

# Maintaining the voice of rare diseases in a new, virtual world: **Insights from ECRD 2020**

Be prepared to truly demonstrate your commitment to the rare disease field, particularly in these uncertain times

## Rare disease diagnosis remains a key challenge

**Can we drive a change in perceptions and attitudes by reframing rare diseases and stressing the importance of patient groups? Alpharmaxim work closely with industry to raise awareness of rare diseases, developing educational materials and resources for HCPs and helping to bring rare diseases into the spotlight**

- There is an important need for physicians to understand the relevance of rare diseases within their clinical career and to consider rare diseases when the clinical picture doesn't provide all the answers
- Further education around genetics and rare diseases for medical students is needed
- Very few GPs have access to rare disease-specific internet resources such as Orphanet; there is limited information regarding when to consider a rare disease and what to do when you come across one in clinical practice

*"COVID-19 may alter perspectives in terms of the fragility of life – now is the time to take advantage of this to help bring about change for rare diseases"*  
Sarah Hunt, CEO, Alex TLC

