#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 a global movement which **aims to promote equity in social opportunities, healthcare, and access to diagnosis and therapies for individuals living with rare diseases.** This initiative brings together a worldwide community, including patients, families, patient organisations, healthcare professionals, industry leaders, institutions, and policymakers to raise awareness. The coordination of Rare Disease Day is a collaborative effort between EURORDIS-Rare Diseases Europe, Rare Diseases International, and 71 National Alliance partners across the globe.

While the main objective of the campaign is to strive for equity, each national alliance may choose to focus on specific aspects. For example, one alliance may emphasise improving access to treatment, while another might spotlight social inequalities. Regardless of the chosen focus, these national alliances greatly benefit from your support in raising awareness to execute an effective and coordinated national campaign.

OUR AIM: EQUITY

On Rare Disease Day, we call for **equity**, which means **advocating for fairness by tailoring support to individuals' specific needs**. We believe that people living with a rare disease should have equal opportunities to fully participate in their families, workplaces, and social lives.

Read our Equity toolkit to learn more

If you have any questions about using our **globally registered trademark logo**, please refer to <u>the terms of use for guidance</u>.





This year, our key message is: "Share your Colours!" It's our way of inviting everyone to participate in the campaign and raise awareness for the 300 million people living with a rare disease.

So, what does this mean for your company and employees? How can you get involved?

SUPPORT YOUR LOCAL PATIENT ORGANISATIONS AND GROUPS

We encourage you not to overshadow the messages of patient organisations and to refrain from running a separate campaign.

We appreciate your commitment to amplifying the efforts of patient organisations in your disease area or communication domains. **They certainly need your support!**

Reach out to them to understand how you can support their initiatives and events. **By championing their message** to the general public and policymakers, whether at the local, national, or international level, you can truly contribute to raising awareness for 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 organise a webinar, challenge your colleagues with a sporting activity, or even showcase the finest Rare Disease Day art pieces. The possibilities are infinite. Check our <u>interactive map</u> to get inspired.

Remember to <u>register all your events on our website</u> and adhere to the terms of use for our logo.





JOIN THE GLOBAL CHAIN OF LIGHTS

On Rare Disease Day, we invite you to light up or decorate your offices with the vibrant Rare Disease Day colours at 7 PM local time. Let's illuminate the world for the 300 million people living with a rare disease worldwide.



Participate in the #LightUpForRare movement and visit our <u>dedicated webpage</u> and <u>toolkit</u> for more information.

Feel free to project our logo outside your office, but please ensure it's not on a wall that displays your own company's logo. See the example below 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!



Capture the moment at a symposium! Take a group photo with lights using your phone's flash. Simply add transparent post-its for colourful effects.

Boost participation by suggesting selfies with our filters (details in "Raise awareness digitally"), light strings, or other creative ideas from <u>our website</u>.

Set up a photo booth in your lobby, near your coffee machine, or any fun spot!



JOIN THE CAMPAIGN DIGITALLY



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 raise awareness within your company, the best approach is to encourage every employee to participate!





You can send your employees our <u>virtual</u> <u>background</u>.

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.