

# INFORMATION PACK



28 FEBRUARY 2017

## RARE DISEASE DAY

PATIENT INVOLVEMENT: RESEARCH

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JOIN THE INTERNATIONAL CAMPAIGN TO RAISE  
AWARENESS FOR RARE DISEASES



**RAREDISEASEDAY.ORG**

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## What is Rare Disease Day?

Launched by [EURORDIS](#) and its Council of National Alliances in 2008, Rare Disease Day has and continues to collaborate with organisations globally in order to put on events, create media coverage, and ultimately raise awareness amongst the general public and policy-makers about rare diseases and their impact on patients' lives.

The strong momentum behind the cause and for the international campaign around Rare Disease Day was started and continues to be led by patients and patient organisations. The primary drivers and beneficiaries of the international campaign are the millions of people around the world living with a rare disease and their families.

Rare Disease Day also serves in helping to generate the political momentum necessary to further advocacy purposes. In the past, Rare Disease Day has notably contributed to the advancement of national plans and policies for rare diseases in a number of countries. The objective is for the last day of February to become officially recognised as Rare Disease Day by the World Health Organisation and to raise increasing awareness for Rare Diseases worldwide.

[Rare Diseases International](#) (RDI) continues to be a strong common voice on behalf of all people living with a rare disease around the world. In October 2016, the Rare Diseases Conference in South Africa saw the launch of the African Alliance for Rare Diseases. The conference proved to be very useful in forwarding the rare disease agenda in South Africa and across the African continent and will hopefully be just the start of the rare disease dialogue in Africa.

November 2016 saw the successful inauguration of an [NGO Committee for Rare Diseases](#). The launch event took place at the United Nations Headquarters in New York, where over a hundred rare disease stakeholders joined together to discuss the global state of play for rare diseases. The Committee will aim to ensure that no one person living with a rare disease is left behind and in turn serves to advance efforts to achieve UN's Sustainable Development Goals (SDGs).

On [rare diseaseday.org](http://rare diseaseday.org) you can find more information about Rare Disease Day as well as about the thousands of events happening around the world to build awareness for people living with a rare disease, and the support groups around them. If you would like to get involved, register your details on our [Post your Event](#) in order to get your event listed.



# Rare Disease Day 2017

Rare disease research is crucial to providing patients with the answers and solutions they need, whether it's a treatment, cure or improved care.

On 28 February 2017, the tenth edition of Rare Disease Day will see thousands of people from all over the world come together to advocate for more research on rare diseases. Over the last few decades, funds dedicated to rare disease research have increased. But it can't stop there.

Rare Disease Day 2017 is therefore an opportunity to call upon researchers, universities, students, companies, policy makers and clinicians to do more research and to make them aware of the importance of research for the rare disease community.



Rare disease patients and families, patient organisations, politicians, carers, medical professionals, researchers and industry will come together to raise awareness of rare diseases through thousands of events all over the world.

Rare Disease Day 2017 is also an opportunity to recognise the crucial role that patients play in research.

Patient involvement in research has resulted in more research, which is better targeted to the needs of patients. Patients no longer solely reap the benefits of research; they are empowered and valued partners from the beginning to the end of the research process. Patients:

- Advocate for research on a specific disease or across diseases. They know where research is needed and work to influence research bodies and companies to prioritise these areas in their research.
- Fund research. Individuals or patient organisations such as the AFM-Téléthon often raise money for clinical trials or research projects, on their own or in partnership with private funding initiatives.
- Partner in research projects and are included in the governance of research.
- Participate as subjects in clinical trials and also in the design of clinical trials. They therefore help to ensure that the development of a medicine takes into account their real needs, so that the patient perspective is not overlooked.

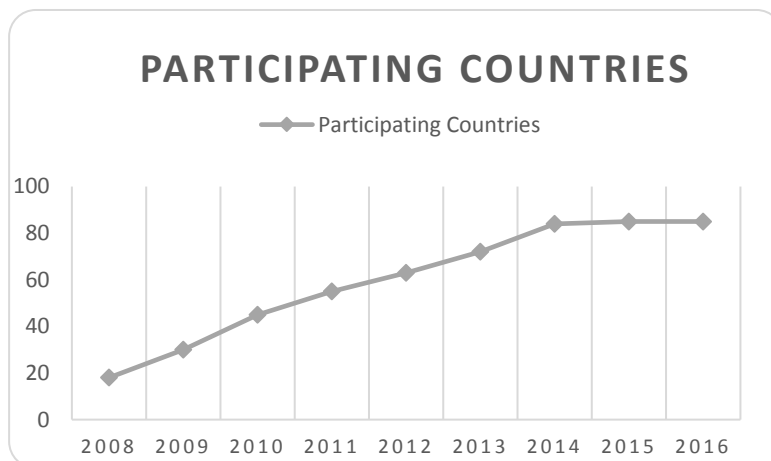


# 10 Years of Rare Disease Day

Succeeding in its vision of raising awareness for rare diseases, Rare Disease Day has grown dramatically since its creation by EURORDIS and the Council of National Alliances in 2008. February 29 2008, assigned 'A rare day for very special people', played witness to events in 18 participating countries, with personalities such as Germany's former First Lady, Lady Eva Luise Köhler, and Swedish Crown Princess Victoria taking part in events.

EURORDIS continues to coordinate the international campaign together with a worldwide patient community. Patient organisations from North America joined in 2009 and then all continents by 2010. In 2016, 39 National Alliances from 37 countries worked together to build the campaign, which includes the theme, slogan and communications materials.

The number of participating countries has increased year-on-year, with thousands of events taking place on all continents for Rare Disease Day 2016. In total, events have taken place in over 100 countries since 2008. Previous years have played witness to events such as Rare Disease Day barbecues on beaches in Australia, to scientific symposiums in Bahrain. On Rare Disease Day in 2013 the number of tweets that were talking about rare diseases reached 17 per minute, and in 2015 the Rare Disease Day official Rare Disease Day official video was viewed by 1.5 million people on Facebook alone.



The infographic below shows the increase in participating countries. Video views have also skyrocketed, reaching a high in 2015 with 1.5 million views. These increases indicate that Rare Disease Day is continuing in its aim of raising awareness for rare diseases.



# The Role of EURORDIS

EURORDIS, with the Rare Disease National Alliances, leads the coordination of Rare Disease Day internationally by developing common communication awareness-raising tools that are freely available in the Download area of the website. As well as overseeing the organisation of Rare Disease Day, EURORDIS also hosts an annual European-level event with policy makers and other stakeholders, moving forward European policy to improve the lives of people living with a rare disease. Finally, EURORDIS disseminates press information to help patient organisations around the world build press relations in order to raise awareness and advance key policies and initiatives, all with the overarching aim of benefitting those living with a rare disease.

EURORDIS regularly updates the rare disease community about the campaign, involving them as far as possible. In the run up to the event EURORDIS collects and disseminates patient stories, photos, and videos from the rare disease community.



## The Role of National Alliances

National Alliances are umbrella patient organisations that group together a wide range of disease organisations within their particular country. There are currently 39 National Alliances in 37 countries, including at least one on each continent. National Alliances ensure the coordination of Rare Disease Day at a national level, working with patient organisations locally and often organising a national event, calling on policy makers.

National Alliances also collect patient stories, often using them to maintain press and media relations in the run up to Rare Disease Day, which builds on the international momentum and international movement for the cause.

You are able to find out more about National Alliances, as well as view the events that they are hosting in their particular countries by visiting the [Events Worldwide](#) section of the Rare Disease Day



# How to Raise Awareness

EURORDIS recognises that each country and/or region has unique needs and therefore requires different approaches to make the most of the campaign. We encourage you to adapt the campaign to reach as wide an audience as possible in your country. The role of EURORDIS and the Council of National Alliances is to provide a framework for the Rare Disease Day campaign, offering guidance, and core materials. You are encouraged to use the theme of [Research](#), as well as to adapt the slogan (which is coming soon) to fit with your language and culture. Theme and slogan translations for French, German, Italian, Portuguese, Spanish, and Russian will be available for your use.

The overall objective of Rare Disease Day is to raise awareness amongst the general public about rare diseases and their impact on patients' lives. At an EU level, the aim is to raise awareness amongst EU institutions in order to make rare diseases a priority in EU public health, research agendas, and budgets. However, depending on the situation of rare diseases in your country, and the aims of the National Alliance, you may want to set up your own specific objectives for the campaign.

## Raising Awareness Activities:

- Send a press release to the media in your region/country.
- Organise interviews with the media to talk about the situation of rare disease patients in your region/country (magazines, newspapers, television, and radio)
- Organise events around rare diseases and the topics important to patients in your country (conference, workshops and meetings, walks, demonstrations, sports events etc.)
- Organise a political event to advocate for rare diseases to your local authorities/present a petition or a manifesto.
- Approach an important/famous personality and invite them to be the patron for the day in your country.
- Give out awards to people who are recognised for having acted effectively or outstandingly for the cause of rare disease patients.
- Hold a competition centred on rare diseases (art competition, photo contest, essay writing challenge etc.)
- Invite schools to involve children via essay writing campaigns or other educational initiatives.
- Display posters, images, or other awareness raising displays.
- Distribute stickers, flyers, or badges to people on the street, in schools, hospitals, or universities.
- Make appointments to meet with your local and national authorities, in particular those involved in research and the diagnosis, treatment, and care.
- Organise a visit by a politician or local authority to a rare disease research laboratory or centre of expertise.
- Organise fundraising events or a special fundraising campaign.

The media is the best way of reaching the general public and serves to shape the opinions that will convince policy makers. Visit the [Download Materials](#) section on the Rare Disease Day website for our tips and tools on the most effective ways to approach the media when planning your Rare Disease Day awareness campaign. For more ideas and to see what has been done in previous years, visit the [Highlights](#) section of the Rare Disease Day website.

## Rare Disease Day Guidelines

EURORDIS makes all communications materials available for free on the website. However, you are asked to use them within the following guidelines:

- Whilst it is stated that Rare Disease Day will always be on the final day of February, individual and national calendars sometimes mean that events may take place on a weekend, for several days, a week, or a single day other than the final day in February, but always as close as possible to the last day in February.
- National Alliances or patient organisations may take the opportunity to collect funds or convince sponsors to support their actions, whilst others may prefer not to carry out any fundraising on the day.
- Rare Disease Day must not serve to promote any specific commercial interest and no visibility should be given to any products.

The Rare Disease Day logo is a registered trademark, not to be used for commercial purposes. The logo may only be used in support of organised activities commemorating and/or promoting the Rare Disease Day. The logo, if used, should stand alone. Do not alter the logo in any way such as by changing the design, colours, or the proportions, or crop it, or combine it with any other logo. In case it is not possible to use the correct colours due to technical limitations, use the logo in black and white. A non-compliant use of the logo constitutes an infringement of EURORDIS' trademark rights.



## Download Materials

EURORDIS makes available a variety of tools which are easy to download from the [Download Materials](#) section of the Rare Disease Day website.

- **Logo:** due to playing fundamental part in creating the brand, we ask for consistent use of the logo to ensure maximum impact. The Rare Disease Day logo has remained the same since the launch of the day in 2008. See above in bold for further details about logo guidelines. All versions of the logo will be available in the materials pack.
- **Video:** the worldwide video campaign will be launched 15 days before Rare Disease Day. Everyone will be encouraged to send the video to a friend or to share online in order to contribute to the viral success of the video campaign. The video can be used to introduce events and to attract media attention. The 2016 video was translated into 34 languages. If the video is not translated into your language, please email [rarediseaseday@eurordis.org](mailto:rarediseaseday@eurordis.org).
- **Banner:** a static digital advert will be created for the 2017 campaign, we encourage you to use it on your website and email signature during the month of February.
- **Information Pack:** we encourage you to use this information pack, to translate it, and to send it to your members and contacts in order to help them organise their own Rare Disease Day activities.



- **Website:** for any additional information please consult the Rare Disease Day website, [rarediseaseday.org](http://rarediseaseday.org). If you are holding an event, tell us about it and send in the details!

## Register Your Event and Become a Friend

Following the update of the Rare Disease Day website in 2015, it is now incredibly simple to get involved in the campaign. If you are an organisation that is ready to host an event, then simply go to the [Get Involved](#) section of the website and fill out the form on the [Post Your Event](#) page. Once your event is approved, you will then be able to manage your event on the Rare Disease Day website.

The Become a Friend of Rare Disease Day initiative recognises that not everyone is able to commit the same level of time and effort to the Rare Disease Day, and **so opens the day up to everyone** willing to participate. Friends may be researchers, carers, health professionals, public authorities, patient groups, or any other person or entity. All that becoming a Friend requires is the posting of the Rare Disease Day logo on your website, and the posting on your website of a link to [rarediseaseday.org](http://rarediseaseday.org). The website will display the list of people and organisations who have signed up as a Friend.

## Tell Your Story and Raise and Join Hands

The Rare Disease Day website also allows anyone to upload a photo or video, and post a short testimony in their own language. The Rare Disease Day Photo Wall and the collection of Rare Disease videos displayed on the website help to both inform and raise awareness – sending a message of solidarity and giving a sense of community. [Tell your story](#) and encourage others to do the same!

The Join and Raise Hands! initiative, which began in 2012, aims to create a stand of solidarity with rare disease patients around the world by showing visually that we are mobilised and share the same objectives. To participate take your picture joining and raising hands, ideally next to or in front of a landmark or in a location that is recognisable in your country, record the event with a photo and submit it on the [Raise and Join Your Hands!](#) page.



## Social Media

Various online platforms have been set up to enable social interaction between all who share an interest in rare diseases and Rare Disease Day. Help us to share information, make contacts, build the rare disease community, and to create a buzz around Rare Disease Day.



