Advocating for the integration of rare diseases in national policies within the framework of UHC

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FEDER’s CEO
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November 2017 How to put rare diseases on the United Nations agenda Information & Brainstorming RDI Webinar

On site Meeting with Martín Remón - Permanent Commission of Spain to the WHO in 2018.

- EURORDIS provided us with the template to encourage Permanent Missions to support the action of including DRs in the Sustainable Development Goals when the 2030 agenda was being programmed.

- They immediately became interested in us!

On site Meeting with Foreign affairs of Spain Consejero de la Representación Permanente de España en Naciones Unidas
**Involve politicians to promote RD on the UN agenda: FEB 2018**

«Our idea is to support FEDER, through the international patient movement, in the upcoming agendas of the WHO-EURO Regional Committee and during the World Health Assembly, in line with the motto of the 2030 Agenda: 'Leave no one behind behind'».

Minister of Foreign Affairs and Cooperation, Alfonso Dastis.

«We will support FEDER in the upcoming agendas of the Regional Committee of the World Health Organization in Europe and during the World Health Assembly».

Secretary-general of Health and Consumer Affairs, Javier Castrodeza.
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First attempts at NCDS HLM: SEPT 2018
Involve politicians to participate in the event at the UN: 2019

- Spain was one of the UN event sponsor countries

- Spain presented our priorities to the UN together with 15 other countries around the world.

- Rare diseases day testimonial in the video displayed in the event.
  » Lorena's family testimony.

FEDER joined the event
Work with the Permanent Missions

Meeting with Agustín Santos, Ambassador Permanent Representative of Spain to the UN in New York in 2019.

- Before the event, the ambassador organized a reception at his home, getting personally involved with the entire group.

- The Spanish Public Administration had a space in this framework from the hand of Pilar Aparicio, General Director of Public Health, Quality and Innovation of the Ministry of Health, Consumption and Social Welfare.
Rare Disease Day: RD Global and holistic challenge

We include the Sustainable Development Goals in our paper and we give visibility in our annual campaigns for RD Day.

- More than 4,000 impacts in the media
- More than 40 public institutions adhered to
- More than 200 activities through the country.
- Furniture advertising in more than 20 cities
‘Rare Diseases: A global challenge, a holistic challenge’ Conference

- The Training School CREER-FEDER aims to be a space to inform and train professionals, families and associations to highlight best practices in political advocacy, promotion of research and integrated support services:
  - More than 25 speakers.
  - More than 12 countries in Europe and America represented.
  - More of 88 patient representatives.

Queen Letizia of Spain learned the importance of the work done by all of us to represent the 350 million people worldwide living with a rare disease.
Electoral process

- We leverage the participation of Pedro Sánchez, President of the Government, in The UN High-Level Meeting on UHC in New York on 23 September 2019 of UCH.

- His words served as the basis for our strategy to include rare diseases without leaving anyone behind in the November 10 general election.
Electoral process

- In the last two years, we have lived 3 electoral processes (2 general elections and 1 regional elections).

- In all of them we have developed an strategy in which we have linked our priorities with each of the Sustainable Development Goals.

- Most of political parties of Congress Building included our proposals.
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Electoral process

New coalition government includes rare diseases in global universal coverage planning

«We will integrate the needs of rare diseases in the global planning of Universal Coverage, guaranteeing access to diagnosis and treatment for all people, independently where they live and the pathology with which they live». 
The international character makes consensus possible

- The European Recommendations have helped us to position the issue of rare diseases through the península, especially in regions such as Catalonia and the Basque Country.

- A global and common framework of action would allow us to increase this solidarity character:
  - Working together Strengths us
  - ALWAYS take the Chance!

Global Actions for RD
Thank you!