International Epilepsy Day event in the European Parliament reports on the unmet needs in the field of epilepsy and the status of epilepsy research priorities at a global level. The event was organised by Epilepsy Alliance Europe joint task force of IBE and ILAE in Europe - and hosted by the European Advocates for Epilepsy MEP group in the parliament.
Two years ago, in February 2017, Epilepsy Alliance Europe organised a very significant meeting in the European Parliament in Brussels to highlight the need for a global effort if appropriate advances were to be made in addressing the unmet needs of epilepsy, both in Europe and around the world.

The meeting heard that, although very little progress had been made in improving medical outcomes of people with epilepsy during the last decades, a large amount of data derived from extensive pre-clinical research has become available which provided a strong rationale for the conduction of potentially ground-breaking academically-driven clinical studies tackling several priority issues that were acknowledged by the epilepsy community:

- prevention of epilepsy;
- prevention of sudden unexpected death in epilepsy (SUDEP);
- optimization of epilepsy surgery;
- worldwide development of mobile health programs to disseminate essential knowledge about epilepsy;
- assembling of a very large well characterized cohort of persons with epilepsy that could be participate in all the above projects and in the development of personalized therapies for seizures, syndromes and related comorbidities.

All of these objectives would require recruitment and financial capacities that could only be achieved at the global level, and justify the building of a global alliance program for epilepsy research.

The closed invitation-only event was hosted by Brian Hayes, President of the 67-member-strong group of Members of the European Parliament (MEPs) who form the European Advocates for Epilepsy group in the parliament, a number of whom attended the event. Also present were some of the most senior representatives of a number of agencies and associations from Europe and North America. These included the Head of Sector for Neurosciences at DG Research, the Head of the ERN program at DG Santé, the NIH Program Director of Epilepsy, the Scientific Director of the Institute of Neurosciences of the Canadian Institute for Health Research, the Presidents of IBE and ILAE, the President of the American Epilepsy Society, the President and CEO of Epilepsy Foundation of America, the Chair of the Epilepsy Panel of the European Academy of Neurology, the President of the European Federation of Neurological Associations, and a number of other stakeholders, including the pharma industry.

“I wish my daughter simply to be happy”

This very successful meeting led to a follow up event in January 2018, when a Breakfast Briefing was organised and, again, hosted by Brian Hayes MEP. The 2018 event was attended by several MEPs, including Mrs Lieve Wierinck (Belgium), Seán Kelly (Ireland), Alojz Peterle (Slovenia), Roberta Metsola (Malta), José Inácio Faria (Portugal), and Franc Bogović (Slovenia). Also present were Stéphane Hogan, Head of Sector for Neurosciences, DG Research & Innovation, European Commission; Anna Graca, DG Research & Innovation with responsibility for epilepsy; and Fredrick Destrebecq, Executive Director, European Brain Council. There to tell the epilepsy story on behalf of Epilepsy Alliance Europe were Helen Cross, Martin Brodie, Lieven Lagae, Philippe Ryvlin, Eugen Trinka, Kristl Vonck, Janet Mifsud, Caroline Morton and Francesca Sofia.

Two other significant events took place in 2018. The first of these was the epiXchange workshop, with seven large EU-funded projects joining forces to organise the one-day event on 23 May, in Brussels. The event was designed to gather a critical mass of epilepsy researchers in order to showcase the latest progress in research aimed to improve the way epilepsy is diagnosed and treated. The projects had been funded mainly through the 7th Framework Programme (FP7).

Participants heard how, despite intensive and ongoing research, epilepsy research still faces several unmet needs, with major gaps in understanding the disease with large economic and societal costs. The event provided the opportunity to synergise the results of the seven diverse projects and to identify the several bottle necks which still remain.

Delegates included basic and clinical epilepsy researchers, big and small pharma, and patient organisations. Other participants included Dr Karim Berkouk, Dr Stefan Hogan and Ms Anna Graca from the European Commission’s Directorate-General Research & Innovation and representatives of the European Brain Council.

The meeting showed how a bottom up approach is needed to coordinate research and policies with more collaborative research, including public partnerships, public private partnerships, and global co-operation.

On the following day, the EU Research Commission held a workshop titled ‘Shaping the Future of Epilepsy Research’ with a
Members of the European Advocates for Epilepsy Group

President: Brian Hayes (Ireland)
Vice President: Nathalie Griesbeck (France)

Members
Heinz Becker (Austria), Bendt Bendtsen (Denmark), Franc Bogovic ( Slovenia), Michal Boni (Poland), David Borelli (Italy), Paul Brannen (UK), Christian-Silviu Bușoi (Romania), Matt Carthy (Ireland), David Casa (Malta), Nessa Childers (Ireland), Lefteris Christoforou (Cyprus), Kostas Chrysogonos (Greece), Deirdre Clune (Ireland), Miriam Dalli (Malta), Tanja Fajon (Slovenia), José Inácio Faria (Portugal), Eleonora Forenza (Italy), Lampros Fountoulis (Greece), Jens Gieseke (Germany), Theresa Griffin (UK), Jytte Guteland (Sweden), Andras Gýürk (Hungary), Marian Harkin (Ireland), Anna Hedh (Sweden), Lisha Jaakonsaari (Finland), Anneli Jätteenmäki (Finland), Barbara Kappel (Austria), Karin Kadenbach (Austria), Seán Kelly (Ireland), Katerina Konečná, (Czech Republic), Miapetra Kumpula-Natri (Finland), Merja Kyllönen (Finland), Giovanni La Via (Italy), Jean Lambert (UK), Marian-Jean Marinescu (Romania), Costas Mavrides (Cyprus), Mairead McGuinness (Ireland), Roberta Metsola (Malta), Tilly Metz (Luxembourg), Ulrike Müller (Germany), James Nicholson (UK), Demetris Papadakis (Cyprus), Dimitrios Papadimoulis (Greece), Emilian Pavel (Romania), Alojz Peterle (Slovenia), Sirpa Pietikäinen (Finland), Pavel Poc (Czech Republic), Dominique Riquet (France), Paul Rübig (Austria), Sofia Sakarova (Greece), Christel Schaldemose (Denmark), Annie Schreijer-Pierik (Netherlands), Olga Sehnalová (Czech Republic), Igor Šoltes (Slovenia), Maria Spyraki (Greece), Neoklis Syliliotis (Cyprus), Eleftherios Synadinos (Greece), Claudiu-Ciprian Tănăsescu (Romania), Patrizia Toia (Italy), Nils Torvalds (Finland), Ivo Vágli (Slovenia), Julie Ward (UK), Theodoros Zagorakis (Greece), Tomáš Zdechovský, (Czech Republic), Jana Žitňanská (Slovakia),

The community of speakers was joined by a global panel of speakers from Europe, Asia, Africa, and North and South America, at which it was reported that the upcoming Horizon Europe framework for research would be calling for bold inspirational approaches with wide societal relevance, including open science, global challenges and open innovation pillars. Also looking to develop a global perspective, a call under the H2020 project titled ‘Coordinating European brain research and developing global initiatives’ was underway with the European Brain Council’s European Brain Research Area (EBRA) proposal being selected to coordinate the project.

So, it was with this, not-insignificant, background of activities, raising the call for the global perspectives that are now required in research, that a lunch meeting took place in the parliament in Strasbourg on Tuesday 12 February 2019, the day after International Epilepsy Day.

Invitations to the meeting were extended to the 67 MEPs who form the membership of the European Advocates for Epilepsy group and the event was hosted, once again, by Brian Hayes MEP. At the lunch, 12 MEPs, from Czech Republic, France, Germany, Ireland, Finland, Luxembourg, Romania and Slovenia, voiced their support for the 6 million people living with epilepsy in Europe. In turn, the MEPs heard from speakers about the continued unmet needs of people living with epilepsy and the need for improved services, novel new treatments and actions designed to educate the public about epilepsy and, thereby, reduce discrimination.

In welcoming all those present, Brian Hayes highlighted the success of the MEP group since its launch in 2011. He advised that he would be retiring from politics at the end of the current EU parliamentary term but would be happy to assist in identifying an MEP to assume the chair once the elections were completed in May. Of note, the average turnover of MEPs at the time of elections is 50%. This means that about half of the membership of the MEP group would be lost, requiring fresh efforts to rebuild it post-election.

Speaking in Strasbourg, Prof Philippe Ryvlin, co-chair of Epilepsy Alliance Europe, thanked Brian Hayes and the MEP group for the support they had provided over the previous seven years. Notable achievements included the Written Declaration on Epilepsy 2011, that had been signed by 459 MEPs and had resulted in major funding for epilepsy research in the Framework Programme 7 (FP7).

Many of the projects funded by FP7 now formed the epiXchange network. Other epilepsy projects that had received EU funding since 2011 included E-PILEPSY, the pilot European Reference Network (ERN) project; EpiCARE, an ERN focussed on rare and complex epilepsies; and ESBACE, a project funded by DG Sante that surveyed epilepsy prevalence and cost burden in a number of countries. Prof Ryvlin highlighted the need for a global focus on epilepsy research if progress is to be made in identifying new and novel treatments for the 30 – 35% of people with epilepsy whose seizures currently are not controlled by existing treatments. There were new opportunities for such global research initiatives through the European Brain Research Area (EBRA).

An issue for concern was the lack of support in Europe for the WHA Resolution on Epilepsy, approved by the World Health Assembly in 2015, with report back in 2018. Few countries had addressed the recommendations of the resolution and efforts were now underway for a call to action. While support had been received from some countries including Russia, China and Brazil, there had been no support from EU Member States, despite their support for the EU Written Declaration in 2011. The argument was that epilepsy was too narrow a topic. However, the counter arguments were that epilepsy encompassed several hundred diseases; was sufficiently wide to have been selected for an EU-funded European Reference Network (ERN); 50 million people worldwide had been diagnosed with epilepsy; and it ranked second in the league of years of life lost.

In her presentation, Francesca Sofia, an Italian mother of a young child with epilepsy, said that her biggest wish was for her daughter simply to be happy, adding that this was a wish shared by all parents for their children. Francesca’s daughter Bea has a complex form of epilepsy which is resistant to medication. She continues to have seizures and requires a lot of support. Despite the hardships that life has thrown at her, Bea remains a happy loving 9-year old, who goes to school and who yearns to have friends. But the sad situation is that she has never had a friend and has never been invited to a play-date or party by classmates. Any invitation sent by Fran-
holders.
the uptake of EBRA results to key stake
features; and increase the visibility of the brain
collaboration, including enabling sharing
provide them with support for effective
selected for involvement in EBRA, and
projects in specific areas in active clusters
across European and global brain initia
development of new global initiatives and
of scale thus achieved would facilitate the
research area, resulting in better use of
the investments that are made in brain
research. The critical mass and economies
of scale thus achieved would facilitate the
development of new global initiatives and
quicker translation of successful outcomes
to clinical applications.
Huge investment has been provided by the
EU for brain research to a number of initia
tives. Although the initiatives generated
a considerable amount of knowledge and
innovative approaches, more coordinated
efforts are needed to avoid fragmentation,
to identify gaps and highlight priorities, in
order to support and foster translation into
new health interventions.
The EBRA Consortium will foster alignment
and co-ordination of research strategies
across European and global brain initia
tives; facilitate the emergence of research
projects in specific areas in active clusters
selected for involvement in EBRA, and
provide them with support for effective
collaboration, including enabling sharing
of data and access to research infrastruc
tures; and increase the visibility of the brain
research portfolio as a whole and promote
the uptake of EBRA results to key stake-
holders.

The EBRA Consortium will foster alignment
and co-ordination of research strategies
across European and global brain initia
tives; facilitate the emergence of research
projects in specific areas in active clusters
selected for involvement in EBRA, and
provide them with support for effective
collaboration, including enabling sharing
of data and access to research infrastruc
tures; and increase the visibility of the brain
research portfolio as a whole and promote
the uptake of EBRA results to key stake-
holders.

**THE SPEAKERS**

**Brian Hayes MEP**
Brian Hayes served as a member of Dail
Eireann (Irish Parliament) from 1997-2002
and 2007-2014, until his election to the
European Parliament in May 2014.

He was appointed to three European
Parliament Committees - Economic & Mon-
etary Affairs, Development, and Budgetary
Control. He is a member of the Delega-
tions to Iraq and South Africa.

**Martin Brodie**
Prof Martin Brodie is President of the
International Bureau for Epilepsy (IBE)
and Co-chair Epilepsy Alliance Europe. His
involvement with IBE goes back more than
30 years, having served as a member of its
board from 2005 to 2009.

His research interests include antiepileptic
drug neuropharmacology, randomised
clinical trials, prognostic outcome studies,
management of epilepsy and factors
affecting antiepileptic drug response.

**Francesca Sofia**
Dr Sofia is a molecular biologist with a PhD
in neuroscience. She specialized in health-
care economics and policy as a research
program manager for an Italian health
foundation, dedicated to rare genetic
diseases.

Her career path changed when her young-
est daughter was diagnosed with a rare
form of epilepsy, in 2011. In July 2014, she
joined the Italian Epilepsy Federation with
the aim of fostering epilepsy research. Re-
cently, she founded Science Compass, an
enterprise that provides services and tools
for effective investments in the biomedical
sector to non-profit organizations.

**Frederic Destrebecq**
Frédéric Destrebecq is Executive Director
of the European Brain Council. In this
capacity, he is responsible for providing
strategic direction and leadership while
managing the day-to-day operations of
EBC and its ongoing relationships with its
member associations and other stakehold-
ers, as well as representing the organi-
sation in various European and national
forums.

Prior to this position, Fred served the Euro-
pean Union of Medical Specialists (UEMS)
as Chief Executive Officer, and previously
as Director for European Affairs.

**Philippe Ryvlin**
Dr Ryvlin is Professor of Neurology and
Chair of the Department of Clinical Neuro-
sciences at University Hospital of Laus-
anne (CHUV), Switzerland, and Director of
the Epilepsy Institute (IDEE) in Lyon, France.

He is President of the European Epilepsy
Monitoring Association (EEMA), co-Chair
of the Epilepsy Alliance Europe Task Force,
founder of the European Network for Epi-
lepsy Research (ENER), and coordinator of
the EU funded pilot ERN - (E-PILEPSY).

Sofia’s story of her daughter’s struggles
shows clearly the continued need for basic
education about epilepsy in the commu-
nity and undermines the reality that many
people with epilepsy face - that epilepsy is
more than seizures.

Fred Destrebecq, Executive Director of EBC
outlined the purpose and expectations of
EBRA, a consortium of the Network of Eu-
ropean funding for Neuroscience research
(NEURON), the Joint Programme Neuro-
degenerative Disease Research (JPND) and
the Human Brain Project (HBP). The EU was
seeking projects that would address the
problems of duplication and fragmentation
of research efforts and that would encour-
age more collaboration and better coordi-
nation of brain research at EU and global
levels. This would lead to improved access
to research systems and data sources by all
stakeholders involved in the neuroscience
research area, resulting in better use of
the investments that are made in brain
research. The critical mass and economies
of scale thus achieved would facilitate the
development of new global initiatives and
quicker translation of successful outcomes
to clinical applications.

Huge investment has been provided by the
EU for brain research to a number of initia-
tives. Although the initiatives generated
a considerable amount of knowledge and
innovative approaches, more coordinated
efforts are needed to avoid fragmentation,
to identify gaps and highlight priorities, in
order to support and foster translation into
new health interventions.
The EBRA Consortium will foster alignment
and co-ordination of research strategies
across European and global brain initia-
tives; facilitate the emergence of research
projects in specific areas in active clusters
selected for involvement in EBRA, and
provide them with support for effective
collaboration, including enabling sharing
of data and access to research infrastruc-
tures; and increase the visibility of the brain
research portfolio as a whole and promote
the uptake of EBRA results to key stake-
holders.

Sofia’s story of her daughter’s struggles
shows clearly the continued need for basic
education about epilepsy in the commu-
nity and undermines the reality that many
people with epilepsy face - that epilepsy is
more than seizures.

Fred Destrebecq, Executive Director of EBC
outlined the purpose and expectations of
EBRA, a consortium of the Network of Eu-
ropean funding for Neuroscience research
(NEURON), the Joint Programme Neuro-
degenerative Disease Research (JPND) and
the Human Brain Project (HBP). The EU was
seeking projects that would address the
problems of duplication and fragmentation
of research efforts and that would encour-
age more collaboration and better coordi-
nation of brain research at EU and global
levels. This would lead to improved access
to research systems and data sources by all
stakeholders involved in the neuroscience
research area, resulting in better use of
the investments that are made in brain
research. The critical mass and economies
of scale thus achieved would facilitate the
development of new global initiatives and
quicker translation of successful outcomes
to clinical applications.

Huge investment has been provided by the
EU for brain research to a number of initia-
tives. Although the initiatives generated
a considerable amount of knowledge and
innovative approaches, more coordinated
efforts are needed to avoid fragmentation,
to identify gaps and highlight priorities, in
order to support and foster translation into
new health interventions.
The EBRA Consortium will foster alignment
and co-ordination of research strategies
across European and global brain initia-
tives; facilitate the emergence of research
projects in specific areas in active clusters
selected for involvement in EBRA, and
provide them with support for effective
collaboration, including enabling sharing
of data and access to research infrastruc-
tures; and increase the visibility of the brain
research portfolio as a whole and promote
the uptake of EBRA results to key stake-
holders.

Sofia’s story of her daughter’s struggles
shows clearly the continued need for basic
education about epilepsy in the commu-
nity and undermines the reality that many
people with epilepsy face - that epilepsy is
more than seizures.

Fred Destrebecq, Executive Director of EBC
outlined the purpose and expectations of
EBRA, a consortium of the Network of Eu-
ropean funding for Neuroscience research
(NEURON), the Joint Programme Neuro-
degenerative Disease Research (JPND) and
the Human Brain Project (HBP). The EU was
seeking projects that would address the
problems of duplication and fragmentation
of research efforts and that would encour-
age more collaboration and better coordi-
nation of brain research at EU and global
levels. This would lead to improved access
to research systems and data sources by all
stakeholders involved in the neuroscience
research area, resulting in better use of
the investments that are made in brain
research. The critical mass and economies
of scale thus achieved would facilitate the
development of new global initiatives and
quicker translation of successful outcomes
to clinical applications.

Huge investment has been provided by the
EU for brain research to a number of initia-
tives. Although the initiatives generated
a considerable amount of knowledge and
innovative approaches, more coordinated
efforts are needed to avoid fragmentation,
to identify gaps and highlight priorities, in
order to support and foster translation into
new health interventions.
The EBRA Consortium will foster alignment
and co-ordination of research strategies
across European and global brain initia-
tives; facilitate the emergence of research
projects in specific areas in active clusters
selected for involvement in EBRA, and
provide them with support for effective
collaboration, including enabling sharing
of data and access to research infrastruc-
tures; and increase the visibility of the brain
research portfolio as a whole and promote
the uptake of EBRA results to key stake-
holders.