#ShowYourRare for Rare Disease Day

Get involved in Rare Disease Day 2018!

What?

The 11th edition of Rare Disease Day will take place on 28 February 2018. Take part in an interactive face paint social media campaign to raise awareness of rare diseases and show your support for the rare disease community! **Show your rare. Show you care.**

Take part in the **#ShowYourRare** campaign during the **entire month of February** 2018.

Who can get involved?

Rare Disease Day is for **everyone** - the general public, rare disease patients, their families, carers, healthcare professionals, researchers, companies and politicians. You do not have to be directly affected by a rare disease, everyone can get involved!

How?

It's simple! Post an image or selfie on any social media channel with your face painted and include the hashtags **#ShowYourRare**, **#MyRare** or **#RareDiseaseDay**. Share an image on your own or with your friends, family or colleagues!



Some ideas:

- Copy the face paint designs from the Rare Disease Day <u>poster</u>.
- Paint your face with the Rare Disease Day logo colours if you have them or with any face paints you have! Eye liner or lipstick can also be an effective replacement for face paints (*please be careful with sensitive skin and allergies!*)
- Paint the hands from the <u>Rare Disease</u> <u>Day logo</u> on your face.
- Draw the #MyRare hashtag on your cheeks or forehead!



Prefer not to paint your face? Let's get creative:

Use your kids' paints to do some hand prints on a piece of paper in the shape of the hands of the <u>Rare Disease Day logo</u>. Or draw around your hands on a piece of A4 paper, paint them, add the hashtag #MyRare or #ShowYourRare, take a selfie and share on social media!

Alternatively, print the <u>Rare Disease Day logo</u> or <u>2018 poster</u>, add the hashtags, take a selfie and share on social media! You could also draw the hashtag on your clothes (with consent from parents!) or bandages.

More about the #ShowYourRare campaign

The **#**ShowYourRare campaign is the inspiration for the <u>Rare Disease Day 2018 poster</u> and video (*out in January*!).

Rare diseases affect an estimated 300 million people around the world. There are over 6000 different diseases. So rare's not so rare after all. Support the rare disease community by showing your rare. With your help, we can raise awareness and increase support for research.

Rare needs research. Rare needs you: rarediseaseday.org/article/show-your-rare

The reality of living with a rare disease

The millions of people affected by rare diseases around the world face huge challenges every day. Imagine going to multiple doctors who cannot diagnose your condition. Or that there is no existing treatment for your disease, or the available treatment is too expensive.

Imagine the social system around you – school, work, social services – is not adapted to your needs. Imagine the financial burden and stress caused by having to travel hours or days to get to the only specialist that can help your child.

Imagine there are only a handful of people living with your disease around the world and little or no research on your disease. Imagine the isolation you would feel. These are just some of the challenges that people living with a rare disease, their families and carers face.

About Rare Disease Day

<u>Rare Disease Day</u> is *the* international awareness-raising campaign for rare diseases. Since Rare Disease Day started in 2008, thousands of events have taken place throughout the world, reaching **millions of people**. The campaign started as a European event and has progressively become a world phenomenon, with participation in <u>94 countries</u> **all over the world in 2017**.

The theme for 2018 is <u>research</u>. Rare Disease Day 2018 is an opportunity for participants to be part of a global call on policy makers, researchers, companies and healthcare professionals to increasingly and more effectively **involve patients in rare disease research**.