Rare Disease Day 2026

Social media promo pack

For Rare Disease Day 2026 (RDD 2026), Genetic Alliance UK are exploring what equity looks like for people with rare conditions. We've been listening to people affected by rare conditions from across the UK to help us understand what equity means to them. Their input has helped us to create:

- Rare Disease Day 2026 messaging which will be delivered across in-person and online events, social media and press work
- An advocacy pack so that anyone can get involved, raise awareness and drive change
- Information sheets and a policy report that highlight the inequities faced by people with rare conditions and showcase important research and initiatives that are helping to inform how healthcare services can be delivered in a more equitable way for people with rare conditions.

Our Rare Disease Day 2026 campaign is delivered by the Genetic Alliance UK team and funded via sponsorships and grants. Thank you to our industry supporters. These organisations have had no involvement in the development of the campaign, or any of its content. Without their support our campaign would not have been possible.

- Alexion Pharmaceuticals
- Amgen
- Amicus Therapeutics
- BioCryst
- Biogen
- Chiesi
- Illumina
- Ipsen
- Jazz Pharmaceuticals
- Kyowa Kirin
- Novartis Pharmaceuticals
- Pharming
- PTC Therapeutics
- Sanofi
- Takeda
- Ultragenyx Pharmaceutical
- Vertex Pharmaceuticals

The project is funded in line with Genetic Alliance UK's working with the life sciences industry policy. Funders have had no involvement in the development of materials or content.

RDD 2026 timeline

Our advocacy pack launches on 30 January 2026.

Our information sheets and report will launch at our England Rare Disease day 2026 reception on 24 February 2026.

Receptions:

Scotland Rare Disease Day 2026 reception | 19 February 2026 | Scottish Parliament, Edinburgh
England Rare Disease Day 2026 reception | 24 February 2026 | Palace of Westminster, London
Wales Rare Disease Day 2026 reception | 25 February 2026 | Norwegian Church, Cardiff
Rare Disease Day 2026 joint nation online event | 5 March 2026 | Online via Zoom

If you have any questions about anything shared in this promo pack, please email us via rarediseaseday@geneticalliance.org.uk

How you can help

We know that when we use our voices collectively, our message is stronger. Copy our post templates and share them from your own channels, alongside our downloadable RDD 2026 images, available in both portrait format (for Instagram, LinkedIn and Bluesky) and landscape graphics (for Facebook, LinkedIn and X).

Even easier, simply reshare our social media posts to amplify our voice and raise more awareness!

Tag us in your social media posts so we can engage with and amplify your messaging, using the hashtag **#RareDiseaseDay #rarequity**.

Instagram | **@RareDiseaseUK**
Facebook | **@GeneticAllianceUK**
LinkedIn | **@genetic-alliance-uk**
Twitter/X | **@GeneticAll_UK**
Bluesky | **@geneticallianceuk.bsky.social**

Rare Disease Day digital assets for you to use on social media

Social media assets

We have created digital assets using the EURORDIS brand to share on your social media. Download our Rare Disease Day 2026 visual assets for social media in:

- Portrait (for Instagram, Facebook, LinkedIn, etc)
- Landscape (for X, LinkedIn, etc)

Download at geneticalliance.org.uk/rdd26

Instagram: @RareDiseaseUK
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Hashtags: #RareDiseaseDay #rarequity
LinkedIn: genetic-alliance-uk
Twitter/X: @GeneticAll_UK
Email: rarediseaseday@geneticalliance.org.uk

Social media post templates

To be posted before Rare Disease Day 2026 (28 February 2026)

Posts for X/Twitter - to be used with landscape Rare Disease Day 2026 digital images

1.
3.5 million people in the UK live with a rare condition. @GeneticAll_UK 's #RareDiseaseDay2026 advocacy pack shares practical tips on how to use your voice to build an #equitable future for everyone in the rare conditions community. **http://bit.ly/4rp81yB**

2.
#RareDiseaseDay2026 is almost here!

@GeneticAll_UK will be sharing factsheets and a report to amplify the views of people with rare conditions and shine a light on their lived experiences of inequity. Coming #RareDiseaseDay 👀

3.
For #RareDiseaseDay, @GeneticAll_UK's report will amplify the voices of the rare community and their experiences of inequity. Raise awareness NOW with @GeneticAll_UK 's advocacy pack and use your voice to build an equitable future for the rare community **http://bit.ly/4rp81yB**

Longer posts for Facebook , Instagram and LinkedIn - to be used with portrait designs on Instagram and landscape or portrait designs on Facebook and LinkedIn

1.
There are 3.5 million people living with a rare condition in the UK. Everyone with a rare condition deserves fair and equitable care from the NHS, no matter how rare their condition is. Equitable care means addressing individual needs, not treating everyone the same.

For Rare Disease Day 2026, @GeneticAll_UK will be sharing factsheets and a report to amplify the views of people with rare conditions and shine a light on their lived experiences of inequity.

To raise awareness now, @GeneticAll_UK 's Rare Disease Day 2026 advocacy pack shares practical tips on how to use your voice to build an equitable future for everyone in the rare conditions community. **http://bit.ly/4rp81yB**

Coming #RareDiseaseDay 28.02.26 👀

Instagram: @RareDiseaseUK
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Twitter/X: @GeneticAll_UK
Email: rarediseaseday@geneticalliance.org.uk

2.
1 in 4 people wait at least three years for a rare condition diagnosis and only 1 in 20 rare conditions have an approved treatment or medicine to help.

Equity means different things to different people but we can all unite in calling for an end to the diagnostic odyssey and demanding timely and equitable access to specialised care, innovative treatments, and medicines.

For #RareDiseaseDay, @GeneticAll_UK will launch factsheets and a report to amplify the views of people with rare conditions and shine a light on their lived experiences of inequity.

You can help by joining us in raising awareness and sharing the report far and wide so that it's seen by changemakers - let's make this happen!

Coming #RareDiseaseDay 28.02.26 👀

3.
Unsure how to support Rare Disease Day 2026? We can help you to share that you care about rare!

To raise awareness now, @GeneticAll_UK 's Rare Disease Day 2026 advocacy pack shares practical tips on how to use your voice to build an equitable future for everyone in the rare conditions community. **http://bit.ly/4rp81yB**

For Rare Disease Day 2026, @GeneticAll_UK will also be sharing factsheets and a report to amplify the views of people with rare conditions and shine a light on their lived experiences of inequity.

There are so many ways to use your voice to build an equitable future for everyone in the rare conditions community. Get involved and share that you care about rare!

👉 geneticalliance.org.uk/rdd26

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To be posted on Rare Disease Day (28 February 2026)

Posts for X/Twitter - to be used with landscape Rare Disease Day 2026 digital images

1.
Happy #RareDiseaseDay!

We are joining @GeneticAll_UK and their 220+ members to call for an equitable future for everyone living with rare conditions. Add your voice to ours by sharing geneticalliance.org.uk/rdd26

2.
IT'S RARE DISEASE DAY!

Today is all about raising awareness and driving change for the 3.5 million people in the UK living with a rare condition, their families and carers. Help us raise awareness and amplify the voices of the rare community geneticalliance.org.uk/rdd26

Longer posts for Facebook , Instagram and LinkedIn - to be used with portrait designs on Instagram and landscape or portrait designs on Facebook and LinkedIn

1.
Happy #RareDiseaseDay!

We are joining forces with @Genetic Alliance UK and their 220+ member organisations to call for an equitable future for everyone living with rare conditions. Add your voice to ours!

Read and share Genetic Alliance UK's new report and access their advocacy pack which has practical tips on making your voice heard, today and throughout the year: geneticalliance.org.uk/rdd26

2.
IT'S RARE DISEASE DAY!

@Genetic Alliance UK has launched factsheets and a report to amplify the views of people with rare conditions and shine a light on their lived experiences of inequity. Their advocacy pack also gives practical tips and step-by-step guidance on how to raise rare awareness today and throughout the year. There are so many ways to share that you care about rare - how will you get involved?

👉geneticalliance.org.uk/rdd26

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