

# Pan European patient group funding

## European Organisation for Rare Diseases (EURORDIS)

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.

We have supported this organisation since 2005.

### During 2018:

- GSK provided €70,000 for continued support of EURORDIS' Rare Barometer programme and RareConnect, the Online Rare Disease Communities programme, as well as membership in EURORDIS' Round Table of Companies (ERTC).

Our support represented 1.18% of their overall income.

### During 2017:

- GSK provided an unrestricted grant of €70,000 for continued support of EURORDIS's Rare Barometer programme and RareConnect, the Online Rare Disease Communities programme.

Our support represents less than 1% of their overall income.

### During 2016:

- GSK provided an unrestricted grant of €70,000 to support EURORDIS's Rare Barometer programme and RareConnect, the Online Rare Disease Communities programme.

Our support represents less than 1% of their overall income.

### During 2015:

- We provided €70,000 to support EURORDIS's *Patient Voices* programme and RareConnect Online Rare Disease Communities to collect patient experiences and expectations.

Our support represents 1.8 % of their overall income.

### During 2014:

- We provided an unrestricted grant of €50,000 to support EURORDIS in delivering its objectives
- We also gave €10,000 for the organisation of the EURORDIS Annual Membership Meeting held in Berlin in May 2014.
- Since 2005 GSK is member of the EURORDIS Round Table of Companies (ERTC). The ERTC was created in 2004 to establish a long-term educational relationship between EURORDIS and companies that have an interest in orphan drugs development. In 2014, GSK contributed with €10,000 for the ERTC.

Our support represents 1.75% of their overall income.

**During 2013:**

- Support to the EURORDIS Membership Meeting which has provided more than 200 patients and patient representatives with capacity-building workshops and the chance to network with policy makers and other Rare Disease stakeholders. The Meeting Workshops were designed to develop patients' knowledge and ability to advance conditions for Rare Disease patients in their country and communities. The 2013 Meeting has focused on National Plans on Rare Diseases, on Standards of Care, Centres of Expertise, and Registries and offered a venue for EURORDIS members to learn from each other by sharing successful models in advocacy and other actions. (10000€)
- Contribution provided to the Third EURORDIS Gala Dinner (held on the 25th of February 2014). This event highlights and strengthens the cause of rare diseases on a European level by bringing together leaders of the healthcare industry, Brussels community and public sector. Overall the funds collected at the occasion of this event are used by EURORDIS in an unrestricted way for the organisation's main actions. (35000€)
- Since 2005 GSK is member of the EURORDIS Round Table of Companies (ERTC). The ERTC was created in 2004 to establish a long-term educational relationship between Eurordis and companies that have an interest in orphan drug development. (10000€)
- Support to the project RareConnect:Online Patient Communities, a web tool that responds to rare disease patients' need for information and connection. Through RareConnect rare disease patients interact and exchange information on their disease and their life managing their disease. The platform currently serves 38 disease-specific communities in 5 languages and is endorsed by more than 200 patient organisations According to the signed agreement EURORDIS retains all aspects of the project and GSK obtains no right other than the donor's rights set in the LoA. (15000€)

Our support represents 1.75% of their overall income.

**During 2012:**

- Support to the EURORDIS Annual Membership Meeting 2012. Each year at the EURORDIS Membership Meeting, patients and patient representatives from throughout Europe come together for the Annual General Assembly of EURORDIS members, followed by workshops designed to increase patients' knowledge and capacity to make changes to improve the lives of rare disease patients and their families. In 2012, the EURORDIS Membership Meeting coincided with the 6th EU Conference on Rare Diseases, the main multi-stakeholders event on Rare Diseases in Europe. (10000€)
- Contribution provided at the occasion of the second EURORDIS Gala Dinner (that will be held on the 26th of February 2013). Overall the funds collected at the occasion of this event are used by EURORDIS in an unrestricted way for the organisation's main actions. (35000€)
- Since 2005 GSK is member of the EURORDIS Round Table of Companies (ERTC). The ERTC was created in 2004 to establish a long-term educational relationship between Eurordis and companies that have an interest in orphan drug development. (10000€)

- GSK Rare Diseases has provided €15000 to support the project RareConnect:Online Patient Communities, a webtool to allow rare disease patients to interact and exchange information on their disease and their life managing their disease. Twenty eight communities are already online in 5 languages. According to the signed agreement EURORDIS retains all aspects of the project and GSK obtains no right other than the donor's rights set in the LoA.

Our support represents 1.8% of their overall income.

**During 2011:**

- We gave an unrestricted grant of €10,000 to become a member of the round table of companies. This was created to establish a long-term educational relationship between Eurordis and companies that have an interest in orphan drug development.
- We gave a grant of €35,000 to contribute to the occasion of the first EURORDIS Gala Dinner (held on 29th February 2012). Overall the funds collected at this event are used by EURORDIS in an unrestricted way for the organisation's main activities.
- In addition, we provided €25,000 to support the RareConnect:Online Patient Communities project, a webtool to allow rare disease patients to interact and exchange information on their disease and their life managing their disease. According to the signed agreement EURORDIS retains all aspects of the project and GSK obtains no right other than the donor's rights set out in the Letter of Agreement. Overall our funding represents 2.26% of their overall income.

**During 2010:**

- We gave an unrestricted grant of €10,000 to become a member of the round table of companies. This was created to establish a long-term educational relationship between Eurordis and companies that have an interest in orphan drug development.
- We gave an educational grant of €5000 to help support the organisation of the 5th European Conference on Rare Diseases ECRD in Krakow, Poland.

Our funding represents around 0.42% of their income overall.

**During 2009:**

- We gave an unrestricted grant of €10000 to become a member of the round table of companies. This was created to establish a long-term educational relationship between Eurordis and companies that have an interest in orphan drug development.
- Also we gave an educational grant of €5000 to support the organisation of Eurordis Membership meeting on 8 and 9 May in Athens.

**During 2008:**

- We gave an unrestricted grant €10,000 to become a member of the round table of companies. This was created to establish a long-term educational relationship between Eurordis and companies that have an interest in orphan drug development.
- In addition we gave an educational grant of €5,000 to help support the Eurordis annual membership meeting held in Copenhagen in May.

**During 2007:**

- We gave an unrestricted grant of €10,000 to become a member of the round table of companies. This was created to establish a long-term educational relationship between Eurordis and companies that have an interest in orphan drug development.
- In addition we gave an educational grant of €1000 to help support the Eurordis annual membership meeting.

Our funding represents around 0.4% of their income overall.

**In 2006:**

- We gave an unrestricted grant of €10,000 to become a member of the round table of companies. This was created to establish a long-term educational relationship between Euordis and companies that have an interest in orphan

Our funding represents less than 1% of their income overall.