Share4Rare: a collaborative platform for rare diseases

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6Assuta 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

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