

# MODULE PARENTS AND ADMINISTRATION

## ACTIVITY 5. DIRECTORY OF RELIABLE WEBSITES AND RESOURCES

- **TIME:** 30m.
- **RESOURCES:** List of reliable websites on RD.
- **LANGUAGES:** ENG / SPA.

### **DESCRIPTION:**

Finding reliable information on rare diseases, whether it is information about the disease, treatments, clinical trials or support organisations can be challenging. It is sometimes difficult to discern the serious professional website from others that might not contain up-to-date information that has been reviewed by professionals.

Therefore we provide a list of the most prominent and active websites that provide reliable information on RD.

### **OBJECTIVES:**

Families of children with RD can access reliable information on Rare Diseases. Reducing uncertainty also contributes to reducing anxiety caused by the diagnoses of a RD.

### **LESSON OVERVIEW:**

Directory of reliable and up-to-date websites that can be consulted by parents with children with RD.

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- Orphanet: Orphanet is a database and online resource offering information on rare conditions and orphan medicines. It provides clinical, epidemiological and inheritable data, as well as information on technical centers and clinical trials. Visit their website at <https://www.orpha.net/>



- RareConnect: A platform that connects people living with rare diseases around the world. It offers discussion forums, support groups and resources in several languages. Visit their website at <https://www.rareconnect.org/>



- EURORDIS: A non-profit association devoted to perfecting the lives of people living with rare diseases. They give information on rare conditions, advocacy, coffers and support services. Visit their website at [www.eurordis.org/](http://www.eurordis.org/)



- Rare diseases International (RDI): A global alliance of rare complaint case and advocacy associations. Their website offers information on rare conditions, advocacy juggernauts, events and resources. Visit their runner at [www.rarediseasesinternational.org/](http://www.rarediseasesinternational.org/)



- Share4Rare is an online platform aimed at connecting cases, families, experimenters and health professionals in the field of rare diseases, including neuromuscular conditions. It provides a virtual community where users can share information, experiences and resources. It also offers the possibility to share in cooperative research and access up-to-date information on clinical trials and research studies. Visit their website at <https://www.share4rare.org/>



- TREAT-NMD: TREAT- NMD is a global network for research and cooperation in neuromuscular conditions. Its aim is to accelerate the development of treatments and ameliorate care for people affected by neuromuscular conditions. On their website they offer information on the different neuromuscular conditions, coffers and exploration programs. Visit their website at <https://treat-nmd.org/>



- National Institutes of Health (NIH) Office of Rare Diseases Research (ORDR): ORDR is part of the NIH in the United States and aims to accelerate research on rare diseases, facilitate collaboration, and provide resources for researchers and patients. Website: <https://rarediseases.info.nih.gov/>



- CIBERER: CIBERER stands for Centro de Investigación Biomédica en Red de Enfermedades Raras, which translates to Biomedical Research Network Center for Rare conditions. CIBERER is a research association in Spain that focuses on advancing knowledge and understanding of rare conditions. CIBERER is a network composed of different research groups and institutions devoted to rare conditions, including universities, hospitals, and research centers. Its main goal is to promote and coordinate research activities related to rare diseases, aiming to ameliorate the diagnosis, treatment, and quality of life for individuals affected by these conditions.