

# EPILEPSY ALLIANCE EUROPE

NEWS FROM THE  
TASK FORCE CHAIRS  
APRIL 2018



under the auspices of:



## Meet the members of the Task Force 2017-2021



*Martin Brodie, Co-chair representing IBE*



*Philippe Ryvlin, Co-chair representing ILAE*



*Janet Mifsud, representing IBE*



*Caroline Morton, representing IBE*



*Francesca Sofia, representing IBE*



*Lievan Lagae, representing ILAE*



*Eugen Trinka, representing ILAE*



*Kristl Vonck, representing ILAE*

FIND OUT MORE

[www.epilepsyallianceeurope.org/epilepsy-alliance-europe-task-force/](http://www.epilepsyallianceeurope.org/epilepsy-alliance-europe-task-force/)





# INTERNATIONAL EPILEPSY DAY IN THE EUROPEAN PARLIAMENT



## A global alliance for epilepsy

The European Advocates for Epilepsy MEP group in the European Parliament, organised a Breakfast Briefing in the parliament in Brussels on 31st January to mark International Epilepsy Day. Hosted by its President, Brian Hayes MEP (Ireland), the event was attended by several MEPs, including Mrs Lieve Wierlinck (Belgium), Seán Kelly (Ireland), Alojz Peterle (Slovenia), Roberta Metsola (Malta), José Inácio Faria (Portugal), and Franc Bogovič (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 Profs Helen Cross, Martin Brodie, Lieven Lagae, Philippe Ryvlin, Eugen Trinkla and Kristl Vonck; Dr Janet Mifsud, Mrs Caroline Morton, and Mrs Francesca Sofia.

**Epilepsy is a  
most complex  
disease.**

**Fighting  
epilepsy is a real  
challenge.**

In opening the briefing, Brian Hayes MEP explained that the workshop focused on the need for a global alliance for epilepsy research

and was a follow up to an important workshop held in 2017 and which involved representatives from the national health agencies in the US and Canada.

Speaking at the event, Francesca Sofia, the mother of an eight-year old girl with difficult refractory epilepsy, said: "My plea to you today is to work with us in a life-changing movement to save a community of 6 million people (with epilepsy). I do not believe in miracles but I have faith in science. I believe in Europe. Europe is the home of human rights."

Philippe Ryvlin, Co-Chair of Epilepsy Alliance task force added: "We need to take Francesca's message and translate it into action. We need to reduce stigma and premature mortality. We need to improve quality of life. Epilepsy is a most complex disease – underlying dysfunction affects all scales of the brain – every aspect of brain organisation is affected. Fighting epilepsy is a great challenge."



# MEP GROUP INCREASES TO 63

In celebrating International Epilepsy Day in the European Parliament, members of the IBE/ILAE Epilepsy Alliance Europe joint task force held private meetings with almost 40 MEPs. This was an opportunity to tell them about the problems faced by people affected by epilepsy and to highlight the need for improved services, better public awareness and increased research.

The members of the task force also invited those MEPs who were not already members, to join the European Advocates for Epilepsy group. We are delighted to report that, as a result, membership of the group increased by nine, bringing the total number in the group to 63 MEPs.

The advocates group is led by Brian Hayes MEP, who acts as its President, with Nathalie Griesbeck MEP its Vice President. Created in April 2011, the aim of the group is to improve the quality of life of all people with epilepsy, their families, caregivers and healthcare providers through European Union (EU) policy. Since 2011, the group has hosted an annual day for epilepsy each February, in addition to accommodating regular workshops on epilepsy related topics. Meetings with the Health and Research Commissions have also been facilitated. More recently, In June 2016, 20 members of the group added their signatures to a letter calling on the support of national members for an application for a European Reference Network on Rare and Complex Epilepsies.

The support of the European Advocates for Epilepsy working group is vital in all our efforts in Europe. It has opened doors and provided direction on avenues we can take in our work to make a difference in Europe.

## HELP US GROW THE ADVOCATES GROUP

A membership of 63 MEPs is impressive but it is possible to increase the numbers even further. We also need to fill the gaps in those countries where there is no member of the group. Do you live in an EU Member State? Is there an MEP that you or your association could ask to join? By attracting one MEP from each country, we could increase the membership to 90 MEPs.

With European elections due to take place next year, already the sitting MEPs are considering their election plans. As a constituent, with the power to vote for them, this is an excellent opportunity to make contact with them. The time commitment in being a member of the advocates group is not onerous - with perhaps two meetings a year - and each member is provided with a certificate of membership that they can use on their website and in their social media to show their support for the epilepsy cause. For help in making contact with an MEP, please contact Ann Little at the IBE office [ibeexecdir@gmail.com](mailto:ibeexecdir@gmail.com).



# European Advocates for epilepsy



Tanja Fajon  
Slovenia



Eleonora Forenza  
Italy



Karin Kadenbach  
Austria



Ulrike Müller  
Germany



James Nicholson  
UK



Annie Schreijer-Pierik,  
Netherlands



Igor Šoltes  
Slovenia



Nils Torvalds  
Finland



Ivo Vajgl  
Slovenia

## CURRENT MEMBERS

**AUSTRIA:** Heinz Becker, Barbara Kappel, Karin Kadenbach, Paul Rübiger  
**CYPRUS:** Lefteris Christoforou, Neoklis Sylikiotis, Costas Mavrides, Demetris Papadakis  
**CZECH REPUBLIC:** Pavel Poc, Olga Sehnalová, Tomáš Zdechovský  
**DENMARK:** Bendt Bendtsen, Christel Schaldemose  
**FINLAND:** Liisa Jaakonsaari, Anneli Jäätteenmäki, Miapetra Kumpula-Natri, Merja Kyllönen, Sirpa Pietikäinen, Nils Torvalds  
**FRANCE:** Nathalie Griesbeck, Dominique Riquet  
**GERMANY:** Jens Gieseke, Ulrike Müller  
**GREECE:** Kostas Chrysogonos, Lampros Fountoulis, Dimitris Papadimoulis, Sofia Sakorafa, Maria Spyraiki, Eleftherios Synadinos, Theodoros Zagorakis  
**HUNGARY:** András Gyürk  
**IRELAND:** Matt Carthy, Nessa Childers, Deirdre Clune, Marian Harkin, Brian Hayes,

Seán Kelly, Mairead McGuinness  
**ITALY:** David Borelli, Eleonora Forenza, Giovanni La Via, Patrizia Toia,  
**MALTA:** David Casa, Miriam Dalli, Roberta Metsola  
**NETHERLANDS:** Annie Schreijer-Pierik  
**PORTUGAL:** José Inácio Faria  
**ROMANIA:** Cristian-Silviu Buşoi, Marian-Jean Marinescu, Emil-ian Pavel, Claudiu-Ciprian Tănăsescu  
**SLOVAKIA:** Jana Žitňanská  
**SLOVENIA:** Tanja Fajon, Alojz Peterle, Igor Šoltes, Ivo Vajgl  
**SWEDEN:** Jytte Guteland, Anna Hedh  
**UK:** Paul Brannen, Theresa Griffin, Jean Lambert, James Nicholson, Julie Ward.

**NO MEMBERS:** BELGIUM, BULGARIA, CROATIA, ESTONIA, LATVIA, LITHUANIA, LUXEMBOURG, POLAND, SPAIN.

You will find a full list of MEPs, by country on the EU website: <http://www.europarl.europa.eu>.