# Pfizer Support to European and International Patient Organisations in 2015

## Support to European organisations

The below list contains information on the support Pfizer has provided to European-level patient organisations in 2015, 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.

## **Active Citizenship Network**

# **Organisation Description**

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 organizations 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.

## Funding

Pfizer Inc provided €35,000 as annual membership and in support of ACN's chronic pain project.

This information is also declared on <u>www.pfizer.it</u>. Please be aware that the format may differ to follow Italian transparency guidelines.

# **Atrial Fibrillation Association (AFA)**

# **Organisation Description**

The Atrial Fibrillation Association (AFA) is an international, UK-registered charity which focuses on raising awareness of Atrial Fibrillation (AF) by providing information and support materials for patients and medical professionals involved in detecting, diagnosing and managing Atrial Fibrillation.

# **Contracted services**

The BMS-Pfizer Alliance paid a consultancy fee for the participation of an AFA staff member in a European Advisory Board meeting which took place in the UK. Pfizer's contribution of £155 was 50% of the total fee.

This information is also declared on <u>www.pfizer.co.uk</u>. Please be aware that the format may differ to follow UK transparency guidelines.

# Europa Donna

#### **Organisation Description**

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. Europa Donna has 46 country members and its Head Office is located in Milan, Italy.

# Funding

i anang	
€50,000	Pfizer Inc provided a contribution to support Europa Donna's annual work plan
	2015.
€16,000	Pfizer Inc provided funding for translation of guidelines for Central & Eastern
	European countries.
€50,000	Pfizer Inc provided a contribution to support Europa Donna's annual work plan
	in 2016.

This information is also declared on <u>www.pfizer.it</u>. Please be aware that the format may differ to follow Italian transparency guidelines.

## **European Cancer Patient Coalition**

# **Organisation Description**

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.

## Funding

runung		
€31,000	Pfizer Inc provided support for the ECPC's Immuno-Oncology Portal in 2015.	
€13,000	Pfizer Inc provided support for ECPC's Annual General Meeting in Brussels.	
€30,000	Pfizer Inc provided support for the ECPC's Immuno-Oncology Portal in 2016.	

This information is also declared on <u>www.pfizer.be</u>. Please be aware that the format may differ to follow Belgian transparency guidelines.

**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 €60,000 to support EFNA's communications campaign and MEP interest group meetings.

This information is also declared on <u>www.pfizer.be</u>. Please be aware that the format may differ to follow Belgian transparency guidelines.

#### **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 £49,950 to support annual membership.

This information is also declared on <u>www.pfizer.co.uk</u>. Please be aware that the format may differ to follow Belgian 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 \$31,150 to support EHC's HTA webinar and toolkit.

This information is also declared on <u>www.pfizer.be</u>. Please be aware that the format may differ to follow Belgian transparency guidelines.

## **European Huntington Association**

## **Organisation Description**

The European Huntington Association supports people affected by Huntington's Disease, using its network to enhance the search for treatment of Huntington's and improve the lives of those living with Huntington's.

#### Funding

Pfizer Inc provided €20,000 to support the European Huntington Congress: "How to cope with HD?". This took place in Warsaw, Poland from 18-20th September 2015.

This information is also declared on <u>www.pfizer.be</u>. Please be aware that the format may differ to follow Belgian transparency guidelines.

#### European Institute of Women's Health (EIWH)

#### **Organisation Description**

Founded in 1996, The European Institute of Women's Health (EIWH), is a non-governmental organisation based in Dublin established to promote gender equity in public health, research and social policies across Europe. The EIWH strives to make the health and well-being of women and the family, a priority for the European Commission and EU Member States.

# Funding

Pfizer GmbH provided €40,000 to EIWH as core funding for the years 2015 and 2016.

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

Tunung	
€20,000	Pfizer Service Company provided core funding to EPF.
€25,000	Pfizer Inc provided support to EFF's Capacity Building Programme.

This information is also declared on <u>www.pfizer.be</u>. Please be aware that the format may differ to follow Belgian & Luxembourgish transparency guidelines.

#### **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 €80,000 for general support of EURORDIS for a new initiative, Rare Disease International.

This information is also declared on <u>www.pfizer.fr</u>. Please be aware that the format may differ to follow French transparency rules.

## Lung Cancer Europe (LuCE)

#### **Organisation Description**

Lung Cancer Europe is a non-governmental organisation which was established in 2013 to provide a voice for lung cancer patients and their families at a European level. Through its member organisations (which are lung cancer organisations with a patient focus), LuCE reflects patients' and their carers' and families' unique and direct experience and expertise in healthcare. LuCE is based in Switzerland.

#### Funding

Pfizer GmbH provided €25,000 to LuCE as 2015 annual membership.

#### Sarcoma Patients EuroNet (SPAEN)

#### **Organisation Description**

Established in 2009, Sarcoma Patients EuroNet e.V./Assoc. (SPAEN) is a collaborative association based in Germany, which brings together European advocacy and support groups working together with patients who have some of the rarest cancers. Acting in partnership with clinical experts, scientific researchers and other stakeholders SPAEN is working to improve the treatment and care of sarcoma patients in Europe through improving information and support, and by increasing the awareness of sarcoma in the medical landscape and amongst the general public.

#### Funding

i unung	
€12,500	Pfizer Inc provided half of 2015 annual membership.
€12,500	Pfizer GmbH provided half of 2015 annual membership.
€35,000	Pfizer Inc provided support to 2016 GIST New Horizons Meeting and planning.

## Support to global organisations based in Europe

The below list contains information on the support Pfizer has provided to global patient organisations in 2015 based in Europe.

#### **CML Advocates Network**

#### **Organisation Description**

The CML Advocates Network is a worldwide network of non-profit organisations supporting patients with Chronic Myeloid Leukaemia (CML) and their relatives. The network does this by sharing knowledge and best practice, running joint campaigns, and educating advocates how to build and grow patient organisations. The network is run by volunteers who are CML patients. The CML Advocates Network is formally hosted by the Leukaemia Patient Advocates Foundation, a global patient-led non-profit foundation registered in Switzerland.

## Funding

Pfizer Inc provided €50,000 support for the annual CML Horizons meeting.

## **Global Lung Cancer Coalition**

## **Organisation Description**

The GLCC is an umbrella organisation that supports lung cancer awareness and best practice sharing among patient groups internationally. The GLCC operates from the UK.

## Funding

Pfizer Inc provided £30,000 to support the annual work programme of GLCC.

This information is also declared on <u>www.pfizer.co.uk</u>. Please be aware that the format may differ to follow UK transparency guidelines.

#### **International Brain Tumour Alliance**

#### **Organisation Description**

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

#### Funding

Pfizer Inc provided £9,000 to support the IBTA annual meeting.

This information is also declared on <u>www.pfizer.co.uk</u>. Please be aware that the format may differ to follow UK transparency guidelines.

#### International Alliance of Patients' Organisations (IAPO)

#### **Organisation Description**

IAPO is a unique global alliance representing patients of all nationalities across all disease areas and promoting patient-centred healthcare around the world. IAPO is registered in the Netherlands.

#### Funding

Pfizer Inc provided £50,000 funding as an annual industry partnership member.

This information is also declared on <u>www.pfizer.co.uk</u>. Please be aware that the format may differ to follow UK transparency guidelines.

## International Federation of Psoriasis Organisations (IFPA)

# **Organisation Description**

IFPA is a non-profit organization 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 \$75,000 as a second tier corporate member contribution to IFPA's 2015 plan.

## International Kidney Cancer Coalition (IKCC)

## **Organisation Description**

IKCC is an independent and democratic network of patient support and advocacy organizations 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 organizations. Management services for IKCC are provided by Das Wissenhaus GmbH, a service provider for scientific and medical information & communication and acts in the world of medicine/oncology/science (experts, researchers, clinics, patients, patient-organizations, media, companies etc.).

Funding

€42,000	Pfizer Inc provided 2015 annual sustaining partner membership.
\$50,000	Pfizer Inc provided support to Kidney Cancer Awareness Day and advocacy strategic
	planning
\$55,000	Pfizer Inc provided 2016 Sustaining Partners Membership

#### 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 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. In 2015 Pfizer Inc provided EBC with €20,000 as an annual membership fee.

**Pain Alliance Europe (PAE):** PAE is a multi-stakeholder alliance that aims to improve the quality of life of people living with chronic pain in Europe, by promoting awareness of chronic pain and promoting a European policy on chronic pain, in order to reduce the impact of chronic pain on all areas of European society. In 2015 Pfizer Inc provided PAE with €20,000 to support annual membership.