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The **Center for Biomedical Network Research on Rare Diseases (CIBERER)** is a **network cooperative structure** integrating 88 research groups and more than 700 investigators located at the main research centers throughout Spain. Our research work is based upon the cooperation of **basic and clinical research groups** with the aim of generating new scientific knowledge enabling us to **elucidate the biological bases** of RD, to develop **new treatments** and to make available **new diagnostic procedures** for these illnesses.

To carry out this research it is vital to ensure interaction with the people affected and the associations which support them in order to fully understand and try to **fulfill their needs**, learn from their experience and contribute to their **empowerment**.

Although collaboration with patient advocacy groups has been a constant since the creation of CIBERER back in 2006, it was in 2017 when patient associations were fully integrated into two of **CIBERER's decision making bodies**: the **Patient Advisory Council** and the **External Scientific Advisory Committee**.



EMPOWERED PATIENTS ARE PART OF CIBERER

PATIENT ADVISORY COUNCIL (PAC)



Created in 2017. Composed by 8 patient organizations (including FEDER) representing different RDs.

Objective:

To become a forum promoting active participation of patient associations working along with researchers, with the aim of improving the quality of biomedical research, contributing their perception on the research activity from the patients' perspective and functioning as an advisory and informative body.

Functions:

- Provide advise regarding CIBERER strategic activities, projects and programs & propose new activities.
- Advise on the patient associations' training needs.
- Review and advise on CIBERER audiovisual materials, documents and instruments aimed at patients.

Activities:

- Organized 2 conferences for the RD Day on 2019 & 2020.
- Reviewed CIBERER Strategic Plans 2018-2021.
- Presented 2 projects to national calls in 2018 & 2019.
- Edited 2 videos focused on collaborations between patients & researchers:
 - [Diagnosis for mitochondrial diseases](#)
 - [Treatment for epidermolysis bullosa](#)
- Conducted a survey investigating the relationship between patient associations & RD research (2018).

What is next:

- Launching the PAC membership biennial renewal in 2020.
- New objectives: participation at the CIBERER intramural calls for projects' evaluation process.
- Developing online training activities for patients.

EXTERNAL SCIENTIFIC ADVISORY COMMITTEE (EASC)



The EASC was renewed in 2017, when patient representatives became full members of this committee and were entrusted with the same responsibilities and decision making capabilities as the scientific members. It is integrated by 6 members including the President, Prof. Josep Torrent-Farnell, and 2 patient representatives:

- Alba Ancochea, from the Spanish RD Federation (FEDER).
- Julián Isla, from Foundation 29 & European Dravet Federation.

Objective:

To incorporate the patient's perspective into the analysis and evaluation of CIBERER's research groups.

Functions:

- Advise on the strategic plans, programmes and activities.
- Advise on the evaluation of the research groups.

Activities:

- During 2017 to 2019 the EASC visited all CIBERER groups.
- It has participated in all the CIBERER's annual evaluations.
- Revision of the CIBERER Strategic Annual Plans.

What is next:

- Participation in the next CIBERER's Annual Meeting.

CONCLUSIONS

Full participation of patients advocates in CIBERER's decision-making Committees has resulted in deep mutual knowledge that has translated, among others, into:

- Further fruitful collaborations, improved communication and mutual confidence.
- Higher engagement of patients in the Center's strategic plans and projects.
- Joined organization of educational and dissemination activities.
- CIBERER has set an example for other institutions aspiring to constitute patient advisory bodies.