

Webinar on *'The impact of rare conditions on self-identity'*



EURORDIS 7th Mental Health & Wellbeing Webinar

November 18th 2024 – From 2:30 pm to 4:00 pm CET (Paris time)

Living with a rare condition can deeply impact the self-identity of an affected individual and their family. Individuals may struggle with whether they are defined by their condition or if they can separate this out from their sense of self and identity. This internal conflict can lead to confusion, particularly during formative years when self-identity and sexuality of a young person developing into being an adult. The stigma and discrimination associated with rare diseases, especially those of genetic origin, add another layer of complexity. Carriers of genetic conditions can also face their own unique challenges, such as the fear of discrimination, which can further complicate their sense of identity and self-worth. However, finding and affirming one's identity beyond the disease is a crucial part of the journey toward self-acceptance. Connecting with others who share the same rare disease can be transformative, providing a sense of belonging and support that helps individuals feel less isolated. Being part of a community facing similar challenges can reshape one's perspective and strengthen a person's identity, allowing them to see themselves beyond their condition and break free from the stigma that often accompanies it.

This webinar explores the impact of a rare condition on self-identity from different perspectives, such as from a person living with a rare condition to the wider family; and from the perspective of different conditions.

WEBINAR AGENDA

Time	Topic	Speaker
14.30 – 14.35	Welcome and opening remarks (5')	Anna Spinou, President of Hellenic Cystic Fibrosis Association & EURORDIS
14.35 – 14.50	Keynote Speech (15')	Sophie Turner, Achondroplasia
14.50 – 14.55	Q&A (5')	All
14.55 – 15.35	Panel discussion: (40') <ul style="list-style-type: none">Impact on the self-identity of a person with a rare condition and their caregivers	Moderator: Rebecca Tvedt Panellists: <ul style="list-style-type: none">David Ross, PTENKate Tyler, ARMSophie Turner, AchondroplasiaClaas Röhl, NF Kinder
15.35 – 15.55	Questions & Answers (20')	All
15.55 – 16.00	Final & Closing Remarks (5')	Anna Spinou, President of Hellenic Cystic Fibrosis Association & EURORDIS

The outcome of the webinar will be a factsheet to help increase awareness about the common mental health needs and how to address them, for the rare disease community.