RARE DISEASE DAY®

RARE DISEASE DAY
28 FEBRUARY 2026

EQUITY FOR RARE

geneticalliance.org.uk/rdd26
#RareDiseaseDay

GENETIC ALLIANCE UK

RARE DISEASE UK

Rare Disease Day 2026

Advocacy Pack

Contents

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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.

Genetic Alliance UK is exploring the theme of equity for rare conditions as part of our Rare Disease Day 2026 campaign.

This advocacy pack will help you to raise awareness of Rare Disease Day 2026, campaign for equity for people with rare conditions and call for vital improvements in services, diagnosis and treatment. Your lived experience is your power. Use your voice to build an equitable future for everyone in the rare conditions community.

What is Rare Disease Day?

Rare Disease Day is a global, patient-led campaign coordinated internationally by EURORDIS-Rare Diseases Europe and organised in the UK by Rare Disease UK, the national campaign run by Genetic Alliance UK.

It takes place every year on the last day of February, the 'rarest' day of the year (29 February in a leap year, 28 February otherwise).

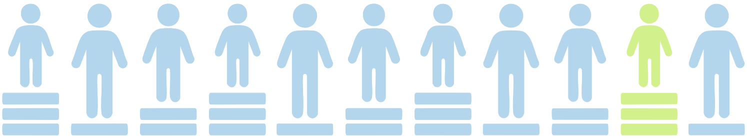
Rare Disease Day is a moment for the entire rare conditions community to stand in solidarity, raise awareness among the public and decision-makers and advocate for equitable access to diagnosis, care, and treatment for all people living with a rare condition.

About rare conditions

- Rare conditions are individually rare but collectively common, with over 3.5 million people in the UK living with a rare condition
- A rare condition is a condition that affects fewer than 1 in 2,000 people
- There are around 7,000 rare conditions, with new conditions regularly identified through scientific progress
- 1 in 17 people are affected by a rare condition at some point in their lives
- 7 in 10 rare conditions affect children
- More than 3 in 10 children with a rare condition die before their fifth birthday

Download our factsheet with more information about rare conditions

A definition of equity



EURORDIS-Rare Diseases Europe defines equity as ‘meeting people’s specific needs and eliminating barriers preventing their full participation in society.’ Rare conditions include rare cancers such as childhood cancers, rare infectious diseases, and some other well known conditions, such as cystic fibrosis and Huntington’s disease.

People living with a rare condition face many challenges with accessing health and social care services. This can happen for many reasons including a lack of knowledge among healthcare professionals to support timely diagnosis and appropriate treatment, or limited access to specialist centres where care is provided.

Other factors can also influence health outcomes and people’s experiences of healthcare, such as ethnicity, sex, socioeconomic status and where people live. People with a rare condition may have worse health outcomes than people in the general population due to the limited services and support available to them, and the support for people with different rare conditions is highly variable.

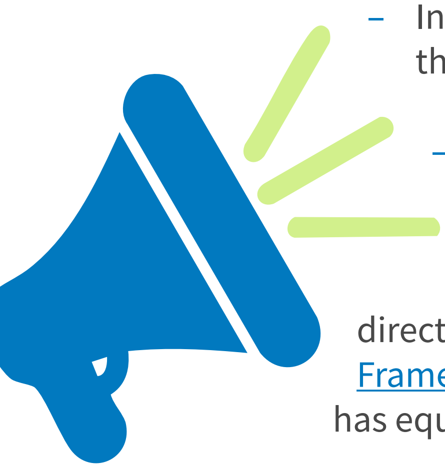
Differences in health opportunities and outcomes which are systematic, avoidable and unfair are defined as health inequities, which are important to address to ensure that services are equitable for all people in the UK. (England 2025 Rare Disease Action Plan - summary of health inequity scoping review).

Why your voice matters

People living with, or affected by, a rare condition are the experts in their rare conditions. Your personal story is the most powerful tool for driving change.

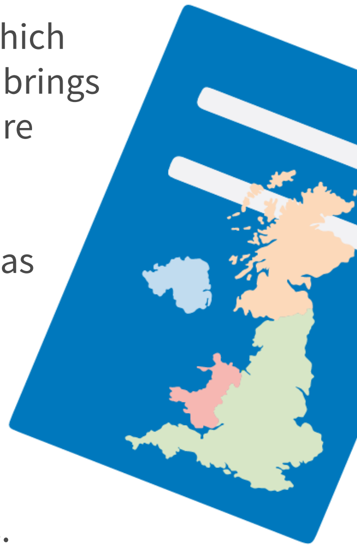
Sharing your experience is important because it can help to:

- Humanise statistics and data: It shows decision-makers and the public the real-life impact of rare conditions.
- Inform better policy: Your lived experience highlights the gaps in the system, such as diagnostic delays or lack of coordinated care, providing evidence for the changes we campaign for.
- Build community: It connects you with others, reducing isolation and fostering a strong, united community.



By raising your voice this Rare Disease Day, you contribute directly to the ongoing work to implement the UK Rare Diseases Framework and secure a future where everyone with a rare condition has equitable access to the best care.

What is the UK Rare Diseases Framework?



The UK Rare Diseases Framework is a UK-wide government strategy which aims to address challenges faced by all people with rare conditions. It brings together the four nations to deliver on key priorities for people with rare conditions.

By raising our voice over the last year, the rare condition community has helped to secure a one-year extension of the Framework so that the four nations can continue driving improvements in care for people with rare conditions until January 2027.

We now need to use the next year to be involved in the conversations about the future of rare disease policy in the UK and set new priorities.

Key messages you can use

When raising awareness and campaigning, it can be helpful to prepare a few clear, impactful messages that tell people and policymakers what changes you want to see and why. It is important that your messages reflect what matters most to you, but you can give your messages greater weight by connecting them to the shared concerns of the 3.5 million people in the UK living with a rare condition.

Here are some examples of key messages. You could focus your awareness raising and campaigning on the messages that mean most to you:

Call for equity for rare conditions

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.

Read the briefing on equity for rare conditions from EURORDIS

Renew the UK Rare Diseases Framework

The UK Rare Diseases Framework must be renewed, refreshed, and underpinned by ring-fenced funding to drive continued progress beyond 2026.

Read about our campaign for a renewed UK Rare Diseases Framework

End the diagnostic odyssey

1 in 4 people wait at least three years for a rare condition diagnosis. People with rare conditions need access to an accurate and timely diagnosis.

Read our factsheet for more information about diagnosis

Improve care coordination

Only 1 in 10 adults in the UK living with a rare condition have a care coordinator to help organise different aspects of their care. People with rare conditions need well-coordinated, holistic care pathways and access to care coordinators.

Read our factsheet on coordination of care for more information

Ensure timely and equitable access to specialised care, innovative treatments, and medicines

Only 1 out of 20 rare conditions have an approved treatment or medicine to help.

Read our factsheet on access to medicines

Invest in innovation

Call on the government to capitalise on scientific advancements, including genomics and AI, to accelerate pioneering research and early detection programmes like newborn screening.

Read our factsheet on newborn screening

Increase healthcare professionals awareness of rare conditions

Healthcare professionals need increased awareness and training of rare conditions to prevent misdiagnosis and improve early support. Medics For Rare Disease (M4RD) provide information and learning resources to healthcare professionals who want to know more about rare conditions.

How you can raise awareness

You don’t need to be a professional campaigner to make a difference! Here are simple and effective ways you can use Rare Disease Day to spread the word.

Talk about rare conditions

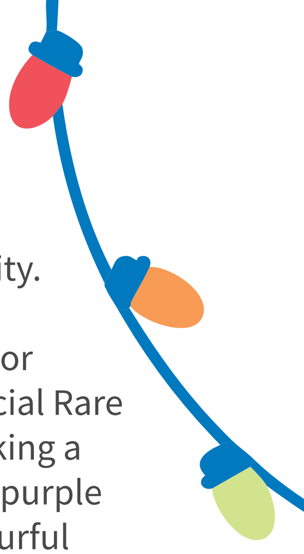
- This is a simple but crucial step. Start a conversation with people you know.
- Share with a friend or colleague: A quick chat over a cup of tea or a short email can be a powerful way to share with those around you. Explain why supporting people with rare conditions is important to you and others may offer their support too.

Share your story on social media

- Write a post about your condition, the impact it has, what you wish people understood or why supporting people with rare conditions is important to you. Adding a photo or graphic adds impact.
- Use the official campaign hashtags: #RareDiseaseDay #rarequity
- Download shareable graphics and factsheets from the [EURORDIS Rare Disease Day website]() or [Genetic Alliance UK’s Rare Disease Day webpage]().
- Tag Genetic Alliance UK on social media to help amplify your message.

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

Tag us in your #RareDiseaseDay posts



Light Up for Rare

The Global Chain of Lights is one of the most visible ways to show solidarity.

Light up or decorate your home: Illuminate or decorate a space, a room or window in your home or your garden with accessories or lights in the official Rare Disease Day colours (blue, green or purple). This could be as simple as taking a photo and then using a filter effect on your phone to add a blue, green or purple tint. You can use garlands, social media filters, candles, disco lamps, colourful decorations… let your creativity shine! At 19:00 local time on Rare Disease Day, share the photo via social media with the hashtags #LightUpForRare and #RareDiseaseDay and remember to tag Genetic Alliance UK.

Encourage a local landmark to light up for rare: Contact your local council, a community centre, or a prominent building in your area (like a school, museum, or business) and ask them to light up in the Rare Disease Day colours. Send them the official ‘Light Up for Rare’ Global Chain of Lights toolkit.

Schools toolkit

Offer to give a short talk to the class or assembly about rare conditions in general: EURORDIS, in collaboration with patient groups including Genetic Alliance UK, has developed free toolkits for explaining rare conditions to children and teenagers (typically ages 5-16), including lesson plans and stories. You can ask local schools to incorporate these into a lesson during February or another point during the year to raise awareness and improve understanding of rare conditions.

Awareness raising in the workplace or social clubs

The workplace, a book club, or sports team are great places to reach new people.

- **Run an event**: Host an afternoon tea, a cake sale or dress up day/casual clothes day. Organise a small event on or around Rare Disease Day. Ask colleagues or members to wear Rare Disease Day colours e.g. blue, green, or purple.
- **Send an email**: Ask permission to send a short email to your colleagues or club members explaining what Rare Disease Day is and why it matters to you. Include some of the key facts from this pack about rare conditions in the UK.
- **Put up a flyer**: Display our official Rare Disease Day flyer in a communal area (do get permission first, if required).

Write to Decision-Makers

Directly influencing politicians and policymakers is essential for improving services. Genetic Alliance UK leads campaigns that need your support and you can also have direct impact.

Contact your local representative

Write to your local representative (Member of Parliament, Member of Senedd, Member of Scottish Parliament, or Member of Legislative Assembly in Northern Ireland) to urge them to support action on rare conditions.

- Search for your representative's name and contact information online. The website TheyWorkForYou.com allows you to search for local representatives using your postcode.
- We have created templates to help shape your communications - our templates cover England, Wales, Scotland and Northern Ireland.
- Personalise it: Even if you use a template, include a few lines about your personal experience, what specific care improvements you need (e.g., better care coordination, faster diagnosis), and what you want them to do (e.g., support the UK Rare Diseases Framework, attend the Rare Disease Day reception).
- Share on social media: Publicly tag your local representative in your Rare Disease Day posts, encouraging them to get involved.

Invite your member of parliament to a Rare Disease Day event

Each year, Genetic Alliance UK hosts a parliamentary reception in Westminster, Holyrood and The Senedd. These events are an opportunity for parliamentarians to learn how they can drive changes in policy to improve the lives of people affected by rare conditions.

You can encourage your local representative (Member of Parliament, Member of Senedd, Member of Scottish Parliament) to attend our parliamentary receptions by writing to them and asking them to attend. Download our templates and send an invitation to your local representative.

- Invitation to the Scottish Parliament Rare Disease Day Reception
- Invitation to the Westminster Rare Disease Day Reception
- Invitation to the Welsh Rare Disease Day Parliamentary Reception

How you can have your voice heard year round

Rare Disease Day is an annual awareness day but the work to improve the experiences of people with rare conditions continues all year.

Get involved with Genetic Alliance UK's work

Genetic Alliance UK and Rare Disease UK rely on the experiences of people like you to drive policy change.

- **Sign up for updates**: Subscribe to the Genetic Alliance UK newsletter (Genetic and Rare News) to receive news on campaigns, policy developments, and opportunities to share your views.
- **Respond to campaign calls**: When Genetic Alliance UK asks the community to contact decision-makers or respond to government consultations, take action! Your collective voice is a powerful instrument and your email could be the tipping point for action.
- **Share your story with Genetic Alliance UK**: You can submit your written or video testimony to the Genetic Alliance UK and Rare Disease UK teams to be used in their policy and media work throughout the year. You can view examples of community stories on our website and we also have guidance on sharing your rare story with Genetic Alliance UK.

Share your story with the local media

Local media (newspapers, radio, community websites) are always looking for local stories that impact communities.

- **Write a press release**: A short summary of your story, what Rare Disease Day is, and your call to action (e.g., 'We need better coordinated care') is a good starting point. Use our guidance on how to write a letter/email to local media.
- **Contact them directly**: Email the news desk or a specific journalist a few weeks before Rare Disease Day. Be clear that you're a local resident and your story ties in with the national awareness day.
- **Be ready with key facts**: Have a few powerful facts about your condition and the overall rare community ready to share. Explain that while your condition is rare, the collective impact of all rare conditions is enormous.

Read our tips on how to share your story safely with local media.

Speak at events

Sharing your personal experience at events can be highly impactful.

- **Genetic Alliance UK events**: We organise high-profile parliamentary receptions in Westminster and the devolved nations as well as other events throughout the year.
- **Support group meetings**: Offer to share your tips and experiences with newly diagnosed families at your support group meetings.
- **Local community events**: Speak at a local rotary club, school, or community centre to raise awareness in your own neighbourhood. A good place to start is a community hub like a library – you can find details of your local library on the LibraryOn website.

Inform teaching and education by sharing your lived experience:

Higher Education Institutions (HEIs) like universities and colleges often incorporate lived experiences sessions into their teaching about genomics and rare conditions. Sharing your story is a powerful way to inform future health professionals about the impact of rare conditions.

- Contact Wales Gene Park (walesgenepark@cardiff.ac.uk) to take part in a Living with Genetic Conditions education session at one of the Welsh Universities.

Information on Genetic Alliance UK

Genetic Alliance UK is an alliance of over 220 organisations, charities and support groups working together to improve the lives of everyone in the UK living with genetic, rare and undiagnosed conditions.

Genetic Alliance UK supports people with genetic, rare and undiagnosed conditions by:

- **advocating for improved care**
- **progressing medical research**
- **increasing awareness**
- **improving information and support**

We run two long standing projects:

Rare Disease UK is a campaign advocating for equitable access to diagnosis, coordinated care, and specialist treatment for the 3.5 million people affected by rare conditions in the UK.
SWAN UK is the only dedicated support community in the UK for families affected by a syndrome without a name (SWAN) – a genetic condition so rare it often remains undiagnosed.

You can find further information on Genetic Alliance UK on our website, email us via rarediseaseday@geneticalliance.org.uk or contactus@geneticalliance.org.uk and keep up to date with our work by following Genetic Alliance UK across all social media platforms.

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