

Information dossier Training School CREER - FEDER

RARE DISEASES: A GLOBAL CHALLENGE, A HOLISTIC CHALLENGE

General information

The Training School CREER-FEDER 'Rare Diseases: a global challenge, a holistic challenge' aims to be a space to inform and train professionals, families and associations about rare diseases. The speakers will have the opportunity to present their most outstanding projects and meet other professionals who have been developing other patient organisations in Europe and America.

We aim to work in collaboration with organisations all over the world, to discuss and assess together better opportunities to improve our actions, to look for new experiences which will feed into our Action Plan and to create synergies which will enable us to thrive together.

Program

Thursday 19/09/2019	Friday 20/09/2019
<p>15:30 - 16:00 h Welcome: 10th Anniversary CREER - 20th anniversary FEDER</p> <p>16:00 - 17:30 h Panel discussion: Knowledge and good practice between organisations</p> <p>17:30 - 18:00 h Coffee break</p> <p>18:00 - 19:30 h Workshop: Care services</p> <p>18:00 - 19:30 h Workshop: Building networks about rare diseases</p>	<p>09:00 - 11:00 h Panel discussion: Research networks</p> <p>11:00 - 12:00 h Coffee break Posters</p> <p>12:00 - 13:30 h Panel discussion : Advocacy – social transformation and rare diseases</p> <p>13:30 - 15:00 h Lunch break</p> <p>15:00 - 17:00 h Panel discussion: The voice of specialised care centres</p> <p>17:00 - 17:30 h Closing plenary</p> <p>17:30h Group photo</p>

THURSDAY 19/09/2019

❖ 16:00 – 17:30 h → *Panel discussion: Knowledge and good practice between organisations*

Roundtable's aim: sharing experiences about each organisation, highlighting the implementation of successful projects in patients' care services.

MODERATOR: MODESTO DÍEZ, FEDER | Spain

Moderator's role:

- » To coordinate the topics of the individual speakers
- » To capture the key ideas
- » To hold participants to time limits (each speaker will have about 15 minutes)

Objectives:

To emphasize the potential value of sharing experiences and the exchange of good practice among the associative movement.



SPEAKERS:

VLASTA ZMAZEK, President of Debra Croacia | Croatia

Timing: 15 minutes. **Key messages:**

Programme for new-borns who live with epidermolysis bullosa.

- Learning gained during the process.
- Successes and proposals for improvements and ideas to replicate/recreate it in other organisations as well as in other pathologies.
- Coordination with DEBRA International.



ADRIANA GUEVARA, President and Founder of Asociación Española de Esclerosis Lateral Amiotrófica (adELA) | Spain

Timing: 15 minutes. Key messages:

- » The information programme and the giving of support to aid in daily living developed by ADELA. *The deepening of work concerning technical assistance and occupational therapy.*
 - What were the first steps to undertake the programme?
 - What were the keys of its sustainability?
 - Knowledge acquired during the process.
 - Successes and suggestions for improvement as well as ideas to recreate it in other organisations or pathologies.



DANIEL GARCÍA, President of Federación Española de Hemofilia (FEDHEMO) | Spain

Timing: 15 minutes. Key messages:

- » The programme of summer camps is oriented to explain to children with hemophilia how to administer the medication by themselves. *An activity that FEDHEMO celebrates annually aimed at children with hemophilia, aged 8 and 12. The summer camp's objective is to make children more knowledgeable about their disease and to learn how to administer the treatment by themselves.*



Learning gained during the process. Successes and proposals for improvements, as well as ideas to replicate/recreate it in other organisations or pathologies.

INÉS CASTELLANO, President and Founder of Federación Argentina de Enfermedades poco Frecuentes (FADEPOP) | Argentina

Timing: 15 minutes. Key messages:

- » Current overview of Rare Diseases in Argentina and Latin America. The idiosyncrasies of the Argentinian federal system, and the Iberoamerican context with regard to rare diseases.
 - To highlight the importance of networking between organisations as a way to progress in Latin America: How the cooperation with ALIBER-RDI-EURORDIS has benefited the Argentinian collective.



❖ 18:00 – 19:30 h. → *WORKSHOP: direct assistance services*

Roundtable's aim: exchanging information about the implementation, development and execution of direct assistance services in organisations.

MODERATOR: FIDE MIRÓN, FEDER Vice President | Spain

Moderator's role:

- » To coordinate the topics of the individual speakers
- » To capture the key ideas
- » To hold participants to time limits (each speaker will have about 15 minutes)



❖ 18:00 – 19:30 h. → *WORKSHOP: Building networks about rare diseases*

Roundtable's aim: exchange of information to create networks of advocacy between organisations.

MODERATOR: TO BE CONFIRMED | Spain

Moderator's role:

- » To coordinate the topics of the individual speakers
- » To capture the key ideas
- » To hold participants to time limits (each speaker will have about 15 minutes)

FRIDAY 20/09/2019

❖ 09:00 – 11:00 horas → Online Research

Roundtable's aim: to share common experiences across organisations, focusing on the need for online research and its potential positive impact from the point of view of the organisations who work with groups of patients whose members live with infrequent/rare pathologies.

INTRODUCE: AITOR APARICIO, Centro CREER Director.



MODERATOR: RAÚL VARA, Corriendo por Hugo Association.

Moderator's role:

- » To coordinate the topics of the individual speakers
- » To capture the key ideas
- » To hold participants to time limits (each speaker will have about 20 minutes)



• INAUGURAL SPEECH:

VERÓNICA ALONSO, Senior Scientist of the Research Institute on Rare Diseases (IIER-ISCIII) | Spain

Timing: 15 minutes. **Key messages:**

- » Value the work among patient organizations, administration and research centers.
- » Causes of diagnostic delay in people affected by rare diseases in Spain
- » Social and familial impact of the diagnostic delay



SPEAKERS:

FRANÇOIS LAMY, Vice-president of AFM-Telethon in charge of research. | France

Timing: 20 minutes. **Key messages:**

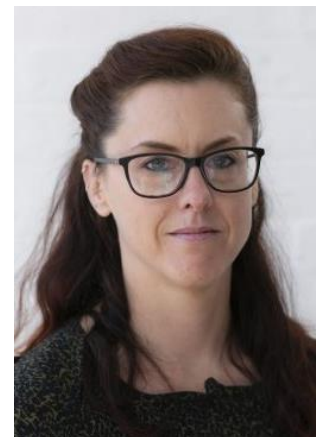
- » Experience of working as Director of research for AFM French telethon
 - Origin of the initiative and its current status.
 - Fundraising formulas.
 - Project evaluation methodology and transparency.
 - Successes and suggestions for improvement, as well as ideas to recreate it in other organisations or pathologies.



LAUREN ROBERTS, SWAN Director in UK | UK

Timing: 20 minutes. **Key messages:**

- » Lauren will present the focus of the work of SWAN UK in building communities that provide assistance in creating new support groups for families with undiagnosed members, at a European level, as well as in developing and strengthening smaller groups which already exist.
 - The innovative project of new “Rare Resources”.
 - Experience in relation to this project that focuses on network research in relation to the diagnostic quest.
 - How to transform a national entity (SWAN UK) into a continental entity (SWAN Europe).



CARMEN SEVER, President of the Spanish Association against Leukodystrophies (ELA España) | Spain

Timing: 20 minutes. **Key messages:**

- » The potential of the associative movement to obtain funds and resources for research projects
 - To deeply explore the details of this initiative and the financing potential of the associative movement in research projects.
 - The value of research for the associative movement and their participation in it. Evolution of leukodystrophies research as a paradigm for the rest of rare diseases: how the causes of each type of leukodystrophy have become known and how new types have been discovered.



MARÍA INÉS FONSECA, President of Asociación Todos Unidos Enfermedades Raras Uruguay (ATUERU) | Uruguay

Timing: 20 minutes. Key messages:

- » Rare disease's context in Uruguay:
 - Number of patients, pathologies, number of diagnosed patients and number of cases without diagnosis.
 - Development of the Iberoamerican Service for Information and Orientation on Rare Diseases (SiiO): search for new associations and contacts, support groups, a regulatory framework and creation of patients' networks.



❖ 12:00 – 13:30 horas → Advocacy - Social transformation and rare diseases

Roundtable's aim: To share experiences particular to each organisation focusing on successful advocacy projects which have aimed towards positive social transformation for patients with rare diseases.

MODERATOR: ALBA ANCOCHEA, FEDER Director | SPAIN

Moderator's role:

- » To coordinate the topics of the individual speakers
- » To capture the key ideas
- To hold participants to time limits (each speaker will have about 20 minutes)



SPEAKERS:

TO BE CONFIRMED , CREER member | Spain

SIMONA BELLAGAMBI, International Relations at Federazione Italiana Malattie Rare - UNIAMO | Italy

Timing: 20 minutes. Key messages:

- » UNIAMO's Advocacy action:
 - Actions and results of volunteering as the engine of advocacy in Italy.



- Ideas aiming to recreate the experience in other countries.
- Relevant advocacy achievements materialised thanks to the volunteers' work

**KARLA RUIZ, Directora Pacientes y Usuarios de Servicios de Salud de Perú.
Esperantra | Peru**

Timing: 20 minutes. **Key messages:**

- The current context in Peru and actions developed to achieve a definition of rare disease.
- Advocacy program developed by Esperantra, since its participation in COPEPOFRE (Peruvian Coalition of RD).



PALOMA TEJADA, Rare Diseases International Director – RDI

Timing: 20 minutes. **Key messages:**

- » Success in coordinating the associative movement worldwide
- » Global Advocacy Actions
 - Actions with the United Nations (UN).
 - Actions with the World Health Organization (WHO).
 - Actions related to the inclusion of rare diseases within the concept of Universal Health Coverage.



**ANTONI MONTSERRAT, Board Director member of Maladies Rares
Luxembourg (ALAN) | Luxemburgo**

Timing: 20 minutes. **Key messages:**

- » Activities developed as Board Director member of Maladies Rares Luxembourg (ALAN)



❖ 15:00 – 17:30 → *The voice and the reality of Specialised Care Centres*

Roundtable's aim: sharing the experiences of different Specialised Action Centres, focusing on their work, their challenges and their successful projects.

MODERATOR: MARTA FONFRÍA, Centro CREER Community worker.

Moderator's role:

- » To coordinate the topics of the individual speakers
- » To capture the key ideas
- » To hold participants to time limits (each speaker will have about 20 minutes)



SPEAKERS:

MARÍA JOAO FREITAS, Director of International Affairs and Project Management | Portugal

Timing: 20 minutes. **Key messages:**

- » Casa Dos Marco: a comprehensive care centre for patients with rare diseases.
 - Their system of work with Public Administration.
 - Services provision.
 - Specialisation in rehabilitation of patients from the first months of life to adulthood, with rare diseases or some type of disability.

Learnings, successes and proposals to improve the undertaken actions.



KARSTEN ROBERT, Head of department. Kompetanse senter for sjeldne diagnoser – Frambu | Norway

Timing: 20 minutes. **Key messages:**

- » Kompetanse senter for sjeldne diagnoser: interdisciplinary centre for patients with rare diseases.
 - The Centre's scope, emphasising the achievement of having the capacity to provide care to all pathologies across the country.
 - How the Centre develops, collects and disseminates interdisciplinary knowledge for people diagnosed with a rare disease.
 - Management processes and care for patients of all ages in all stages of life.



MARÍA ACARALITEI, Social Worker. Representative NoRo - Center for RareDiseases | Romania.

Timing 20 minutes. **Key messages:**

- » NoRo - Centre for Rare Diseases
 - First steps as a care centre: specialisation in Prader-Willi Syndrome and funding sources.
 - Development, consolidation and openness to other pathologies.
 - Pilot Project - started under the framework of INNOVCare - case management for people with rare and complex diseases.



MIGUEL ÁNGEL RUIZ, D'Genes Association Director | Spain

Timing: 20 minutes. **Key messages:**

- » Multidisciplinary Care Center: Celia Carrión Pérez de Tudela and Pilar Bernal Center
 - The importance of sharing care resources between the associative movement: openness of its services to different organisations.
 - To showcase how the associative movement (not only administration and institutions), is a pioneer in the promotion of this type of integral care centre.
 - Experience of direct care at their centres.
 - Examples of difficulties that the organisation faced and how they have overcome them.



CARMEN LÓPEZ, Director of Federación Galega de Enfermedades Raras e Crónicas | Spain

Timing: 20 minutes. **Key messages:**

- » Experience in direct care, highlighting the Healthcare Assistance Program
 - Agreements and synergies between specialised clinics. Copayment Model.
 - How to manage integral work in the associative movement: physiotherapy, occupational therapy, speech therapy, clinical psychology, neuropsychology and the protection of rights in health, legal and social work.
 - Learnings, successes and proposals to improve the



actions undertaken.