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/
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 Trinka and Kristl Vonck; Dr Janet Mifsud, Mrs Caroline Morton, and Mrs Francesca Sofia.

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.”
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.

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.

HELP US GROW THE ADVOCATES GROUP

CURRENT MEMBERS

AUSTRIA: Heinz Becker, Barbara Kappel, Karin Kadenbach, Paul Rübig

CYPRUS: Lefteris Christoforou, Neoklis Syllikiotis, Costas Mavrides, Demetris Papadakis

CZECH REPUBLIC: Pavel Poc, Olga Sehnalová, Tomáš Zdechovský

DENMARK: Bendt Bendesen, Christel Schaldemose

FINLAND: Liisa Jaakonsaari, Anneli Jäätteenmäki, Mia Petra Kumpula-Natri, Merja Kylönén, Sirpa Pietikäinen, Nils Torvalds

FRANCE: Nathalie Griesbeck, Dominique Riquet

GERMANY: Jens Gieseke, Ulrike Müller

GREECE: Kostas Chrysogonis, Lampros Fountoulis, Dimitris Papadimoulis, Sofia Sakorafa, Maria Spyral, Elefterios 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-Pierk

PORTUGAL: José Inácio Faria

ROMANIA: Christian-Silviu Buşoi, Marian-Jean Marinescu, Emilian Pavel, Claudiu-Cipriean Tănăsescu

SLOVAKIA: Jana Žitňanská

SLOVENIA: Tanja Fajon, Alojz Peterle, Igor Šoltes, Ivo Vajgl

SWEDEN: Jytte Gute

UK: Paul Brannen, Theresa Griffin, Jean Lambert, James Nicholson, Julie Ward

NO MEMBERS: BELGIUM, BULGARIA, CROATIA, CZECH REPUBLIC, ESTONIA, LITHUANIA, LUXEMBOURG, POLAND, SPAIN.

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

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