

Voices from patient organisations and government officials

Munich, as of April 2024

"The campaign gave us the opportunity to have an interactive element in our social media campaign for Rare Disease Day. This element was, among other things, used to reach out to many stakeholders encouraging them to take part in the campaign to create more visibility around rare diseases. Also, we had two life size zebras to colour up! This was a very nice and inclusive activity on Rare Disease Day in Aarhus and Copenhagen.

The attendance of Her Majesty Queen Mary colouring up parts of the zebra together with children with a rare disease created a lot of valuable attention.

It is about creating a strong community for rare people to break the isolation and loneliness, that often comes along with rare diseases and handicap, where knowledge is a scarce resource. It is also about creating more public attention for patients living with a rare disease not to be ignored and overlooked."

Lene Jensen, Director of the patient organization Sjældne Diagnoser, Denmark



Her Majesty Queen Mary is the Patron of the WHO Regional Office for Europe. On 29 February 2024, she honoured the event in Copenhagen, organised by the Danish patient organisation Sjældne Diagnoser, by painting the life-size colourUp4RARE zebra statue together with children living with a rare disease.
© Photo credit: Michael Stub, Copenhagen

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This campaign supports people with rare diseases and the work of:



The colourup4rare partners 2024 vary per country. Collectively, they are:



"The interactivity in social media was a wonderful add-on to our awareness campaign and could engage those of our members that were stuck home due to their rare diseases.

The colouring post cards and posters made so many adults happy we sent a lot of postcards from 13 hospitals all over. It gave our volunteers time to chat with people in an easy way and gave them a physical activity at the same time.

Exactly as Lene said, rare diseases and disabilities are not outliers of statistics, but a large group of people with a voice, life, and purpose beyond their diagnoses. The general awareness brings us closer to the politicians and law makers, so we don't fall through the cracks of healthcare and social welfare systems but are recognized as valid population groups with very specific needs."

Katri Asikainen, President of the patient advocacy group HARSO ry, Finland

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"I'm glad that there are campaigns like this to raise awareness of this issue. Rare diseases are often not as rare as one might think – the more, they are associated with a high level of suffering for people. That's why we need to make progress in research. We have various centres, including in Bavaria, where we carry out research at university hospitals, but I think we need to do more. It's important to take people with you, to inform them and I do hope that we really keep on doing so."

Klaus Holetschek, MdL, CSU parliamentary group leader in the Bavarian State Parliament, Germany



(from left to right) Erich Irlstorfer, Member of the Bundestag and of the Health Committee; Josef Kammermeier, Chairman 'Nothing is Forever e.V.' of the patient organisation Neurofibromatosis; Klaus Holetschek, Chairman of the CSU parliamentary group in the Bavarian State Parliament; Andrea Passalacqua, VP and General Manager Alexion Pharma Germany; Dominika Kowalski, Director Government Affairs and Policy, Alexion Pharma Germany; and Stephanie Ralle-Zentgraf, Director Communications Alexion Pharma Germany.

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"Making the concerns of people with rare diseases visible is not just something we can do alone. This is another reason why SoMA e.V., the self-help organisation for people with anorectal malformations, www.soma-ev.de, is a member of the umbrella organisation ACHSE e.V. I am personally very pleased that so many partners joined forces here in Munich on 29 February 2024 to support the colourUp4RARE initiative.

As the mother of a child affected by a rare malformation, I was a board member of SoMA e. V. for 25 years and can say that a lot has changed in society's awareness since then. I hope that such public relations work will continue to improve research and therapies - and that those affected by a rare disease will no longer feel alone."



Nicole Schwarzer, Network and Register Officer SoMA e.V., Germany

(from left to right) Nicole Schwarzer and Susanne Fröhler, SoMA Freundeskreis, Germany
© Photo credit: Rainer Haeckl, Munich, Germany

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"We at NF & Friends are grateful to be part of such a great campaign that has a global reach. Only through joint actions and the use of synergies do the rare ones have a chance of realising their goals."

Richard Lange, First Chairman of NF & Freunde e.V., Germany

Richard Lange, First Chairman of NF & Freunde e.V., testing the pens for colouring the zebra at the colourUp4RARE public event with a painting competition for children on 29 February 2024 in Neuss, Germany.

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