

## MEDIA RELEASE

**From Munich via Copenhagen and London to Montreal: More than 44,500 zebra stripes for people living with a rare disease.**

**More visibility for people living with a rare disease – this is what the campaign *#colourUp4RARE. Painting for the rare* stands for. Around the International Rare Disease Day in the last week of February 2024, the public was invited to participate in the colourUp4RARE online challenge to colour up stripes of zebras - the symbol for rare diseases. More than 6,000 people in 14 countries followed the call and coloured more than 44,500 zebra stripes.**

**Munich, April, 11, 2024** – This year, Rare Disease Day (RDD) has once again generated significant awareness for people living with rare diseases. For the second time in a row, a group of leading research-based pharmaceutical companies – this year with Alexion, Chiesi, Janssen, Novartis, Takeda, and UCB, in cooperation with the toy manufacturer Ravensburger - supported the worldwide awareness day with the online challenge *colourUp4RARE. Painting for the rare*. The call reached a large community: Over 6,000 people from 14 countries coloured more than 44,500 stripes of a digital zebra herd in the RDD colours blue, pink, green, and purple during the campaign period from February 26 through March 3. Each stripe represents increased awareness for people living with a rare disease and for their families.

### **Zebra colouring – in-person and digital**

The digital campaign complemented the in-person events in Munich, Berlin, Neuss, Copenhagen, London, and in many other cities, where attendees at campaign booths could colour life-size zebra models and exchange ideas with experts, representatives of patient organizations, and government officials. The *colourUp4RARE campaign. Painting for the rare* has been implemented in numerous countries across Europe and in Mexico and Canada.

"The Internet and social media provide us with the reach we need to spread our messages," says Stephanie Ralle-Zentgraf, Director of Communications at Alexion, AstraZeneca Rare

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

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



Canadian Organization  
for Rare Disorders



Disease, and initiator of the campaign. "By raising public awareness of the challenges affected people are facing, we are also increasing awareness of the need for improved framework conditions for research and development of new diagnostic and treatment options."

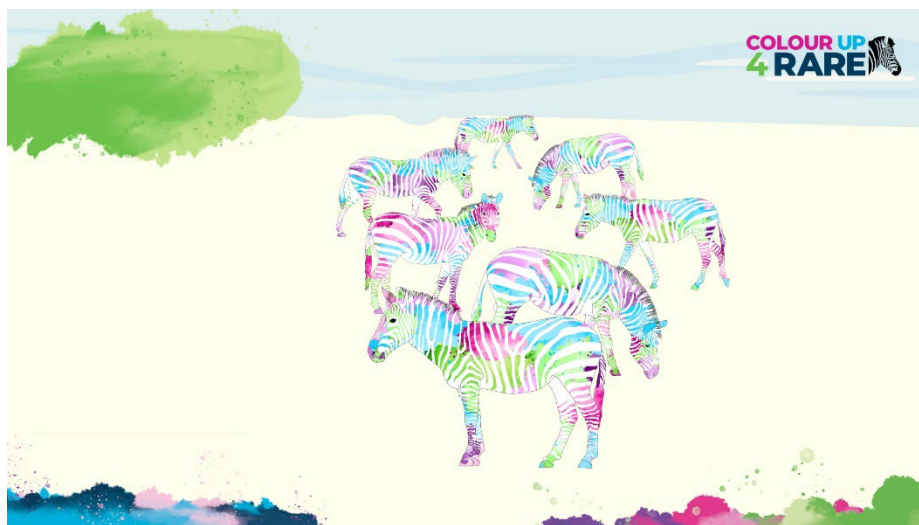
#### **Briefly – colourUp4RARE online challenge 2024 in figures**

- **44,592** stripes were coloured digitally.
- **6,028** people (unique visitors) participated in the online challenge.
- Campaign activities took place in **14** countries: Germany, Austria, Switzerland, Belgium, Denmark, Finland, France, Iceland, Italy, The Netherlands, Spain, and United Kingdom as well as Mexico and Canada.
- **13** life-size zebra models will continue their journey following the 2024 campaign to draw attention to rare diseases on various occasions throughout the year.
- **11** patient organisations – international and national umbrella organisations for rare diseases along with their member organizations, gained increased visibility for their ongoing efforts in support of patients affected by a wide variety of rare diseases.

#### **Media contact**

The Syneos Health agency is happy to receive your questions: [rdd@syneoshealth.com](mailto:rdd@syneoshealth.com)

## Artwork



A total of 44,592 stripes were painted at the **colourUp4RARE** 2024 online challenge – coming close to 14 online zebras. © Photo copyright: [www.colourUp4RARE.com](http://www.colourUp4RARE.com). Event pictures are part of the media kit available on [www.colourUp4RARE.com](http://www.colourUp4RARE.com) under NEWS.

## From a Patient Organisation and Government Official Perspective

The significance and impact of the campaign from a patient organisation and government official perspective – please find a **Collection of Statements and Quotes** enclosed in a separate media document.

### About colourUp4RARE

colourUp4RARE is organised by the research-based pharmaceutical companies Alexion, Chiesi, Janssen, Novartis, Takeda, UCB and supported by the toy manufacturer Ravensburger. The campaign is part of a joint commitment in the rare disease field, as called for by patient advocacy groups, the medical community, policy makers and the EU Commission, while promoting better conditions for research and development of new diagnostic and treatment options, and for improved care. The aim is to join forces to improve the quality of life of people living with a rare disease. colourUp4RARE was initiated by Alexion in 2023. In 2024, the campaign was expanded from the D-A-CH region (Germany, Austria, Switzerland) to include many other European countries (Belgium, Denmark, Finland, France, Iceland, Italy, The Netherlands, Spain, and United Kingdom) as well as Mexico and Canada. Learn more about the international campaign at [www.colourUp4RARE.com](http://www.colourUp4RARE.com).

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