

MODULE PARENTS AND ADMINISTRATION

ACTIVITY 3. WHERE TO GO

IF YOUR CHILD IS DIAGNOSED WITH A RD.

- **TIME:** 30m.
- **RESOURCES:** A “map” with the institutions, organisations and professionals to go to in order to receive support.
- **LANGUAGES:** ENG / SPA.

DESCRIPTION:

Mapping the organisations and institutions that can give support to parents with a kid that has a rare disease might be confusing and overwhelming at first. Therefore it is crucial to mentally map the general resources that are available.

OBJECTIVES:

Aid families in finding resources and reference institutions and organisations that can provide them with resources and useful information for their situation.

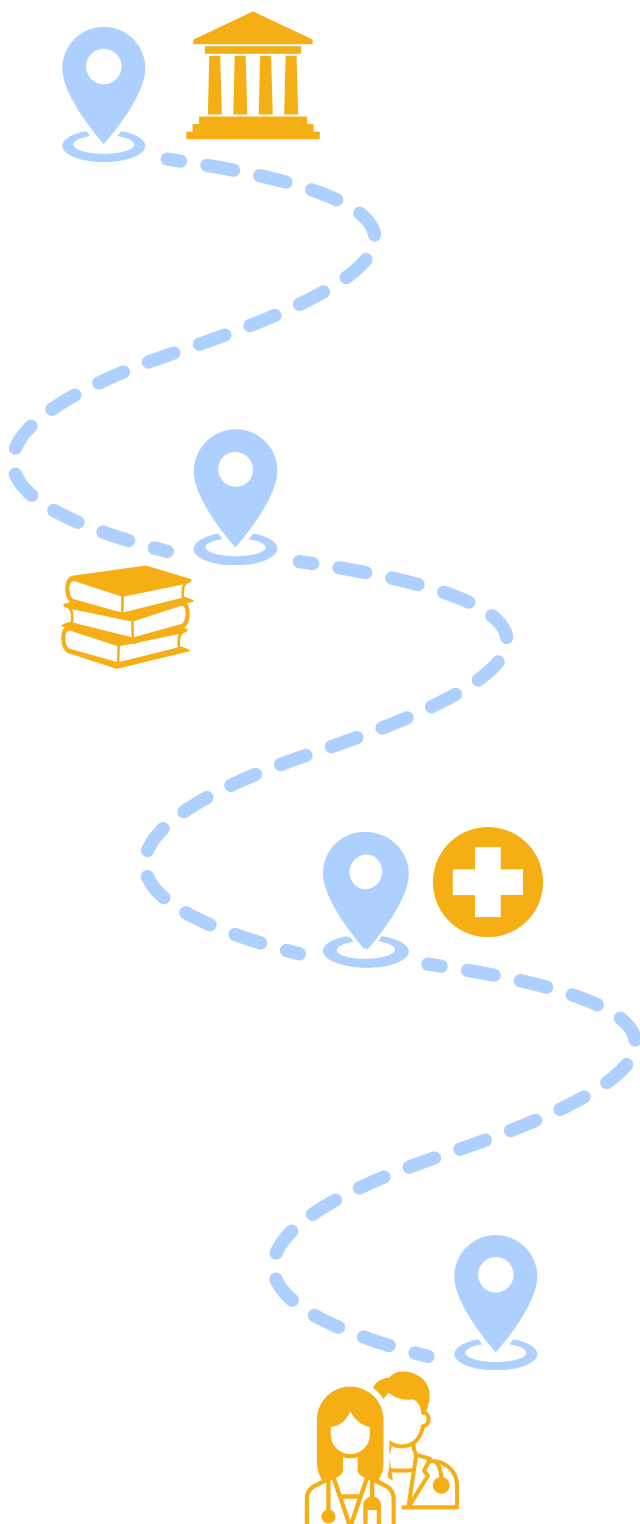
LESSON OVERVIEW:

A map that includes all the organisations a family can go to in order to obtain information and aid.

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→ Government and community support programs: Explore government-sponsored programs or community support networks that offer financial assistance, medical grants, or other resources for families dealing with rare diseases.

→ Work with your child's school: Communicate with your child's school about their condition and any accommodations or support they may need. Some rare diseases can affect a child's ability to attend school regularly, and it's important to ensure they receive appropriate educational support.

→ Experts: To learn more about the illness, its effects, and potential treatments, speak with the physician who made the diagnosis. Ask for comprehensive information on the illness, how it develops, and the resources that are accessible.

→ Second opinion: Rare diseases can be complex to identify and understand, which many times leads to misdiagnosis. It is recommended to ask for a second medical opinion. Consider getting a second opinion from another medical specialist or a specialized center with expertise in rare diseases to confirm the diagnosis and explore treatment options.

→ Ombudsman or Patient Advocacy Offices: In many countries, families can receive assistance from these groups in negotiating the legal and administrative complexities associated with healthcare. They can clarify your rights, deal with grievances, and give advice on how to get the best care.

→ Legal Aid Organizations: These organizations give low-income individuals and families access to free or affordable legal services. These organizations may employ attorneys with expertise in healthcare law and disability rights who can offer legal counsel and representation.

→ Disability Rights Organizations: Disability rights organizations advocate for the rights of people with disabilities, including those with rare diseases. They can offer details on the services and legal rights that are open to those with disabilities.

→ Rare Disease Patient Advocacy Organizations: Your child's rare disease-specific patient advocacy groups may also be able to provide advice on any connected legal issues. They may have contacts, resources, and expertise about the legal challenges that families in comparable circumstances frequently deal with. These groups can help you connect with other families facing similar challenges, access research updates, and offer emotional support.

