

MODULE PARENTS

ACTIVITY 1. PARENTS WITH COURAGE

- **TIME:** 10m.
- **RESOURCES:** Video.
- **LANGUAGE:** ENG / SPA.

DESCRIPTION:

Your child's disease can generate anxiety and uncertainty on many occasions. You have many questions to answer and decisions to make. Besides, these pathologies are unknown to a large part of the population. In this activity we present testimonies of parents who faced the same situation which may inspire you.

OBJECTIVES:

Learning about other parents' experiences can help you to:

- Deal with feelings of sadness and frustration.
- Learn new coping strategies and methods.

LESSON OVERVIEW:

In the following video you will see the stories of Cristina, Rocío, Mónica, Teresa y Alfredo. They are parents of young people affected by diseases such as: Congenital Disorders of Glycosylation (CDG), muscular dystrophy, non-progressive congenital Ataxia, Spastic Paraplegia and Charcot Marie Tooth, respectively. Throughout the video they will discuss about first symptoms, discovery of the disease, delay of diagnosis, family environment and friends, inclusion and accessibility.

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RESOURCES:



Rocío

Her daughter Alicia is a young woman of 22 years old who suffers from muscular dystrophy.



Mónica

Her son Bruno is 13 years old, and he suffers a disease called non-progressive congenital Ataxia.



Cristina

Her son Juan, suffers from Congenital Disorders of Glycosylation (CDG).



Alfredo

His daughter Olivia is 14 years old and she suffers the Charcot Marie Tooth degenerative disease.

You can watch more testimonies on the Erasmus+
YOUNG PEOPLE WITH RARE DISEASES



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