

## **Pfizer Support to European and International Patient Organisations in 2018**

### **Support to European organisations**

The below list contains information on the support Pfizer has provided to European-level patient organisations in 2018, and services contracted from them (e.g. speaker fees), and to national and global patient organisations for European-level work. It follows the standards set out in the EFPIA code of practice governing relationships between the pharmaceutical industry and patient associations. Note that many of these declarations have also been declared in the country in which an organisation is based, dependent on local guidelines.

<b>Action Duchenne</b>					
<p><b>Organisation Description</b> Action Duchenne is a patient organisation focused on advancing science and care for Duchenne and Beckers muscular dystrophy.</p>					
<p><b>Funding</b> Pfizer Inc provided £7,500 in support for the International Conference.</p>					
<p>This information is also declared on <a href="http://www.pfizer.co.uk">www.pfizer.co.uk</a>. Please be aware that the format may differ to follow UK transparency guidelines.</p>					
<b>Active Citizenship Network</b>					
<p><b>Organisation Description</b> Active Citizenship Network (ACN) was initiated in December 2001 as the European and international interface of the Italian civic participation organisation Cittadinanzattiva (Active Citizenship). ACN is a flexible network of European civic organisations which are involved as partners in its different projects, addressed to encourage active participation of citizens in European policy-making, including patients' rights as a priority area.</p>					
<p><b>Funding</b></p> <table border="1"> <tbody> <tr> <td>€12,500</td> <td>Pfizer Inc provided a charitable contribution to support the 'patient's right to avoid pain' initiative. This payment was on behalf of the Pfizer Lilly Alliance, and represents 50% of the total paid.</td> </tr> <tr> <td>€1,730</td> <td>Pfizer Inc provided fees for participation in Pain Policy Advisory Boards.</td> </tr> </tbody> </table>		€12,500	Pfizer Inc provided a charitable contribution to support the 'patient's right to avoid pain' initiative. This payment was on behalf of the Pfizer Lilly Alliance, and represents 50% of the total paid.	€1,730	Pfizer Inc provided fees for participation in Pain Policy Advisory Boards.
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<b>AGORA</b>					
<p><b>Organisation Description</b> AGORA is an umbrella platform representing patient organisation for people with rheumatic and musculoskeletal diseases in Southern Europe.</p>					
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<b>Alzheimer Europe</b>
<p><b>Organisation Description</b> Alzheimer Europe is a non-governmental organisation aimed at raising awareness of all forms of dementia by creating a common European platform through co-ordination and co-operation between Alzheimer organisations throughout Europe. Alzheimer Europe is also a source of information on all aspects of dementia.</p> <p><b>Funding</b> Pfizer provided €20,000 as sponsors of Alzheimer Europe’s corporate programme.</p>
<b>Digestive Cancers Europe (DiCE)</b>
<p><b>Organisation Description</b> DiCE is the voice of digestive cancer patients in Europe. Its aim is to save lives by bringing together all key stakeholders in the fight against these cancers.</p> <p><b>Funding</b> Pfizer Inc provided £18,730.80 to support the third EuropaColon/DiCE advocacy masterclass.</p> <p>This information is also declared on <a href="http://www.pfizer.co.uk">www.pfizer.co.uk</a>. Please be aware that the format may differ to follow UK transparency guidelines.</p>
<b>Europa Donna</b>
<p><b>Organisation Description</b> Europa Donna, the European Breast Cancer Coalition, is an independent non-profit organisation founded in 1993, whose members are affiliated groups from countries across Europe. The Coalition works to raise awareness of breast cancer and to mobilise the support of European women in pressing for improved breast cancer education, appropriate screening, optimal treatment and care and increased funding for research. Europa Donna represents the interests of European women regarding breast cancer to local and national authorities, as well as to institutions of the EU.</p> <p><b>Funding</b> Pfizer Inc provided €50,000 to support Europa Donna’s annual work plan 2018.</p> <p>This information is also declared on <a href="http://www.pfizer.it">www.pfizer.it</a>. Please be aware that the format may differ to follow Italian transparency guidelines.</p>
<b>European Cancer Patient Coalition</b>
<p><b>Organisation Description</b> Established in 2003, the European Cancer Patient Coalition is the voice of the European cancer patient community, uniquely representing the interests of all cancer patient groups from the most common to the rarest forms of cancer.</p> <p><b>Funding</b> Pfizer Inc provided €15,000 to support the 2018 ECPC annual meeting.</p> <p>This information is also declared on <a href="http://www.betransparent.be">www.betransparent.be</a>.</p>

### European Federation of Allergies & Airways (EFA)

#### Organisation Description

The European Federation of Allergies and Airways Diseases is a European patient organisation dedicated to supporting the needs of people with allergies, asthma and COPD.

#### Funding

€30,000	Pfizer Inc provided support for EFA's 2018 Annual General Meeting.
€2,000	Pfizer Inc provided consultancy fees.

This information is also declared on [www.betransparent.be](http://www.betransparent.be).

### European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA)

#### Organisation Description

EFCCA is a European umbrella organisation representing 33 national patients' associations. EFCCA aims to work to improve life for people with IBD and give them a louder voice and higher visibility across Europe and beyond.

#### Funding

€48,500	Pfizer Inc provided support for EFCCA's 2018 annual work programme.
€30,000	Pfizer Inc provided partnership support for the UC Narrative initiative.
€2,400	Pfizer Inc provided consultancy fees.
€800	EFCCA received a consultancy fee paid by Synergy Medical.

This information is also declared on [www.betransparent.be](http://www.betransparent.be).

### European Federation of Neurological Associations (EFNA)

#### Organisation Description

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, in what has been termed a 'Partnership for Progress'. EFNA engages in activities, which contribute to the advancement of neurology and related areas with a view to improving the quality of life of people living with neurological conditions, their families and carers.

#### Funding

Pfizer Inc provided a policy-focused healthcare charitable contribution of €15,000 for EFNA's update to the 'Book of Evidence' for the Brain, Mind & Pain MEP Interest Group.

This information is also declared on [www.betransparent.be](http://www.betransparent.be).

### European Gaucher Alliance (EGA)

#### Organisation Description

The EGA is an umbrella organisation that supports and represents national Gaucher associations on a pan-European level. It has provided patient focused guidance, support and advice to industry, healthcare providers, governments, the EU, developing patient organisations, scientists and physicians and all other stakeholders in the Gaucher Community.

**Funding**

Pfizer Inc provided £57,400 to support the 2018 EGA work programme and awareness activities.

This information is also declared on [www.pfizer.co.uk](http://www.pfizer.co.uk). Please be aware that the format may differ to follow UK transparency guidelines.

**European Haemophilia Consortium (EHC)****Organisation Description**

The European Haemophilia Consortium (EHC) is a European patient group representing national member organisations from 43 countries in Europe including members in all 28 Member States. The EHC is working to reduce the burden of the disease on both the individual and on society. Its mission is to improve the quality of life of people with Haemophilia in Europe.

**Funding**

Pfizer Inc provided €129,862.61 funding to support EHC's European Roundtables, Youth Leadership and Economics Workshops.

This information is also declared on [www.betransparent.be](http://www.betransparent.be).

**European Patients' Forum (EPF)****Organisation Description**

The European Patients' Forum (EPF) is the umbrella patients' organisation at EU level. It brings together a broad range of leading European and national patients' organisations in different disease areas. Representing over 150 million patients, the EPF is a key interlocutor with European institutions, and promotes patients' rights, participation and involvement in EU healthcare developments.

**Funding**

€25,000	Pfizer SA/NV provided a grant to support EPF's annual work programme.
€1,000	Pfizer SA/NV provided a grant to support EPF's European Parliament elections campaign.
€25,000	Pfizer Inc provided a grant support to EPF's Capacity Building Programme.
€30,000	Pfizer Inc provided funding to support the EUPATI project.

**EURORDIS (European Organisation for Rare Diseases)****Organisation Description**

EURORDIS is a patient-driven alliance of patient organisations and individuals active in the field of rare diseases. EURORDIS' mission is to build a strong pan-European community of patient organisations and people living with rare diseases, to be their voice at the European level, and - directly or indirectly - to fight against the impact of rare diseases on their lives.

**Funding**

Pfizer Inc provided €130,000 to support the EURORDIS international initiatives, ECRD congress, and Ruby membership.

This information is also declared on [www.pfizer.fr](http://www.pfizer.fr). Please be aware that the format may differ to follow French transparency rules.

### International Diabetes Federation Europe (IDF-Europe)

#### Organisation Description

As the only European advocate for people with diabetes and their healthcare providers, the International Diabetes Federation European Region works together with its member associations and other diabetes stakeholders to enhance the lives of people with diabetes. Many IDF member associations are made up of people with diabetes and health care professionals. The mission of the IDF is to promote diabetes care, prevention and a cure worldwide.

#### Funding

Pfizer Inc provided a policy-focused healthcare contribution of €27,000 for the IDF Europe Corporate Partnership.

This information is also declared on [www.betransparent.be](http://www.betransparent.be).

### Myeloma Patients Europe (MPE)

#### Organisation Description

Myeloma Patients Europe (MPE) is an umbrella organisation of myeloma patient groups and associations from across Europe.

#### Funding

Pfizer Inc provided €15,000 to support MPE's Haematology Advocacy Community Advisory Board.

This information is also declared on [www.betransparent.be](http://www.betransparent.be).

### Pain Alliance Europe (PAE)

#### Organisation Description

PAE is an NGO umbrella organisation of national associations which are all committed to improving the quality of life of people with chronic pain.

#### Funding

€10,000	Pfizer Inc provided a charitable contribution to support PAE's core activities and 2018 survey. This support represents 50% of the total support provided by the Pfizer-Lilly Alliance.
€243.08	Pfizer Inc provided fees for participation in a pain policy advisory boards. This fee represents 50% of the total support provided by the Pfizer-Lilly Alliance.
€1,260	Pfizer Inc provided fees for participation in a pain policy advisory boards.

This information is also declared on [www.betransparent.be](http://www.betransparent.be).

### Parent Project Onlus

#### Organisation Description

Parent Project Onlus is a patient organisation focused on advancing science and care for Duchenne and Beckers muscular dystrophy.

#### Funding

€15,000	Pfizer Inc provided support for the 2019 annual conference.
€15,000	Pfizer Inc provided support for gene therapy education and materials.

This information is also declared on [www.pfizer.it](http://www.pfizer.it). Please be aware that the format may differ to follow Italian transparency guidelines.

#### **PHA Europe (Pulmonary Hypertension Association)**

##### **Organisation Description**

The mission of Pulmonary Hypertension Association (Europe) is to find ways to prevent and cure pulmonary hypertension, and to provide hope for the pulmonary hypertension community through support, education, advocacy and awareness.

##### **Funding**

Pfizer Inc provided \$15,000 support for European advocacy.

#### **Stroke Alliance for Europe (SAFE)**

##### **Organisation Description**

SAFE is a non-profit-making organisation that represents a range of patient groups from across Europe whose mutual goal is to drive stroke prevention up the European political agenda and prevent the incidence of stroke through education.

##### **Funding**

Pfizer Ltd on behalf of the BMS-Pfizer Alliance (an alliance between Bristol-Myers Squibb Pharmaceuticals Ltd and Pfizer Ltd) provided a contribution of €18,750 as corporate sponsorship for the SAFE Working Conference in Berlin, 27-30 November 2018. This figure is the total of Pfizer's contribution via the Pfizer-BMS Alliance, and is 50% of the total paid.

This information is also declared on [www.betransparent.be](http://www.betransparent.be).

## Support to global organisations based in Europe

The below list contains information on the support Pfizer has provided to global patient organisations in 2017 based in Europe.

<b>Amyloidosis Alliance</b>
<p><b>Organisation Description</b> The Amyloidosis Alliance is the global alliance of patient groups working in Amyloidosis. The alliance has a mission to promote diagnosis, awareness, research and coordination between organisations in order to improve outcomes for patients and their families suffering from Amyloidosis.</p> <p><b>Funding</b> Pfizer Inc provided €20,000 to support the first Amyloidosis Alliance patients meeting in Paris.</p> <p>This information is also declared on <a href="http://www.pfizer.fr">www.pfizer.fr</a>. Please be aware that the format may differ to follow French transparency rules.</p>
<b>Global Lung Cancer Coalition</b>
<p><b>Organisation Description</b> Established in 2001, the GLCC comprises 28 non-government patient organisations from around the world. The GLCC is committed to improving disease outcomes for all lung cancer patients and place lung cancer on the global healthcare agenda, change public perceptions and lessen the stigma of lung cancer, empower lung cancer patients to take an active role in their care and effect change in legislative or regulatory policies to optimise treatment and care.</p> <p><b>Funding</b> Pfizer Inc provided £30,000 as partner membership.</p> <p>This information is also declared on <a href="http://www.pfizer.co.uk">www.pfizer.co.uk</a>. Please be aware that the format may differ to follow UK transparency guidelines.</p>
<b>International Alliance of Patient Organisations (IAPO)</b>
<p><b>Organisation Description</b> IAPO is a unique global alliance representing patients of all nationalities across all disease areas and promoting patient-centred healthcare around the world.</p> <p><b>Funding</b> Pfizer Inc provided \$38,250 as support for IAPO's gene therapy project.</p> <p>This information is also declared on <a href="http://www.pfizer.co.uk">www.pfizer.co.uk</a>. Please be aware that the format may differ to follow UK transparency guidelines.</p>
<b>International Brain Tumour Alliance</b>
<p><b>Organisation Description</b> The International Brain Tumour Alliance (IBTA) is a unique global network for brain tumour patient and carer groups around the world. We work alongside, and represent, members of our community - including researchers, scientists, clinicians, nurses and allied healthcare professionals</p>

- to engage in advocacy, to raise awareness and to share information.

**Funding**

Pfizer Inc provided £11,000 to support the IBTA annual work programme.

This information is also declared on [www.pfizer.co.uk](http://www.pfizer.co.uk). Please be aware that the format may differ to follow UK transparency guidelines.

**International Federation of Psoriasis Associations (IFPA)**

**Organisation Description**

IFPA is a non-profit organisation made up of psoriasis associations from around the world. IFPA unites psoriasis associations so that their global campaign for improved medical care, greater public understanding and increased research will improve the lives of people who live with psoriasis and psoriatic arthritis and explore the challenges psoriasis presents to the international psoriasis community. IFPA is based in Sweden.

**Funding**

Pfizer Inc provided €65,000 to support IFPA's annual work programme.

**International Kidney Cancer Coalition (IKCC)**

**Organisation Description**

IKCC is an independent and democratic network of patient support and advocacy organisations established with the mission of improving the quality of life of patients and their families living with kidney cancer. IKCC provides information, support and assistance to national kidney cancer organisations.

**Funding**

Pfizer Inc provided \$12,500 support for patient advocacy and clinical outcomes in cancer.

**International Patient Organisation for Primary Immunodeficiencies (IPOPI)**

**Organisation Description**

International Patient Organisation for Primary Immunodeficiencies, is the Association of national patient organisations dedicated to improving awareness, access to early diagnosis and optimal treatments for primary immunodeficiency (PID) patients worldwide. Established in 1992, IPOPI works as the global advocate for the PID patient community in cooperation with its National Member Organisations (NMOs) and key PID stakeholders.

**Funding**

Pfizer Inc provided €50,000 to support IPOPI's operating plan and new-born screening campaign.

This information is also declared on [www.pfizer.co.uk](http://www.pfizer.co.uk). Please be aware that the format may differ to follow UK transparency guidelines.

**World Alliance of Pituitary Organisations**

**Organisation Description**

The World Alliance of Pituitary Organisations (WAPO) is a self-governed non-profit organisation created in order to unite the international pituitary patient community to push for optimal treatment and care for all patients with pituitary and related conditions worldwide. The goal of



our organisation is to share information, work together and support all pituitary patients' advocates all around the world.

**Funding**

Pfizer Inc provided €25,000 support for the WAPO annual summit.

## **Appendix: Funding to organisations engaged in some work with patients.**

Pfizer provides funding to a number of organisations that are not patient organisations, but which have patient organisation membership or are otherwise relevant to patients. As such, they are listed here for the sake of transparency.

**European Alliance for Personalised Medicine (EAPM):** Founded in 2012, The European Alliance for Personalised Medicine (EAPM) brings together Europe's leading healthcare experts, healthcare organisations and institutions, and patient advocates to improve patient care by accelerating the development, delivery and uptake of personalised healthcare including personalised medicine and diagnostics. EAPM is based in Belgium. In 2018, Pfizer Inc. paid €15,000 for EAPM health congress sponsorship.

**European Brain Council (EBC):** The European Brain Council (EBC) is a coordinating council formed by European organisations in neurology, neurosurgery, psychiatry, basic brain research (neuroscience), as well as patient organisations and companies from within the pharma and biotech industries. It represents a vast network of patients, doctors and scientists, and these stakeholders along with its industrial partners make it eminently suited to work in close partnership with the European Parliament and Commission, national governments as well as other policy making bodies. EBC is based in Belgium. In 2018, Pfizer Inc provided EBC with €20,000 as an annual industry partnership fee; Pfizer Inc provided an honorarium of €162 for participation in a pain policy advisory board (this represents 50% of the total paid by the Pfizer-Lilly Alliance); Pfizer Ltd provided an honorarium of €847 for participation in an atrial fibrillation advisory board and Atrial Fibrillation Summit (this represents 50% of the total paid by the Pfizer-BMS Alliance).

**European Network for Smoking and Tobacco Prevention (ENSP):** ENSP has more than 60 member organisations from across Europe. It aims to create greater coherence among smoking prevention activities and to promote comprehensive tobacco control policies, at both national and European levels, in order to prevent ill health and early death from tobacco-related causes. In 2018, Pfizer Inc provided ENSP with a policy-focused healthcare charitable contribution of €53,000 to support the ENSP-SRP 4<sup>th</sup> International Conference on Tobacco Control; Pfizer Ltd provided €3,500 as a charitable donation for WCTOH 2018 attendance; Pfizer Ltd provided €50,000 as corporate sponsorship of the ENSP International Conference on Tobacco Control (June 14-16 2018, Madrid); Pfizer Ltd provided an educational grant of €20,000 to support the ENSP Italy Consensus Statement; Pfizer Ltd provided an educational grant of €20,000 to support the ENSP Declaration of Madrid Roundtable; Pfizer Ltd provided an educational grant of €50,000 to support the ENSP Roundtable on Heated Tobacco Products.

**European School of Oncology (ESO):** The European School of Oncology was founded with the aim of contributing to the reduction of deaths from cancer due to late diagnosis and/or inadequate treatment. By improving the skills of all health professionals dealing with cancer patients, ESO helps shorten the time needed to transfer knowledge from research centres to daily practice, combining advanced technology with humanism in care. In 2018, Pfizer Inc provided €7,500 to support the Advanced Breast Cancer Global Alliance.

**European Society for Medical Oncology (ESMO):** ESMO is the leading European professional organisation for medical oncology. Comprising more than 15,000 oncology professionals from over 130 countries, ESMO is the society of reference for oncology education and information. In 2018, Pfizer Inc provided €15,000 to support the Patient Advocacy Track at the 2018 ESMO Congress.