**#RAREDISEASEDAY** 

# GUIDELINES FOR COMPANIES TO JOIN RARE DISEASE DAY



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### Thank you for your interest in raising awareness for Rare Disease Day!

Taking place every year on the last day of February, Rare Disease Day is the globally-coordinated movement on rare diseases, working towards equity in social opportunity, healthcare, and access to diagnosis and therapies for people living with a rare disease. It brings together the worldwide community of patients, families, patient organisations, healthcare professionals, industry, institutions & policy-makers to raise awareness. It is coordinated by EURORDIS-Rare Diseases Europe, Rare Diseases International and 70 National Alliances partners worldwide.

While the overarching purpose of the campaign is to work towards equity, each national alliance may choose to focus on a different aspect of it. For instance, while one may emphasize access to treatment, another might highlight social inequalities. In any case, those national alliances will need your support in raising awareness to have an effective and coordinated national campaign.

### **OUR AIM: EQUITY**

**Equity** means promoting fairness by treating people differently, depending on their needs. On **Rare Disease Day** we call for action for people living with a rare disease to have equal opportunities to realise their full participation in family, work and social life.

### Read our Equity toolkit to learn more

For any questions you might have concerning **how you can use our logo** (a registered trademark globally), **please read the terms of use.** 





This year, our creative concept is: "More than you can imagine!" This is the way we are inviting everyone to join the campaign and raise awareness for the 300 million people living with a rare disease.

In concrete term, what does it mean for you as a company and for your employees?

How can you get involved?

# SUPPORT YOUR LOCAL PATIENT ORGANISATIONS AND GROUPS



We encourage you to not take away from the patient organisations' message and thus to avoid holding a parallel campaign.

We know your dedication to look to amplify the efforts of patient organizations in the disease area you are working in or in the areas you are communicating in. **They definitely need your support!** 

You can **contact them** to learn how to best assist them and their events. **By carrying their message** to both the general public and policymakers (locally, nationally or internationally), you can make a real difference in spreading awareness for the people living with a rare disease.

### ORGANISE AN EVENT FOR RARE DISEASE DAY

Let your creativity unfold and organise an event with your employees, suppliers, partners... to raise awareness for Rare Disease Day!



You can plan a webinar, challenge your collaborators with a sporting activity or even exhibit the best Rare Disease Day art pieces. The possibilities are infinite. Check our interactive map to get inspired.

Don't forget to register all of your events on our website and to follow our logo's terms of use.





### **JOIN THE GLOBAL CHAIN OF LIGHTS**

## In an effort of global solidarity, you are invited to light or decorate your offices with the Rare Disease Day colours at 7 PM your local time on Rare Disease Day.



On Rare Disease Day, we initiate the #LightUpForRare movement to shine a light on the 300 million people living with a rare disease worldwide. Read our dedicated webpage and toolkit to learn more.

You are welcome to project our logo outside your office as long as it is not on a wall that displays your own company's logo. Please see the following example using the logo "the Y" to represent a fictitious company:





If you are in doubt, please refer to the logo's terms of use.

The #LightUpForRare movement is a great opportunity to get your employees involved!



You can take advantage of a symposium to take a picture all together with lights using your phone's flash.

By simply using transparent post its you can even easily achieve coloured lights.



You can encourage them to take selfies using our filters (more information on that in "Raise awareness digitally"), guirlands, or following any other suggestions mentioned on our website.

You can install a photobooth in your lobby, next to your coffee machine...



### JOIN THE CAMPAIGN DIGITALLY

### Leverage all of our resources and spread our call for equity with your online community.



Every year we produce digital assets for everyone in the rare disease community to use. They are made available on our <u>website</u> on **the campaign launch 100 days before Rare Disease Day**.

Once again if you are in doubt, please refer to the logo's terms of use.



Every year we produce an official video. It will be available on our YouTube channel.



On our website, you can download social media filters as well as social media cards. We are encouraging you to share those assets on your social media channels. We are inviting you to use the #RareDiseaseDay and not embed your commercial logo.

On our <u>website</u>, you can download **social** media frames and banners. Those assets should not be used as your profile or cover picture on your company's professional page. It could confuse the general public.

Nevertheless, we encourage you to invite your employees to use them on their own social media channels, including LinkedIn, on Rare Disease Day or during the countdown after the campaing's launch.

Please see an example below with the logo "the Y" still representing a fictitious company:





All of those materials can be **translated and adapted.** If you choose to translate them to target specific audiences, we would appreciate you **sending them to us so we can upload them to the website,** making them available for others.

### INVOLVE EVERYONE AT YOUR OFFICE



To spread awareness inside your company, the best option is to encourage every employee to get involved!





You can send your employees our **virtual** background.

It can be used for Zoom, Teams or Google meet. We would like to kindly ask you to **not embed your logo on it**.

### **BECOME OUR FRIEND**

Show your support for the campaign and share how you are raising awareness.



You can register to become a Rare Disease Day friend on our website.

We are very grateful for all of your help in **raising awareness for Rare Disease Day**. We need you for the campaign to be successful worldwide.

Each and every one can make an impact!

Together, we are stronger.