



Rare Disease Week 2021

Kostas Aligiannis

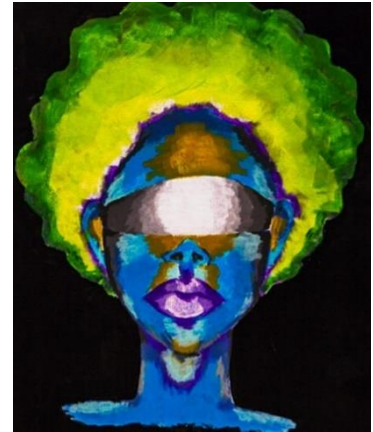
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Inspired by Rare Disease Week USA

RARE
DISEASE WEEK
ON CAPITOL HILL



Based on the idea that initiated in the USA, but adjusted to Europe to take into account:

- European political context (EU vs Member States)
- Importance of interplay between European and national level
- Addressing issues relevant to people living in Europe

Testimonial on the potential for Rare Disease Week

“The goal of this Rare Disease Week is that **people living with a rare disease are trained and supported to engage in arenas where decisions are made that affect their lives** - and to connect the important rare disease policy work that is happening at the national levels with EU-level policy-making.

As a long-time member of the rare disease community myself, I have had the opportunity to meet very special people. People who, despite the heavy impact of a Rare Disease in their daily life, found the strength, and the time I should add, to set up organisations to help other families living in the same situation, and to advocate for the rights of all people living with RD. They have done a very good job and many of them have succeeded in establishing fruitful collaboration with their national policy makers, contributing with their concrete input to improve the health and social care in their country. But I’ve always felt that a piece of this virtuous circle was missing despite EURORDIS restless and efficient activity.

Having patient representatives serve as a link between the national and European levels can be an important turning point, to boost a coherent strategy in which national parliamentarians and their colleagues in the European parliament work in the same direction. The two levels will benefit tremendously from this type of patient engagement”



Simona Bellagambi
--UNIAMO, the Italian Federation
for Rare Diseases

RDW WG

- Amanda Bok (Haemophilia Consortium)
- Astri Arnesen (Huntington's Association)
- Dorica Dan (RO)
- Eva Schoeters (BE)
- Ingunn Westerheim (NO)
- Monika Benson (Dystonia Europe)
- Simona Bellagambi (IT)
- Stefan Zivkovic (RS)
- Kostas Aligiannis (EURORDIS)
- Valentina Bottarelli (EURORDIS)



Rare Disease Week in Brussels



The main objectives of Rare Disease Week (RDW) would be to:

1. **Raise awareness on RDs** with MEPs and other policy-makers
2. Engage and expand the members of the [network of Parliamentary Advocates for Rare Diseases](#) on a yearly basis
3. Empower participants with **knowledge about advocacy in Brussels** – which they can take back home
4. Establish an **EU/national network of people who can readily participate in advocacy campaigns** carried out in Brussels



Rare Disease Week



An annual advocacy (series of) events gathering a large number of people living with a rare disease and caregivers from across Europe in the EU capital

- **What?** Creating a direct connection between MEPs/Council and their constituency, allowing for a solid relationship-building
- **How?** A series of events (policy, networking, artistic, etc.), F2F meetings, trainings, site visits

	01					02					03				
	53	1	2	3	4	5	6	7	8	9	10	11	12	13	
①		4	11	18	25	1	8	15	22	1	8	15	22	29	
②		5	12	19	26	2	9	16	23	2	9	16	23	30	
③		6	13	20	27	3	10	17	24	3	10	17	24	31	
④		7	14	21	28	4	11	18	25	4	11	18	25		
⑤	1	8	15	22	29	5	12	19	26	5	12	19	26		
⑥	2	9	16	23	30	6	13	20	27	6	13	20	27		
⑦	3	10	17	24	31	7	14	21	28	7	14	21	28		

Ahead of the week - webinars

Topic	Description
Welcoming	Introduction to RDW, meeting other participants, opportunity to answer any questions
Skills	How to attract an audience, how to pass convincing messages, how to communicate efficiently and adjust your methods to the relevant audience
EU affairs 1	meet the EU institutions
EU affairs 2	Different (legislative) procedure
EU affairs 3	how to navigate your way through the “Brussels maze”
Topic	Tbd – deep-dive into a selected topic that will come back during the RDW
Logistics	An overview of practical information and tips regarding your travel to Brussels. Information about the buildings you will be visiting, how to get there, etc. Chance to ask any question you still have

What Rare Disease Week will it look like?

One full **Rare Disease Week** that will include:

- **5 pre-meeting training webinars (completed in advance)**
- **In personal policy training (“model EU”)**
- **1-1 meetings with MEPs/Permanent Representations (set up by EURORDIS)**
- **Participation in Black Pearl Awards**
- **Group exercise on how to work together with the EU Council**
- **Taking part in Rare2030’s closing session**
- **Ending with Rare Disease Day on Sunday 28/02!**



Week programme

Rare Disease Week 2021 Schedule

EURORDIS

Date and Time	Monday	Tuesday	Wednesday	Thursday	Friday
8:00-8:30					
8:30-9:00					
9:00-9:30		Meeting with MEP			
9:30-10:00					
10:00-10:30	Model EU		Meeting with Commission	Group work: unravelling the Council	Debriefing+feedback
10:30-11:00					
11:00-11:30					
11:30-12:00					
12:00-12:30					
12:30-13:00					
13:00-13:30	Model EU	Closing Rare2030			
13:30-14:00					
14:00-14:30					
14:30-15:00	Meeting with PermRep				
15:00-15:30					
15:30-16:00					
16:00-16:30					
16:30-17:00					
17:00-17:30			Black Pearl Awards		
17:30-18:00					
18:00-18:30					Activity?
18:30-19:00					
19:00-19:30	Secret fun activity	Cultural activity			
19:30-20:00					
20:00-20:30					
20:30-21:00					
21:00-21:30					

Future of RDW



- Participants can be involved in various ways in the next edition
 - Identifying people in the organisation that can take part in next year's edition
 - Help in the meetings with MEPs during the week itself
 - Maybe become chaperones
- Build a network of people that understand the peculiarities of EU advocacy-making and can help in coordinated efforts at national and European level
- Help achieve a better future for people living with a rare disease by convincing MEPs to be part of our network

