



Share4Rare

www.share4rare.org

Share4Rare: a collaborative platform for rare diseases

Hernandez-Ortega S¹, Athanasiou D², Brooke N³, Chapi I⁴, Hedley V^{5*}, Lecorvec A^{6,7}, Perera A⁸, Ryll B⁹, Nafria Escalera B¹, **S4R Consortium**

¹Sant Joan de Déu Research Foundation

²World Duchenne Organization

³The Synergist

*Presenting author

⁴Omada

⁵John Walton Muscular Dystrophy Research Centre, Newcastle University

⁶Asserta Global Healthcare Solutions

⁷ClicLab SL

⁸Universitat Politècnica de Catalunya

⁹Melanoma Patient Network Europe

Share for rare: co-create and collaborate

Education

- **Medical content** co-created with clinicians, patients and families
- Languages: English and Spanish
- Links to Family Guides and other materials developed by clinicians and patient organisations
- **Toolkit for patient advocacy**
- Guide to paediatric palliative care
- **Blog articles** written in collaboration with clinicians, patients and families

Research

- **Surveys** designed and **submitted by researchers**
- Boost research into rare diseases
- Open to eligible Share4Rare users
- **Data analysis** using state of the art tools
- **Aggregated data available to participants**

Sharing

- **Secure platform** co-designed with patients, families and clinicians
- Validated users – rare disease and undiagnosed patients and carers
- Connect with ‘people like me’
- **Match users** based on symptoms, diagnosis and country
- User dashboard
- **Q&A section**
- Private messaging
- Expert patient and carer ‘Ambassadors’

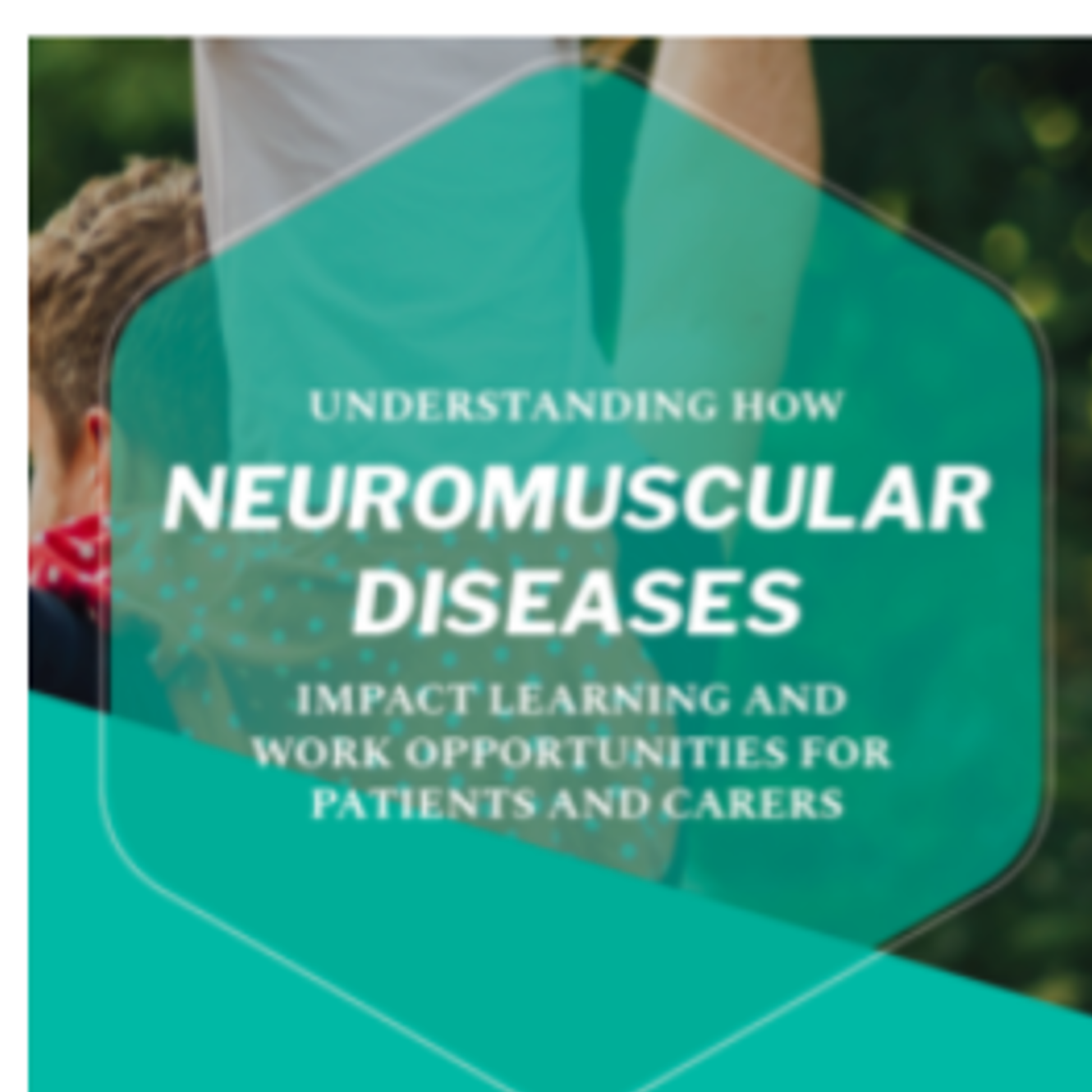
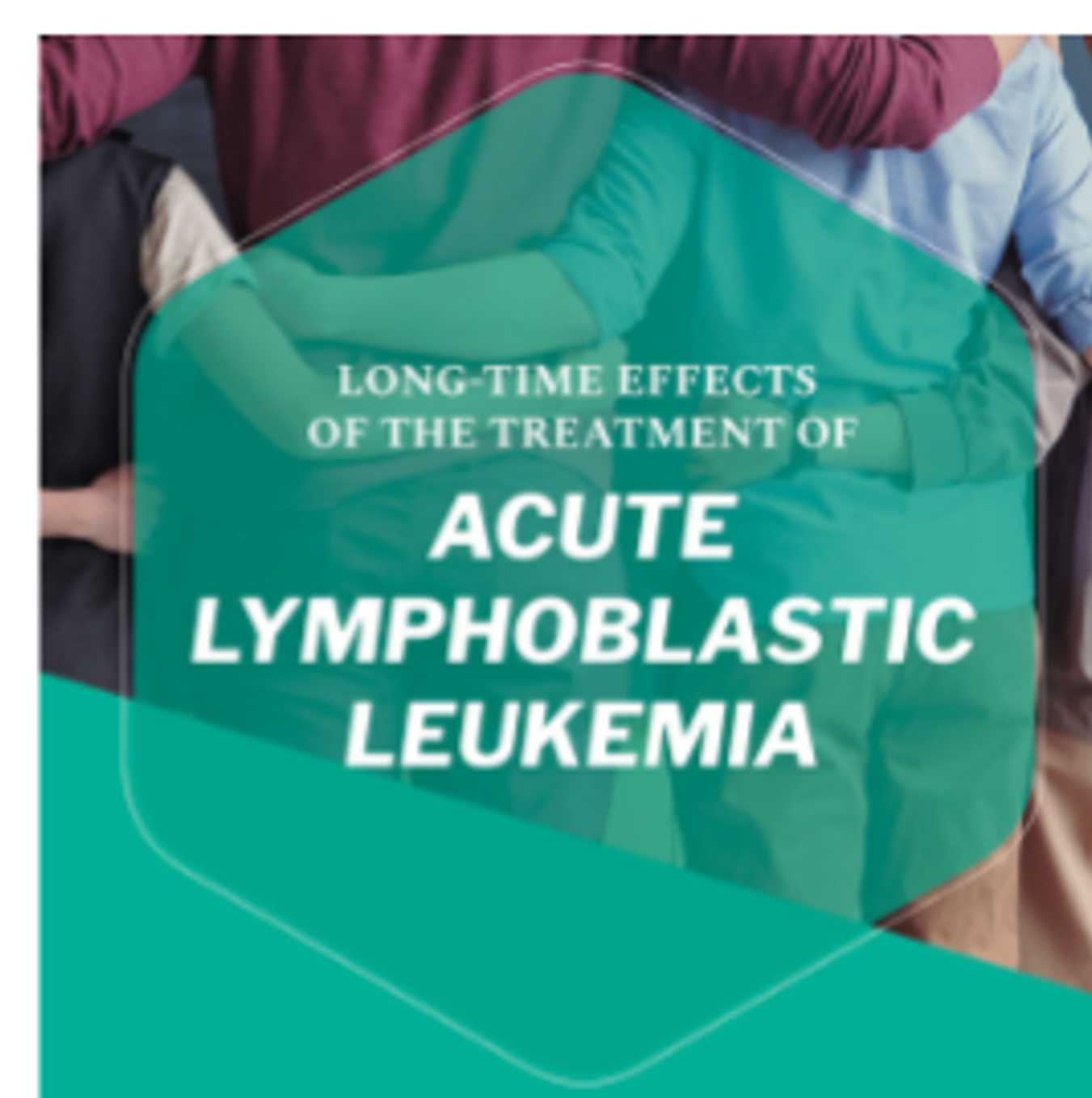
Collaboration and Networking

- **Collaboration with rare disease European initiatives**, research networks and other European granted projects.
- **Collaboration with patients organisations** to connect patients and caregivers globally.
- Involving **clinicians and researchers** affiliated with rare diseases.

Currently ongoing: Share4Rare pilots

- **PAEDIATRIC RARE TUMOURS**: Document the natural history of selected tumours.
- **ACUTE LYMPHOBLASTIC LEUKAEMIA**: Long-term side effects of treatments after 5 years of disease remission of paediatric onset ALL.
- **NEUROMUSCULAR DISEASES**: Impact of the disease on education and employment opportunities
- **UNDIAGNOSED PATIENTS**: Describe the burden of disease of the undiagnosed

LATEST FEATURE
Special profile
for patient organisations



Partners involved



Find out more and register
www.share4rare.org



This project has received funding from the European Union's H2020 research and innovation programme under grant agreement No 780262



European Commission