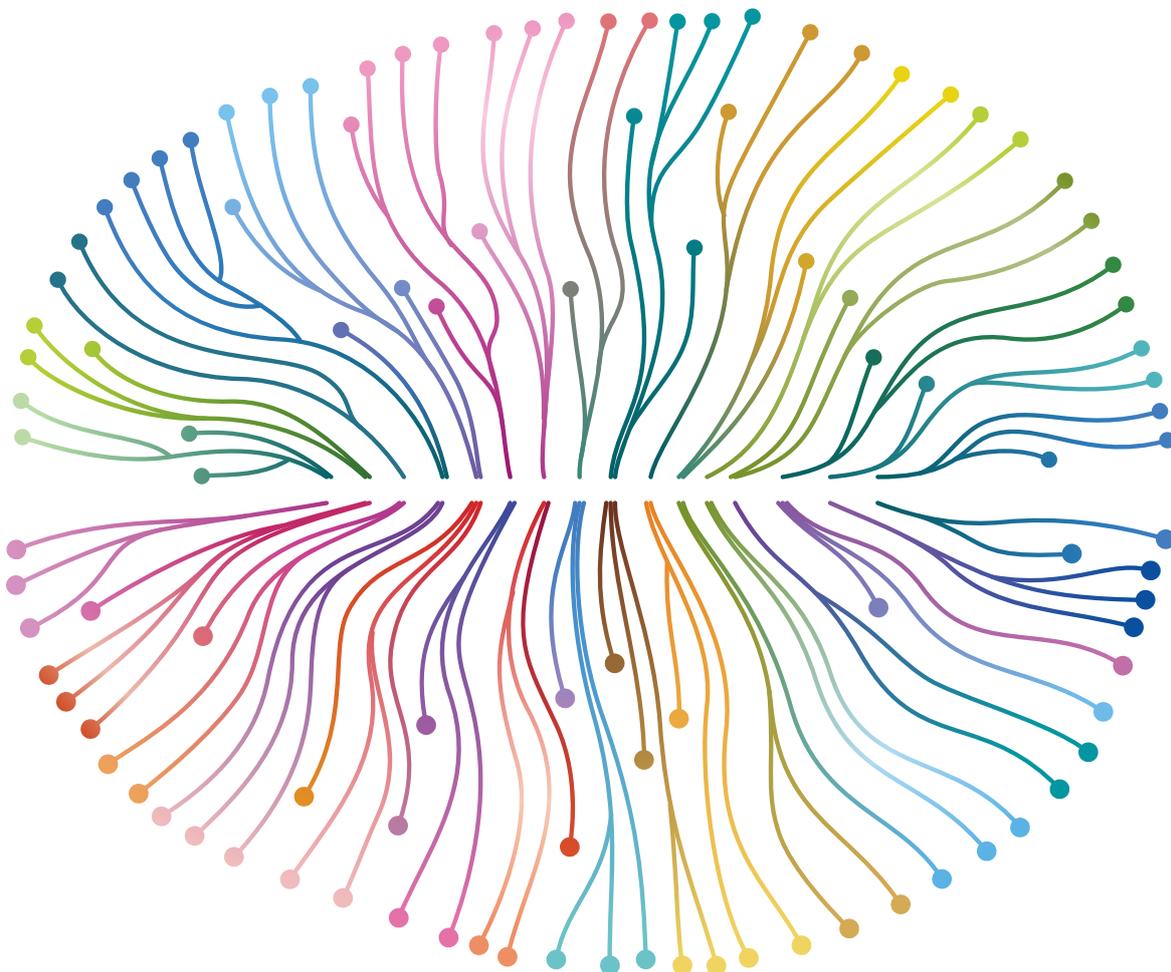
## Joint Action on Mental Health and Wellbeing

On 25 February 2015, EBC participated to the EU Joint Action on Mental Health and Wellbeing (JAMHW) meeting presenting policy recommendations on the following thematic areas: depression, suicide and e-health, community-based approaches in mental health, and mental health at work.

The main concerns raised on this occasion were **the lack of implementation of policies and the need to take into consideration the different levels of resources** - and thus the different needs - from one country to another.

**Jürgen Schefflein**, Policy Officer in charge of the Mental Health Unit at the European Commission, expressed the Commission's perspective on the JAMHW by stressing the critical importance of investing in mental health at EU and Member States level.

Mr Schefflein concluded the debate by pointing to the work done by the **ROAMER project**, in which EBC was involved. The goal of this project is to create a coordinated roadmap for the promotion and integration of research in mental health and wellbeing across Europe.



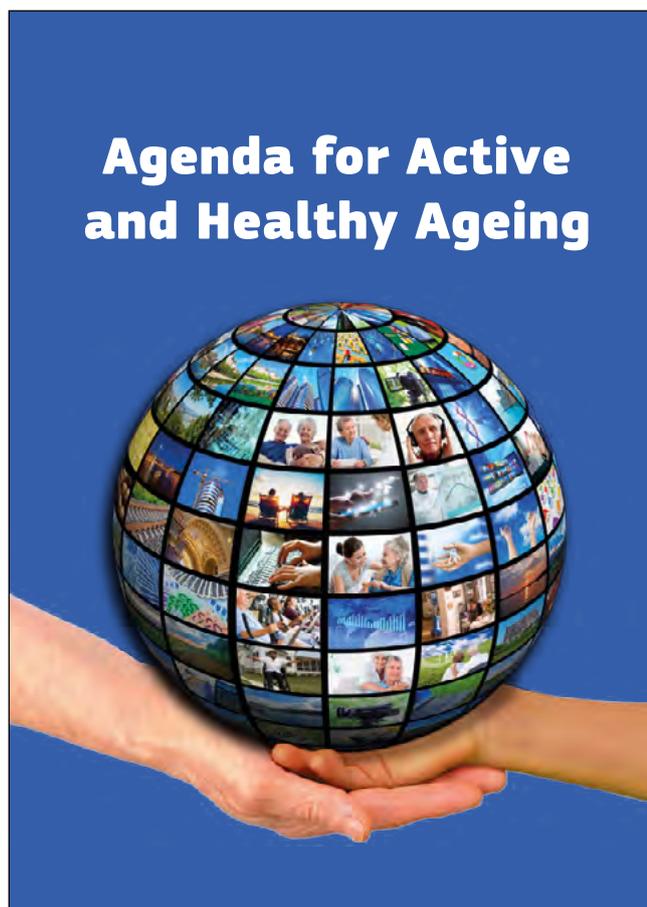
# STAKEHOLDERS HIGHLIGHTS

## EU Summit for Active and Healthy Ageing

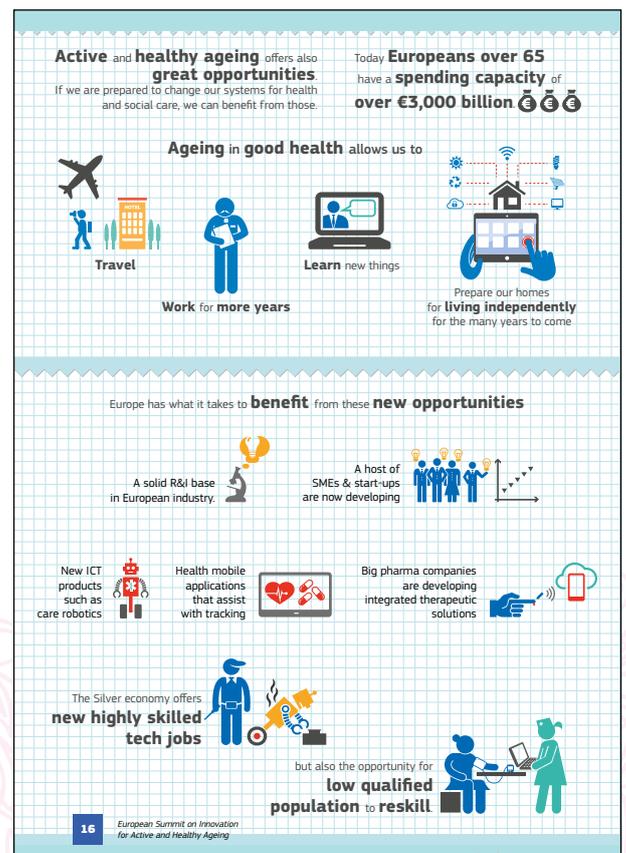
The **Summit on Innovation for Active and Healthy Ageing** took place in Brussels on 9-10 March 2015. The European Commission invited participants to discuss how Europe can address the challenges and seize the opportunities arising from demographic change through ICT and innovation.

European Commissioner for Digital Economy & Society, **Günther Oettinger** called for an intelligent pension reform in order to keep the balance between the pensioners and pension contributors. In this context, he mentioned pension at the age of 70 as a possibility.

There was a consensus among participants that **ageing should be seen as an opportunity** linked with growth and economy.



### Agenda for Active and Healthy Ageing



# STAKEHOLDERS HIGHLIGHTS

## WHO Conference on dementia

Dementia is a growing issue for global public health, and one of the major health challenges for our generation. 47 million people currently live with dementia and, as the population is ageing, this figure is expected to triple by 2050.

In the light of this data, the World Health Organisation (WHO) hosted on 16-17 March 2015 its first Ministerial Conference on Global Action Against Dementia in Geneva.

One of the main conclusions of the event: there is a growing need for collaboration between all stakeholders to improve the general quality of care and address the impact of dementia.

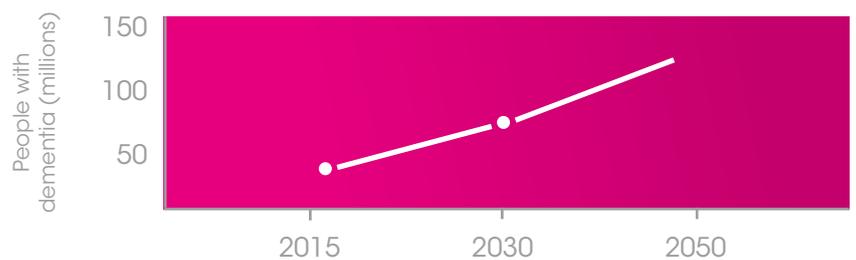
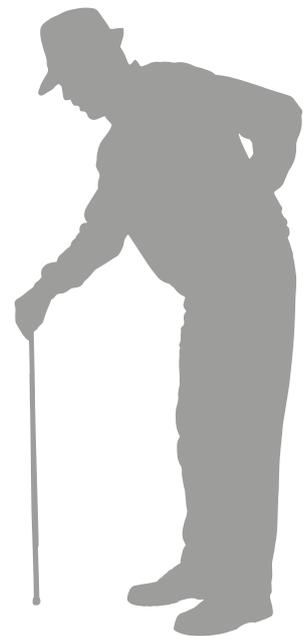
### Who is affected?

Over 47 million people worldwide

Nearly 60% live in low- and middle- income countries

Close to 8 million new cases every year

Cases set to almost triple by 2050



### What does it cost?

**US\$ 604 billion:** estimated costs to society in 2010

### What is the cause?

Conditions that affect the brain, such as Alzheimer's disease, stroke or head injury



# STAKEHOLDERS HIGHLIGHTS

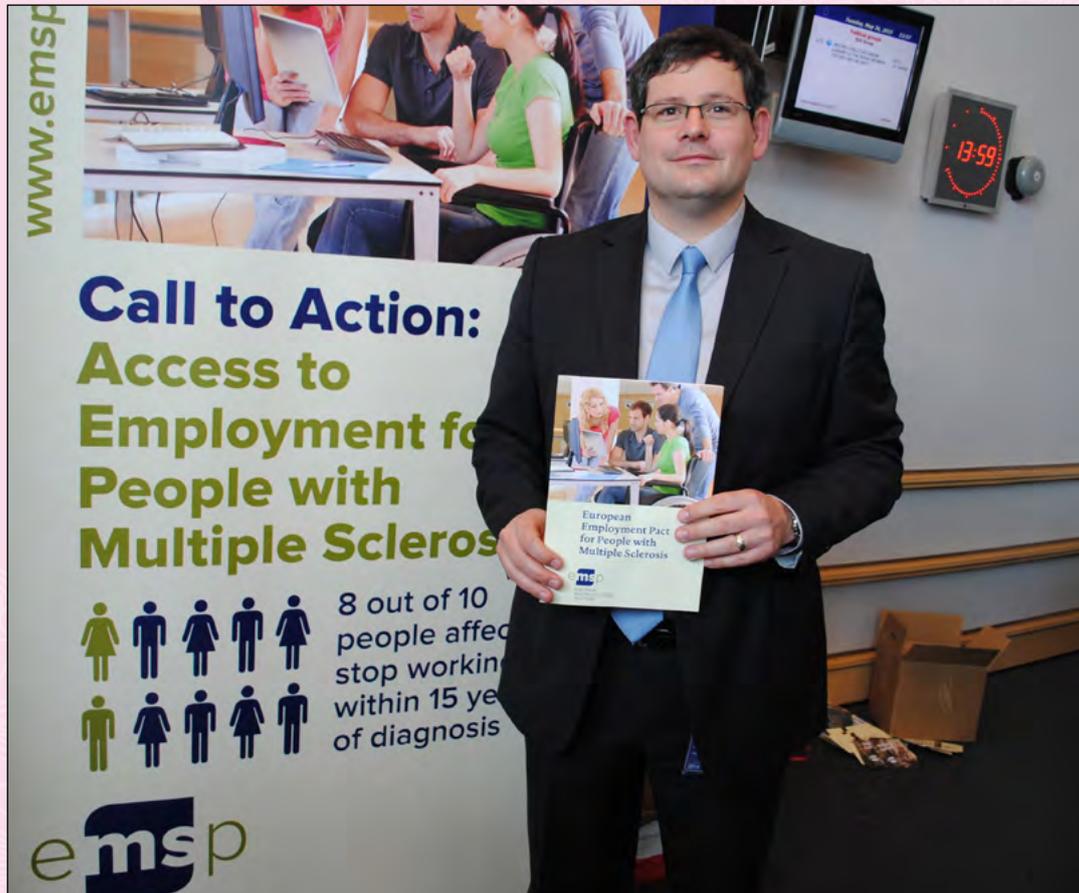
## EMSP Launch of Employment Pact

EBC's partners from the European Multiple Sclerosis Platform (EMSP) launched on 26 May 2015 a Call to Action around their European Employment Pact for people with multiple sclerosis and other neurodegenerative diseases.

The launch was supported by MEPs Adam Kosa (pictured), Rosa Estaras-Ferragut and Jeroen Lenaers.

EMSP is asking fellow patient organisations, national and European decision-makers and European employers to support the Pact.

By doing so, the supporters sign for **improvements in employment policy, recruitment, equal opportunities, training and awareness in the workplace, reasonable accommodations**: flexible hours, rest areas, accessibility, return to work policy.



# PROJECTS REPORT

The background of the entire page is a complex, repeating pattern of light-colored (pale yellow or cream) lines and shapes. The pattern consists of various floral motifs, including stylized flowers, leaves, and clusters of small circles, interspersed with geometric and swirling lines. The overall effect is a rich, textured, and ornate background that complements the golden-yellow color of the page.

This section is a round-up of progress achieved throughout 2015 with projects where EBC is either coordinator, or partner, or active collaborator. More project-related data is available on our website [www.braincouncil.eu](http://www.braincouncil.eu)

## Reports

### Value of Treatment



- This project is coordinated by EBC to address the treatment gap in Europe and develop a workable care model for brain disorders, alongside analysis of related case studies.
- EBC planned for the project throughout 2015 and went on to produce a project brochure and a discussion paper document, which were presented during the kick-off meeting organised on 27 January 2016.

### Advance HTA



- A research project funded by the European Commission's Research Framework Programme (FP7).
- EBC played a central role in delivering in April the Work Package designed to create new data on health related quality of life (HRQoL).
- The project final conference and final consortium meeting took place in London in November 2015.

### Aetionomy



- A consortium project under the Innovative Medicines Initiative (IMI) framework tackling the challenge of classifying neuro-degenerative diseases.
- EBC participated in the 2nd General Assembly and Advisory Board meeting on 3-4 November 2015, in Barcelona, Spain.

# PROJECTS REPORT

## Reports



### MARATONE

- A Marie Curie Initial Training Network project that directly addresses the need for high level training and career pathways in mental health.
- EBC facilitated a patient survey.
- EBC participated in the annual project meeting in Munich on 19-20 March 2015



### NERRI

- It works to establish productive dialogue between potential users, potential “designers” (researchers, engineers, developers) and potential legislators of neuro-enhancement technologies, before products access the market.
- EBC conducted several mutual learning events between Board representatives, member societies, patient organisations and national brain councils.
- EBC participated to the annual project meeting in Vienna on 30 November - 01 December 2015.

### Ox-Paq



- This project aims to develop a short patient-reported outcome measure designed specifically to assess participation, activities and level of independence. The intention is to develop a short measure which will assess
  - a) the ability of individuals to engage in various activities and
  - b) the level of dependency an individual has on others.
- EBC continued to provide its expertise to the project including attending a number of project meetings.

# POLICY REPORT

## Reports

While it is difficult to ascribe an exact value to our informing and lobbying activities with European Union leaders and decision-makers - because political influence is, at best, a subjectively nebulous concept - there are nevertheless statistics that hint strongly at the scale of the organisation's contribution. One of EBC's most significant achievements, which became even more pronounced in 2015, has been the role played in the increase of EU brain-related research funding.

During the European Union's Fifth Framework Programme (FP5) from 1998-2002 - before the EBC was established - 85 million euros were spent on research into brain. That has since risen to 260 million during FP6, and **in 2015 we learnt that the FP7 spent on brain reached 3 billion euro.**

We are grateful to the European Commission for this much needed increase and recognise that EBC has clearly had a massive role to play in this upward trend and will continue to do so.

Invitations for EBC to participate in European Commission or other stakeholder-led activities have become more current, demonstrating our increasing influence at EU level.

At the same time, EBC has been very proactive in reaching out to key stakeholders. EBC approached new EU Commissioners - relevant for our area of activity - with significant results. We were able to meet with Research Commissioner Carlos Moedas and Health Commissioner Vytenis Andriukaitis.

### ▼ Meeting with EU Research Commissioner Carlos Moedas - 18.06.2015



## Reports

We have also met with a number of Members of the European Parliament, including Chairman of ITRE Committee Jerzy Buzek and Chairman of AGRI Committee Czesław Siekierski. The latter meeting was related to an EU-wide campaign promoting scientifically and ethically justified use of animals in biomedical research, which EBC is a vital part of.

In conjunction with the calendar of EU Presidencies, we have met with Permanent Representations of the Netherlands, Slovakia and Malta to discuss their health and research priorities as well as to look into ways of collaborating in this framework. Particularly promising is the cooperation with Malta in view of holding a launch event of the Value of Treatment study that EBC started developing in 2015.

Last but not least, in November 2015 the EBC launched a Call to Action to foster a dialogue on developing National Brain Plans, which would be brought under the umbrella of EU-wide strategy addressing brain health in a comprehensive and collaborative way. We are building a solid base of support among European organizations to carry this activity forward towards developing related strategies both at the national and EU level.

*By Tadeusz Hawrot,  
EBC Public Affairs Manager*

▼ **Meeting with Jerzy Buzek, Chair of EP ITRE committee - 17.11.2014**



# MEDIA REPORT

## Reports

2015 was a year of exponential growth for EBC in terms of media and social media outreach: our messages attracted high profile coverage in recognised policy publications, our social media accounts gained increased traction and our own publications were disseminated widely.

This Thought Leader is sponsored by the European Brain Council (EBC)

A healthy brain is Europe's platform for national wealth, argues **David Nutt**

The Parliament Magazine's  
**THOUGHT LEADER**



**W**e do not have to search the far reaches of space or the depths of the Earth to find the whereabouts of the most complex structure in the universe. It is the human brain and it lies inside every one of us. It controls our bodies and is the home of our personalities, thoughts and feelings. The brain is a true wonder that needs to be nurtured, protected and cared for.

**“Healthy brains need to be put right at the heart of Europe and its 2020 Strategy”**

The human brain is also the origin of many chronic, disabling disorders, including developmental, psychiatric, neurodegenerative and pain-related diseases that represent an enormous burden in terms of both human suffering and economic cost. Brain disorders affect at least one in three people during their lifetime.

I have the privilege of being the President of the European Brain Council- a non-profit organisation that brings together scientists, clinicians, patients and industry from the field of the brain. We have published a report demonstrating that brain disorders cost Europe €800bn in 2010. That's more than cardiovascular disease, cancer and diabetes combined. The World Health Organisation echoes our concerns and has concluded that brain disorders account for 35 per cent of the burden of all diseases in Europe and will become the major medical need of this century.

We consider that improved cooperation and coordination are absolutely critical to address in an efficient manner both the challenges and opportunities posed by our brains. With this in mind, we recently launched a call to foster a dialogue on developing national brain plans, which would be brought under the umbrella of an EU-wide plan addressing brain health in a comprehensive and collaborative way. Successful examples of strategies in other disease areas already exist in Europe. These efforts will focus on implementing evidence based strategies for research, prevention, early detection and diagnosis, and adequate treatment. The aim is to meet the needs of patients, carers, doctors, researchers and industry.

Timely and cost effective interventions lie at the heart of our thinking. Against this backdrop, we are now developing a study looking at the value of treatment. Its objective is to assess the socio-economic impact of medical interventions, or the lack of thereof, and to provide evidence and tools that can assist policy-makers and all health actors in shaping effective policy responses to some of the most prevalent brain disorders.

**“We have published a report demonstrating that brain disorders cost Europe €800bn in 2010. That's more than cardiovascular disease, cancer and diabetes combined.”**

As professor of clinical neurology and Year of the Brain in Europe ambassador Martin Rossor, says, “It is only with a healthy brain that we will solve so many of the challenges that face modern societies. Brain Health equals National Wealth.” Healthy brains need to be put right at the heart of Europe and its 2020 Strategy if indeed we are to increase Europe's economic competitiveness.

**Professor David Nutt** is president of the European Brain Council (EBC)

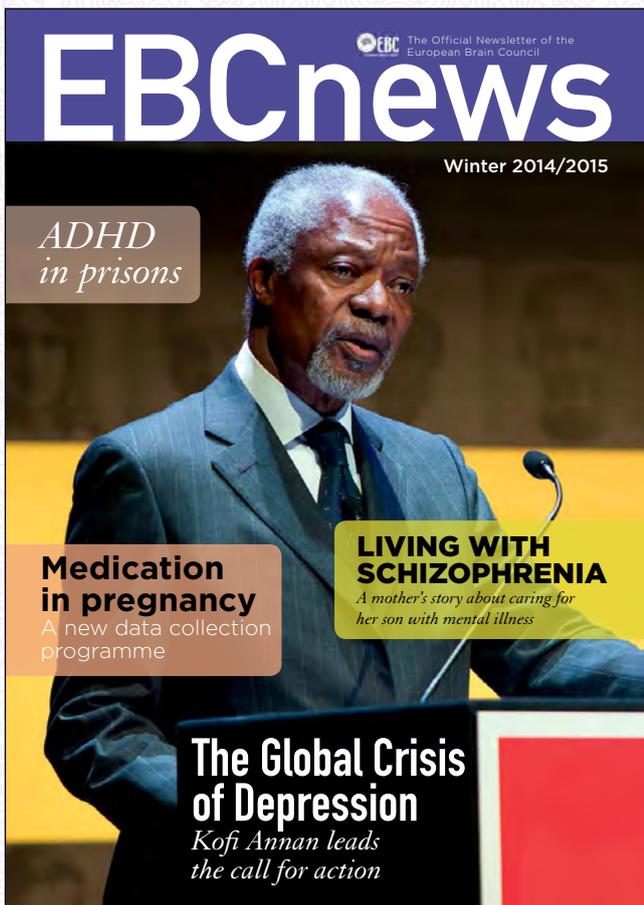
- EBC's President **David Nutt** signed an article in The Parliament Magazine (TPM) advocating for brain health to be at the heart of the Europe 2020 Strategy;
- This view was supported in a 'twin' TPM article by **MEP Philippe de Backer**, who stressed that 'it is time that EU come forward with a strategy to tackle brain health';
- The Parliament Magazine reaches thousands of EU stakeholders monthly, and boasts over **20,000 followers on social media**.

# MEDIA REPORT

## Reports



- EBC has reached **500 Twitter followers** at the end of 2015, and the number is growing;
- Among them: High profile EU decision makers such as Health Commissioner Vytenis Andriukaitis.

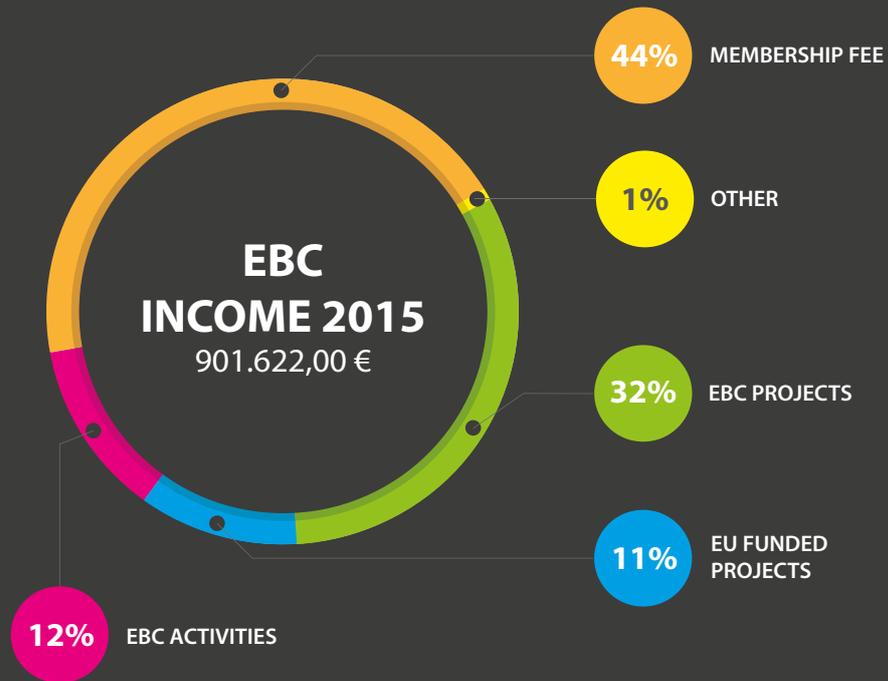


- EBC News was printed in 1,500 copies;
- The magazine was disseminated to Members of the European Parliament, Commission officials as well as other stakeholders at key events throughout 2015.

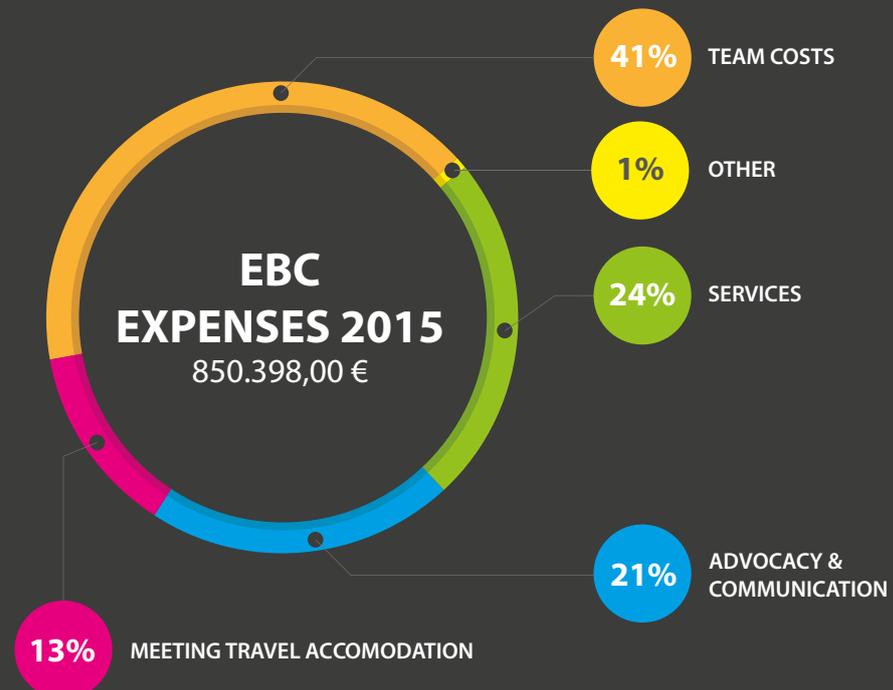
# FINANCIAL DATA

## Reports

### INCOME 2015



### EXPENSES 2015



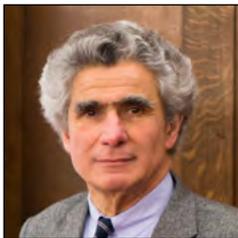
# **EBC EXECUTIVE & BRUSSELS OFFICE**

The progress achieved in 2015 was made possible by the great efforts from EBC's Executive as well as the team of our Brussels Office.

## EBC Executive



**Prof. David Nutt**  
President



**Prof. Patrice Boyer**  
Vice-President



**Prof. Monica Di Luca**  
Vice-President

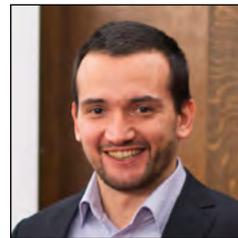


**Prof. Wolfgang Oertel**  
Treasurer

## EBC Brussels Office



**Frederic Destrebecq**  
Executive Director



**Giovanni Esposito**  
Research Project Manager



**Tadeusz Hawrot**  
Senior Public Affairs  
Manager



**Cécile Grebet**  
Finance & Administration  
Manager



**Vinciane Quidbach**  
Project Coordinator

# Obituary



## **Pedro Montellano, EBC Vice-President (2013-2015)**

It is with great sorrow that we have marked the passing of our dear colleague and friend Pedro Montellano, on 2 October 2015.

Pedro was the Vice-President of the European Brain Council and President of GAMIAN Europe, the Global Alliance of Mental Illness Advocacy Networks.

Pedro was not only a colleague, he was for all of us a person full of dedication to the cause that he defended, and to many a true friend.

We shall sorely miss his wisdom, knowledge and warm enthusiasm. Our thoughts go to his family: his wife Filomena, his children and relatives.

# ACKNOWLEDGEMENTS

The success and impact of EBC's work is built on the effective partnerships, cooperative working and close collaborations with a very wide range of stakeholders whose contributions are gratefully acknowledged.

In particular, we would like to recognise and note our appreciation for the support we have received from the following groups: EBC member organisations and national brain councils, EBC Year of the Brain ambassadors, our extremely knowledgeable academia partners and the very dynamic patient advocates.

EBC has continued to benefit from the unconditional backing from corporate supporters who between them have provided part-funding for key EBC projects.

The EBC Board has yet again shown great flexibility and an impressive capacity for decision-making, both features necessary in implementing our vision for the European Brain Council.

Our partners from the European institutions played a central role in furthering our activities and projects, and we would like to both show our gratitude for their support and our openness to continue to work together for the benefit of people living with brain disorders in Europe.

And, last but not least, the extraordinary EBC team, a dedicated, hard-working and committed group whose contribution to meeting all the key milestones for the year is gratefully acknowledged.

In particular, we would like to acknowledge the support of all those who have contributed to these efforts as part of our Team: Charlotte Wiingaard Behrenthz, Lola Coly-Layani, Christelle Ubertalli, Monika Kalkusova as well as Philippe Heymans and Claudiu Berbece.

We also want to add a special word to express our gratitude to Eveline Sipido who has worked with dedication for EBC until June 2015. We would like to express hereby how thankful EBC is to her for having supported the organisation over so many years.

The background is a solid purple color with a dense, intricate white pattern of floral and geometric motifs. The pattern is symmetrical and repeats across the entire page, creating a rich, textured effect.

# **EBC MEMBERS & INDUSTRY PARTNERS**

The membership of EBC consists of patient groups, scientific and professional organisations as well as industry partners. As per its statutes, EBC accepts as Full Members pan-European umbrella organisations with an interest in the brain. Moreover, any organisation that supports the aims of the EBC can apply to become associate or 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.

## Members

### ..... Full Members .....



The **European Federation of Neurological Associations** (EFNA) brings together European umbrella organisations of neurological patient advocacy groups, to work with other associations in the field of neurology, including the European Academy of Neurology (EAN), in what has been termed a "Partnership for Progress".



The **Global Alliance of Mental Illness Advocacy Networks-Europe** (GAMIAN-Europe), a patient-driven pan-European organization, represents the interests of persons affected by mental illness and advocates for their rights. Its main objectives are: advocacy, information and education, anti-stigma and discrimination, patients' rights, co-operation, partnerships and capacity building.



The **European Academy of Neurology** (EAN) is the organisation that unites and supports neurologists across 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.



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.



The **European College of Neuropsychopharmacology** (ECNP) is an organization committed to ensuring that advances in the understanding of brain function and human behaviour are translated into better treatments and enhanced public health.



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. EPA deals with psychiatry and its related disciplines and it focuses on the improvement of care for the mentally ill as well as on the development of professional excellence.

# PROJECTS REPORT

## Members



The **Federation of European Neuroscience Societies** (FENS) is the voice of European neuroscience. With 42 neuroscience member societies across 32 European countries, FENS as an organisation represents close to 23,000 European neuroscientists with a mission to advance European neuroscience education and research.



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 PanEuropean 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.

## ..... Associate Members .....



The **Brains for Brain** (B4B) aims to develop new and innovative therapeutic strategies to cross the Blood-Brain Barrier, a capillary system which shields and defends the CNS from circulating neurotoxin compounds. B4B mission consists of the promotion of an International Network of health professionals in rare disorders, specifically in the field of rare neurological paediatric diseases.



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 **Federation of the European Societies of Neuropsychology** (ESN) aims to further scientific and professional issues within the field of neuropsychology by developing European programmes of clinical and experimental neuropsychological research as well as pre- and postgraduate teaching and to put forward any instances related to Neuropsychology. Such objectives are pursued by holding periodical scientific meetings and such other activities as may be deemed appropriate.

# PROJECTS REPORT

## Members



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 **International League Against Epilepsy** (ILAE) is the world's preeminent association of physicians and other health professionals working towards a world where no persons' life is limited by epilepsy. ILAE's mission is to ensure that health professionals, patients and their care providers, governments, and the public world-wide have the educational and research resources that are essential in understanding, diagnosing and treating persons with epilepsy.

## Industry Partners

abbvie



BIOMARIN

Boston  
Scientific



# CREDITS

This report was compiled by  
EBC's Communications Coordinator **Claudiu Berbece**  
with the support and collaboration of  
EBC's Brussels Office.

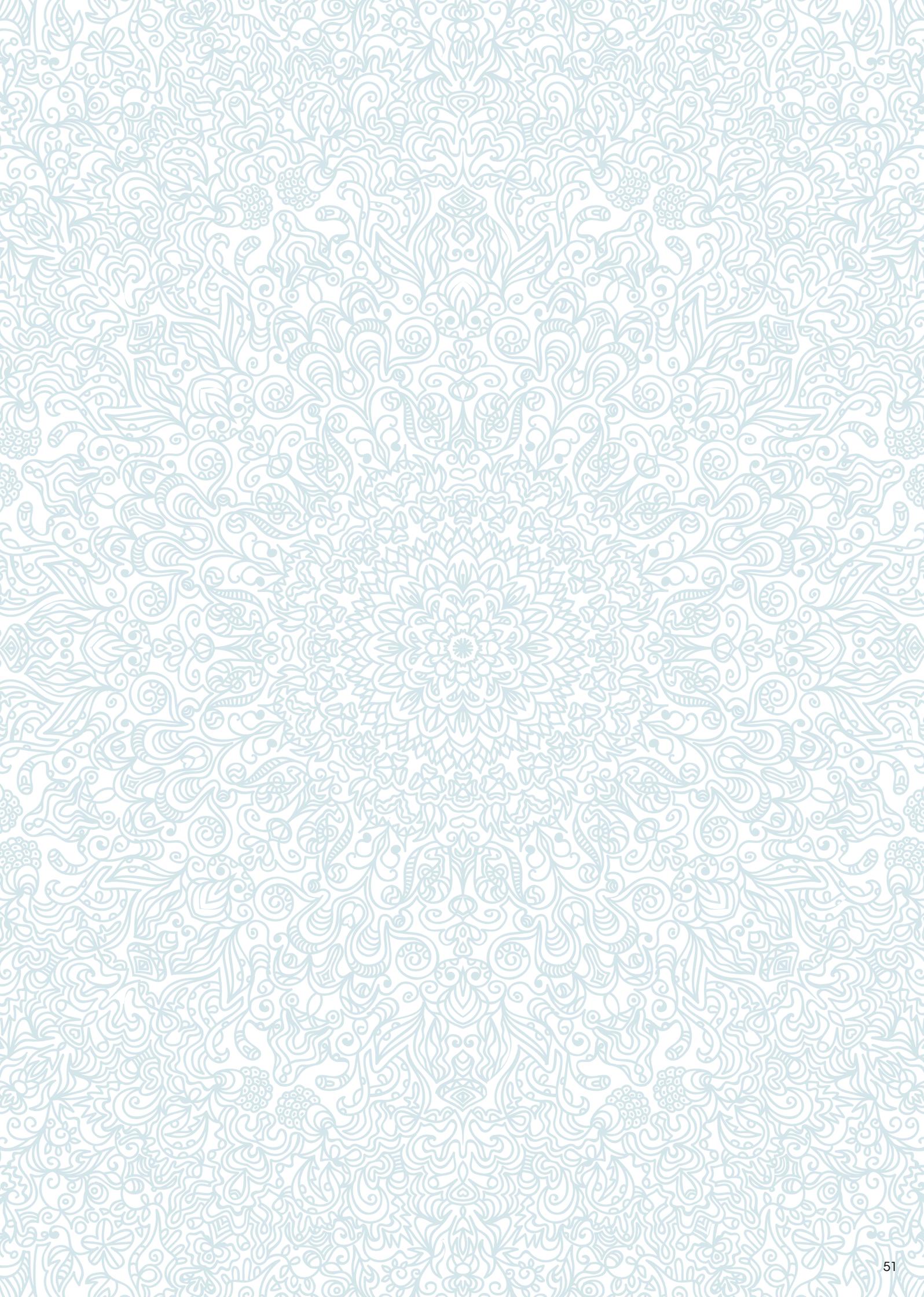


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This report has been designed in line  
with best practice guidelines of visual accessibility.

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

Please email your comments to  
**[info@braincouncil.eu](mailto:info@braincouncil.eu)**





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