Rare Disease Day 2026 Launch Webinar: Minutes

🗓️ Meeting Minutes: Rare Disease Day 2026 Campaign Launch

Dates: 27 & 28 October 2025
Organised by: EURORDIS – Rare Diseases Europe
Format: Webinar (recorded)
Audience: National Partners, Patient Organisations, Companies, Individuals

🎯 Purpose of the Meeting

To introduce the Rare Disease Day 2026 campaign, explain its goals, new resources, and ways for individuals, organisations, and companies to get involved globally.

1. Overview of Rare Disease Day

Annual event since 2008, held on the last day of February. In 2026, it will take place on 28 February.
Coordinated by EURORDIS, in collaboration with 72 National Alliance Partners worldwide.

The mission: to promote **equity** in social opportunity, healthcare, diagnosis, and therapies for people living with a rare disease.
The campaign is decentralised — EURORDIS provides resources and coordination while partners organise local and national events.

2. 2026 Campaign Theme and Visual Identity

Continuing slogan: "More Than You Can Imagine." Builds on the 2025 campaign, now completing the global "hero" series with new faces:

- Ayca and Burak (Turkey)
- Micah (United States)
- Lignes (Malaysia)
- Mak (France)

Each hero has chosen a word to represent their experience of living with a rare disease — reflecting what equity means in practice (e.g. community, research, care, breakthroughs). Encourages participants to interpret equity through their own community lens.

3. Key Updates for 2026

🔹 Accessibility & Resource Improvements

- All campaign resources available on Canva — editable, translatable, and easier to use.
- Website redesign for improved navigation and user experience.
- Expanded language access to reduce English dominance.

🔹 Repurposed and New Content

- Official video launch: 20 November 2025 — decentralised rollout across all national partner channels in local languages.
- Podcast series "Rare on Air Stories" continues to highlight global diversity in rare experiences.
- Webinar series (Accessibility & Engaging Healthcare Professionals) now available in 12 languages, in short 10-minute segments on YouTube.
- Raising Youth Voices Project - a new 2026 initiative, details to be released soon.

🔹 Campaign Timeline

May-August 2025: Co-creation with heroes and partners.
September 2025: Finalisation of resources.
October 2025: Launch webinars.
20 November 2025: Official campaign launch (100 days before Rare Disease Day).
28 February 2026: Rare Disease Day.

4. How to Get Involved

🧍 Individuals

- Use the hashtag #RareDiseaseDay (without the year) to maintain campaign continuity.
- Tag @rarediseasedayofficial on social media (Instagram, Facebook, LinkedIn, BlueSky, Twitter).
- Join the Instagram Challenge during February.
- Attend local events via the interactive map on the website.
- Participate in the Global Chain of Lights – illuminate homes, offices, or landmarks in RDD colors.

🧩 Patient Organisations

- Translate, adapt, and share social media posts, posters, and flyers (via Canva).
- Submit events to appear on the RDD global map.
- Use and localise toolkits, including:
- Illumination Toolkit – guide to lighting landmarks.
- School Toolkit – resources to teach about rare diseases at age-appropriate levels.
- Equity Toolkit – materials to explain and advocate for equity.
- Share new translations with EURORDIS to expand language accessibility.

🏢 Companies

- Support local and national patient organisations first and foremost.
- Encourage internal awareness (office discussions, internal ambassadors).
- Participate in the Global Chain of Lights creatively (projections, office displays).
- Follow non-commercial use guidelines for the RDD logo (no corporate logos beside RDD logo).
- Contact rdd.support@eurordis.org for collaboration opportunities.

5. Q&A Summary

Will the presentation and recording be shared?
Yes – participants and national partners will receive slides, notes, and the recording by the end of the week.

I**s this webinar available in other languages?** Using the minutes of the meeting you can translate its content into your language.

How can we get support using Canva resources?
Contact the RDD team at rdd.support@eurordis.org. Tutorials or calls can be arranged for patient organisations.

Can patient organisations use the RDD logo and add their own?
Yes – patient organisations and individuals may use and co-brand the logo. Companies may not place their logo beside the RDD logo.

Where can I find logo usage rules?
Full guidelines are on the Rare Disease Day website or HERE.

Are 2025 materials still valid?
Yes – same slogan, similar design. Both 2025 and 2026 visuals can be used.

Will the slogan "More Than You Can Imagine" continue in 2027?
Likely yes, but not yet confirmed. Strategic decisions are typically made between April–May each year.

How are campaign heroes chosen?
Through nominations from national partners. Selection aims for diversity (geographical, gender, condition). Nominations for 2027 open around March–April 2026.

Can translations or new language versions of resources be shared? Yes — we welcome community-created translations to expand inclusivity. Please share with us any translated resources that you make so that we can make them available for everyone else.

How can we get support for #LightUpForRare? We have a dedicated toolkit on our website but organisations can also get in touch with us if they would like more advice on how to coordinate the lighting up of landmarks.

📩 **Contact Information**
Email: rdd.support@eurordis.org
Website: www.rarediseaseday.org

Thank you for attending!

If you missed the webinar live, please see the recording and PowerPoint slides links below.

RDD 2026 Launch Webinar Recording

PowerPoint Slides