

Brussels Rare Disease Week 2021

Information sheet



When is Brussels Rare Disease Week?

Brussels Rare Disease Week (RDW) will take place during the week of 22 February 2021 in Brussels, organised in the lead up to Rare Disease Day 2021 (28 February)

What is Brussels Rare Disease Week?

Brussels RDW is a week-long series of events organised by EURORDIS in Brussels, plus a series of preparatory webinars. The goal is to empower you, rare disease patient advocates, with knowledge and skills to effectively participate in advocacy activities at the **European level** and as a result influence the EU decisions that have a direct impact on your lives.



Through RDW, the hope is to raise awareness of rare diseases and present a strong and united message to MEPS and other policy-makers in Brussels on behalf of the rare disease community.

The week will be made up of events including trainings, meetings with policy makers and networking events. During the week, participants will be able to put their knowledge into practice and raise awareness of their rare disease at the European Parliament.

Brussels RDW 2021 schedule of **events** in Brussels (subject to change):

<i>Monday 22 Feb</i>	Welcome lunch/ Model EU role-playing/ dinner
<i>Tuesday 23 Feb</i>	Rare2030 European Parliament event/ Lunch & discussion with MEP/ Individual meetings with MEPs/ Black Pearls Award dinner
<i>Weds 24 Feb</i>	Visit to the EU Council or European Commission/ Lunch & discussion/ Meeting with a journalist/ Individual meeting with national MEPs
<i>Thursday 25 Feb</i>	EURORDIS Round Table of Companies virtual workshop/ RDW debrief

In preparation for the week, participants will be invited to participate in a series of preparatory **webinars** (dates subject to change, obligatory attendance to at least 4):

- Introduction to RDW (20 October)
- Advocacy skills webinar (12 November)
- EU affairs 1, meet the EU institutions (recording, watch at your own convenience)
- EU affairs 2, legislative procedures (recording, watch at your own convenience)
- EU affairs 3, how to navigate your way through the "Brussels maze" (8 December)
- Webinar topic tbc (14 January)
- Logistics webinar ahead of RDW (12 February)

Why apply?

- >> Are you already involved in advocacy activities at your patient organisation?
- >> Do you already work in public affairs and on influencing your national policy makers?
- >> Do you want to know more about what the EU can do for people with a rare disease?
- >> Would you like to improve your knowledge of how to engage in EU advocacy?

Then Brussels Rare Disease Week is for you - **become empowered with knowledge and engage directly with policy makers! Become a link between your organisation & Brussels.**

Who can apply?

- Patient representatives working for or directly affiliated to a rare disease national alliance or European federation (and from the EU, EFTA & EU candidate countries) that is a EURORDIS member organisation.
- Before applying please consider whether you are able to make the **time commitment** to participate in all events in Brussels 22-25 February and the preparatory webinars listed above (10 hours over 4 months).
- Knowledge gained from participating in RDW will help you to continue to advocate at the EU level and engage in future EURORDIS advocacy efforts for years after.

How to apply

[Apply via this form](#)

The deadline to apply is **18 September**. Two options:

1. If your national alliance or European federation has an idea of an individual they would like to suggest to take part in RDW, you can share www.eurordis.org/rdw2021 with them and invite them to apply by 18 September, or
2. If your national alliance or European federation would like to share the application process with all of your members, please do so by sharing a link to www.eurordis.org/rdw2021 in your newsletters or communication. If you are a patient representative applying directly, you will need to confirm your affiliation to your organisation in your application form.

The final selection of participants will be made in consultation with the Brussels RDW Working Group. Applications will be selected based on the appropriateness of the candidate to participate in RDW and benefit from the skills gained during RDW in the future.

Costs of participating

EURORDIS will cover the costs of return economy travel to Brussels & hotel accommodation for the duration of RDW (3 nights) and some meals. Hotel bookings will be organised by EURORDIS. Participants will need to make arrangements for return economy travel to Brussels and reclaim the costs after RDW.