

# 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

## Newborn screening is essential to improve diagnosis and outcomes

Alpharmaxim work closely with industry to provide education around newborn screening and can help to drive awareness of newborn screening panels. It is important to increase the number of newborn screening panels and harmonise their number and size across Europe. **Newborn screening:**

- Allows for early diagnosis and, therefore, management of rare genetic diseases
- Could have a significant impact on the burden on healthcare systems and patients/families
- Could lead to a reduction in later misdiagnosis and suffering

*“Rare diseases have been a health emergency for as long as they’ve been around, for as long as they’ve been identified. We have so many common challenges with the COVID-19 pandemic”*

Professor Kate Bushby, Neuromuscular Genetics, Newcastle University JWMDRC

