Share4Rare

www.share4rare.org

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Co-creation and Collaboration

Education

- Content in English and Spanish
- Medical 'chapters' co-created with clinicians, patients and families
- Links to Family Guides and other materials developed by TREAT-NMD and patient organisations
- Toolkit for patient advocacy
- Guide to paediatric palliative care
- News articles written in collaboration with clinicians, patients and families

Sharing

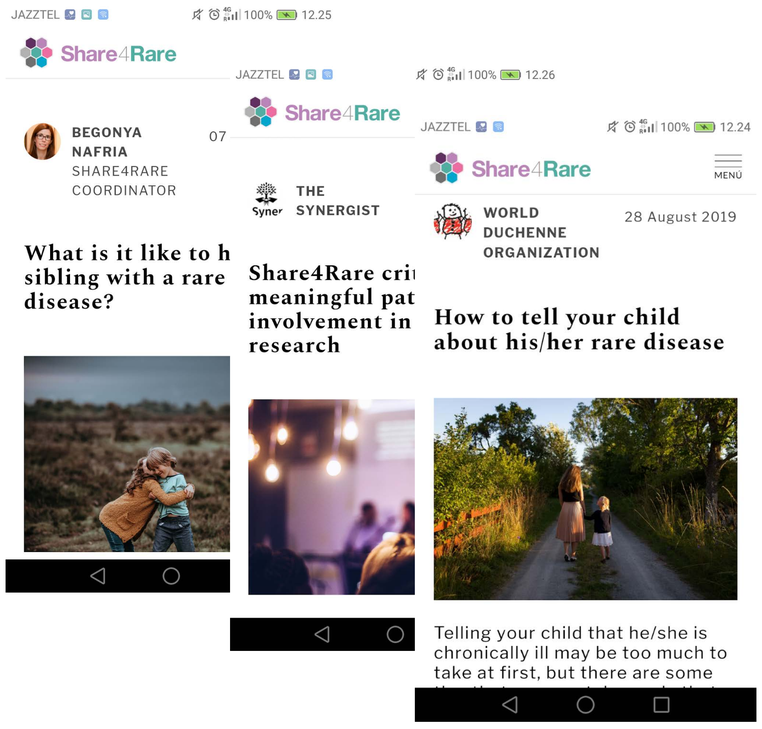
- Secure platform co-designed with patients, families and clinicians
- Validated users – rare disease and undiagnosed patients and carers
- Connect with 'people like me'
- Match users based on symptoms, as well as diagnosis
- User dashboard
- Q&A section
- Private messaging
- Expert patient and carer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

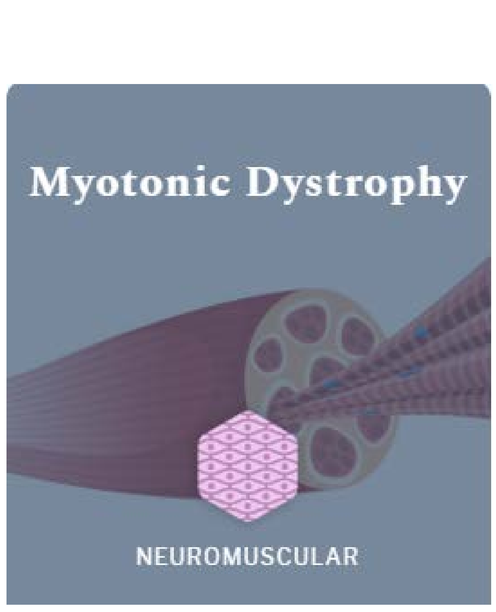
Research

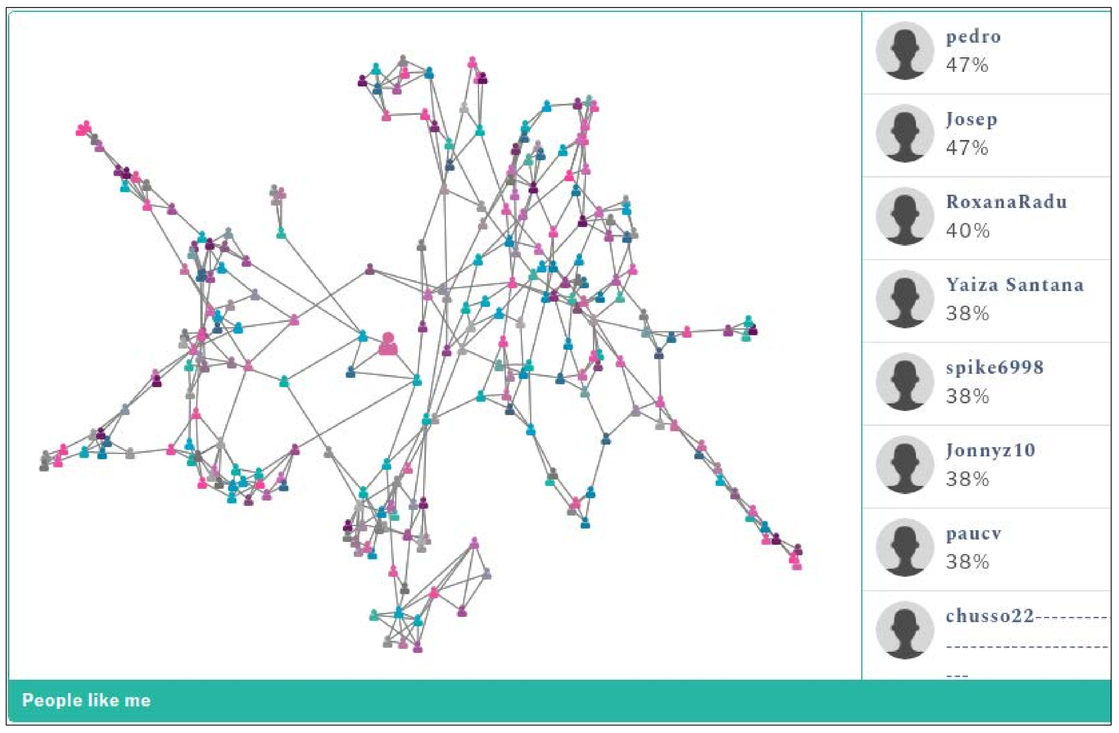
- Surveys designed and submitted by researchers
- Boost research into rare diseases
- Open to eligible Share4Rare users
- Data analysis using state of the art tools
- Aggregate data available to participants

Collaboration and Networking

- Collaboration with TREAT-NMD, EURO-NMD and other rare disease networks and organisations through newsletters and social media
- Collaboration with TREAT-NMD registries to reach patients and families
- Reaching out to clinicians and researchers affiliated with TREAT-NMD and EURO-NMD to involve them in the S4R community

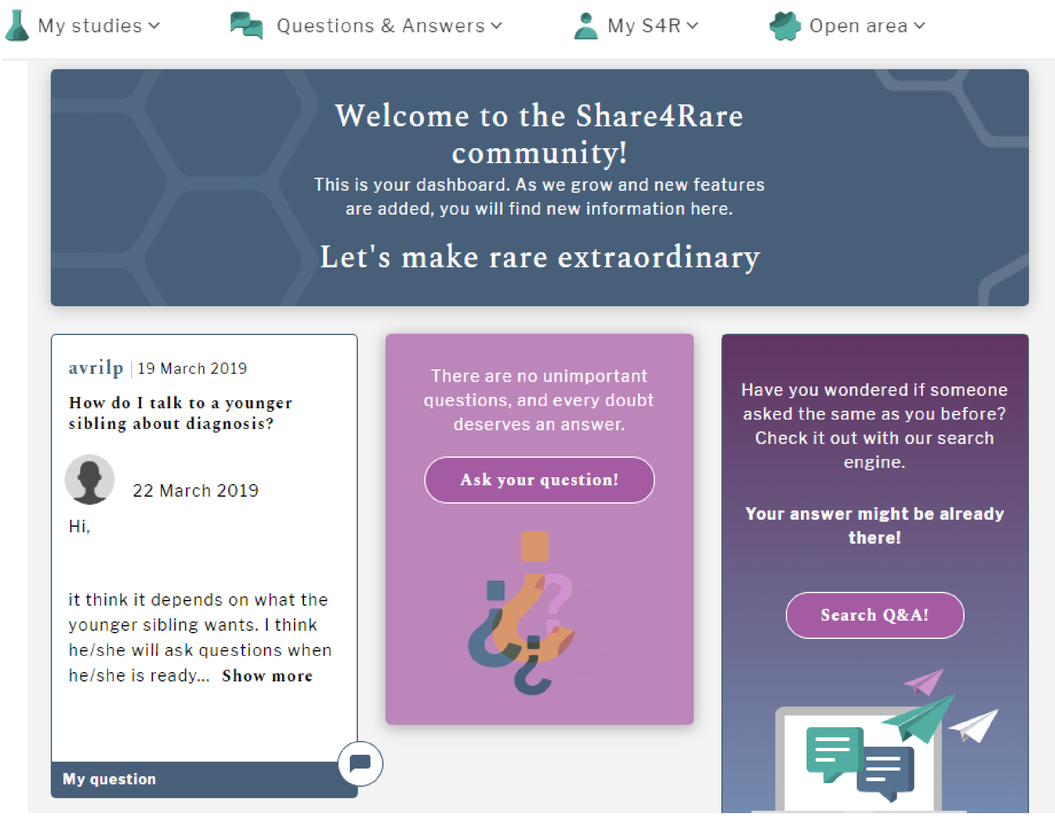






Neuromuscular Disease Pilot

- Administered through the 'Research' layer of the S4R platform
- Coordinated by World Duchenne Organization and John Walton Muscular Dystrophy Research Centre at Newcastle University
- Diseases: Muscular Dystrophies (DM1 & DM2, FSHD, LGMD, CMD), ALS, Peripheral Neuropathies, Congenital Myasthenias, Congenital Myopathies
- Open to eligible adult patients and carers (on behalf of paediatric patients)
- QoL, burden of illness and the effect of rare neuromuscular diseases on employment and educational opportunities
- Access to aggregate data for comparison with other users
- Analysis of results by end of 2020



Register at

https://www.share4rare.org/registration/s4r

Partners involved

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