


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

Embracing European Reference Networks for patient engagement

Awareness of ERNs and education around their potential involvement needs to be a core focus to ensure that patients are at the centre of drug and trial development. Alpharmaxim have a deep understanding of the field of rare diseases and the challenges faced by patients in this unique area

- Patients are at the heart of the focus of ERNs
- It can be challenging for patient groups and organisations to access ERNs
- Involving ERNs and patients at the earliest stage in the drug development process will help to ensure that patient-reported outcomes are realistic and achievable, ensuring that patient outcomes are improved



“This is a good time for us to try and ride the wave of greater solidarity and think about our fellow people and trying to support everybody, even if they have no condition”

Victoria Hedley, Rare Disease Policy Manager,
Newcastle University

