Share4Rare

ADVANCING A PATIENT-CENTRIC RESEARCH AGENDA

Virtual coffee with patient organisations
June 16, 2020

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

Share4Rare

About the project

Beyond research- a tool for networked capacity and evidence-based advocacy

- Effectively connecting our people
- Sourcing valid and accurate information
- Build unexpected synergies and complement resources
- Build coalitions- patients/ research/ clinical
- Make research work for you: Collect, control, use and reuse your data beyond research for evidence-based advocacy

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Advancing patient-centric research

44

COUNTRIES INVOLVED

Countries across the world involved in the Share4Rare project

1.601

REGISTERED USERS

Patients and caregivers registered in Share4Rare

8.566

ADVOCACY TOOLKIT

Accessing the Share4Rare toolkit for Patient Advocacy

24.246

MEDICAL CHAPTERS

Reading the validated disease specific and cross cutting chapters

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Advancing Patient-Centric Research

Why Share4Rare was built

- Validate that a secure research platform driven by patients and POs is feasible and sustainable
- Allow patients to drive research in a way that is cheap, fast and of high quality
- Develop a place where patients are the owners and controllers of their data
- **Develop a business model without selling patient data**

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SJD Sant Joan de Déu Barcelona · Hospital

MELANOMA Patient Network EU

The John Walton Muscular Dystrophy Research Centre

WORLD DUCHENNE ORGANIZATION UPPMD

cliclab

UPC

The Synergist

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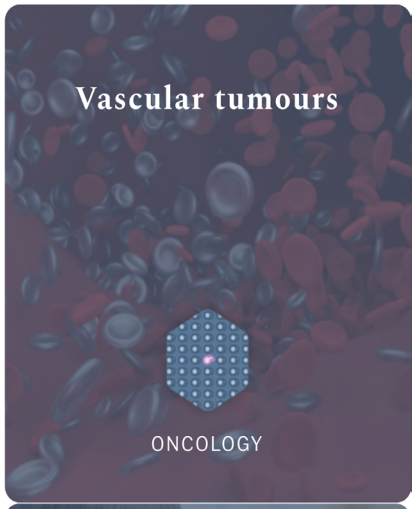
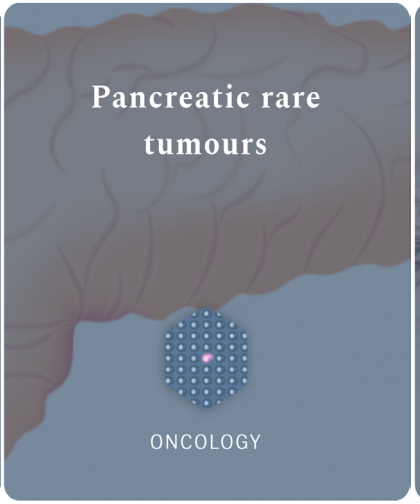
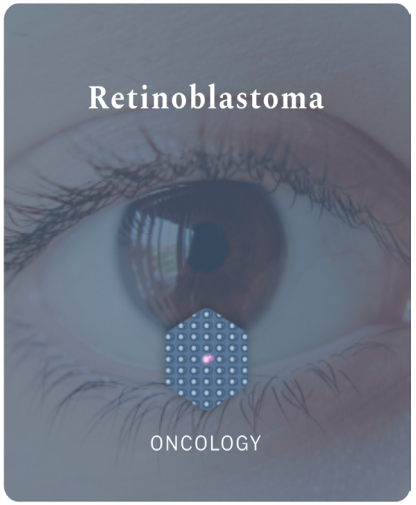
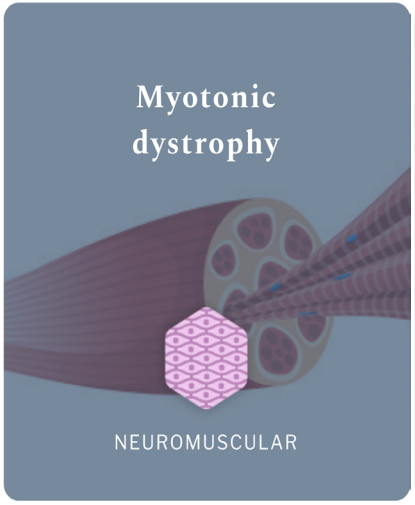
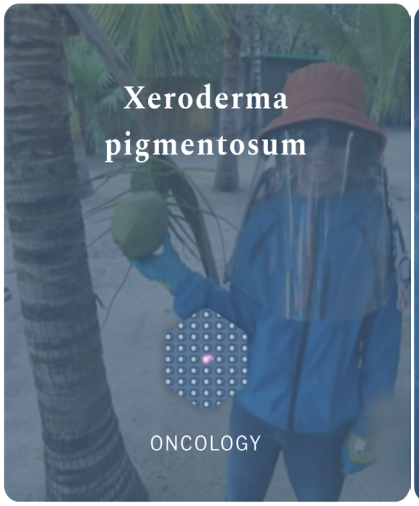
Disease specific medical chapters

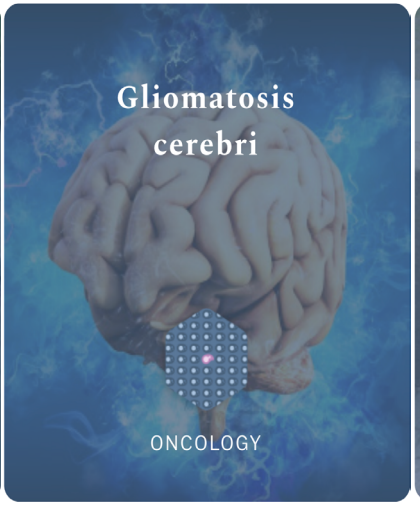












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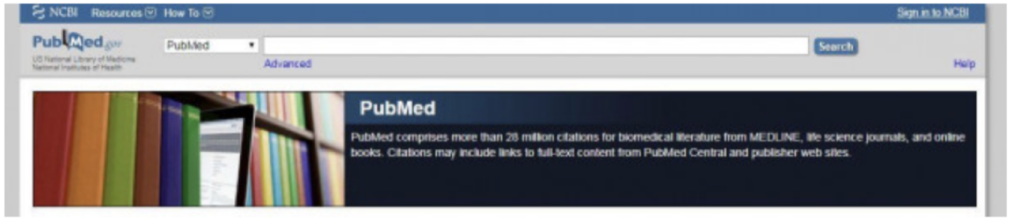
Share4Rare toolkit for patient advocacy

Finding medical research publications

PubMed is a useful place to find medical publications.



Pubmed Quickstart

PubMed **comprises** over 28 million citations for biomedical literature from **MEDLINE**, life science journals, and online books. PubMed citations and abstracts include the fields of biomedicine and health, covering portions of the life sciences, behavioural sciences, chemical sciences, and bioengineering. PubMed also provides access to additional relevant web sites and links to the other NCBI molecular biology resources.

PubMed is a free resource that is developed and maintained by the National Centre for Biotechnology Information (**NCBI**), at the U.S. National Library of Medicine (**NLM**), located at the National Institutes of Health (**NIH**).

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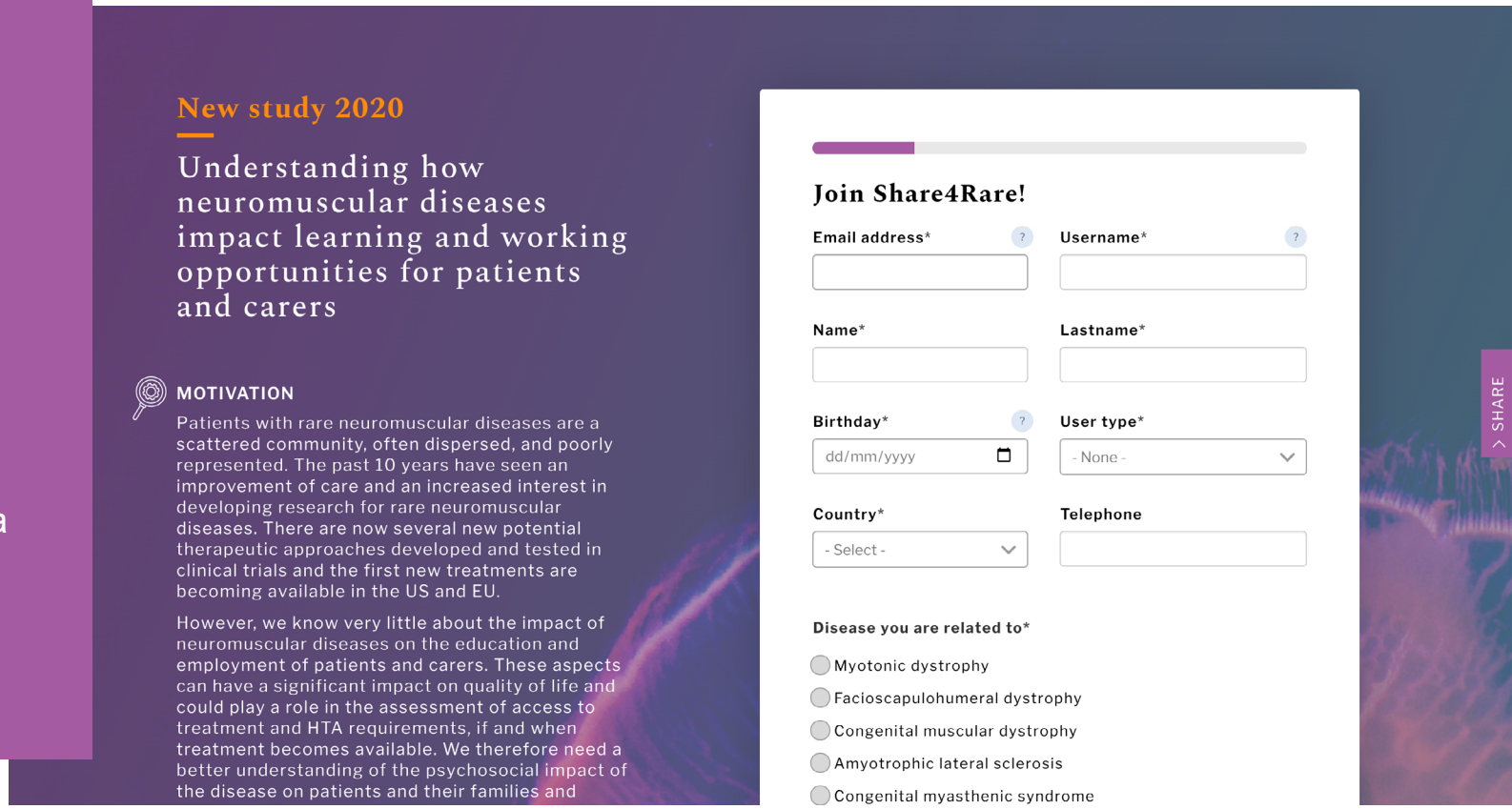
Research Study Example 1

NMD Disease Burden

- Understanding how neuromuscular diseases impact learning and working opportunities for patients and carers
- Led by Newcastle University, World Duchenne Organization and Sant Joan de Déu Barcelona
- Enrolling 281 participants

Join this study



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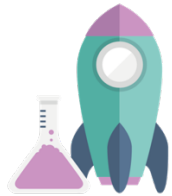
Research Study Example 2



COVID Registry

- Facing uncertainties in RDs during COVID-19: S4R International Registry
- The burden of COVID-19 in people affected by a rare disease
- Led by Sant Joan de Déu Barcelona in collaboration with various patient organisations

Join this study

New study 2020

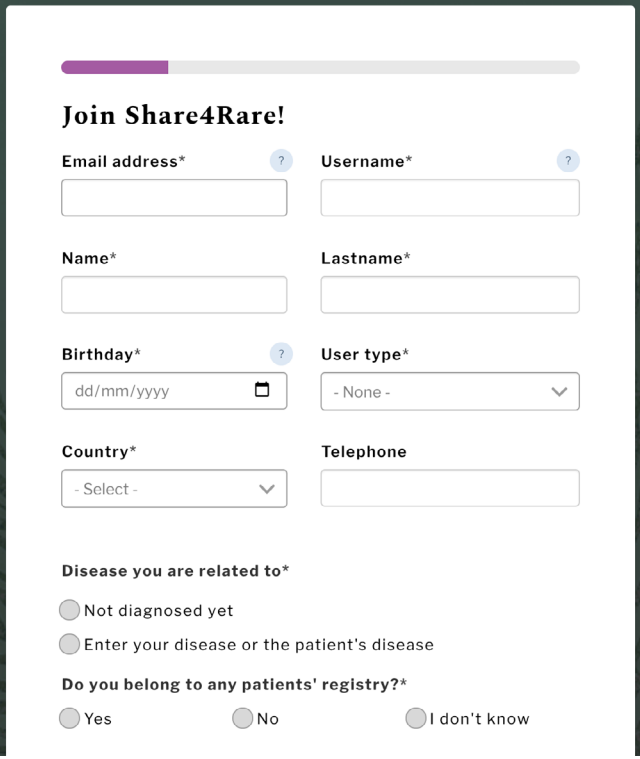
The burden of COVID-19 in people affected by a rare disease

MOTIVATION

People with rare diseases are doubly vulnerable to COVID-19: on the one hand, many of these pathologies put patients' health at a higher risk during a SARS-CoV-2 infection, and, on the other, confinement and lack of medical care due to the saturation of certain health services are making it difficult to treat these patients. If little is known about how this new infectious disease affects people without previous pathologies, even less is known about the effect of COVID-19 in people with unknown rare diseases.

OBJECTIVES

The objective of the study is to better understand how COVID-19 affects patients with rare or undiagnosed diseases. Thanks to this project, a registry of patients with rare diseases and with a positive diagnosis for COVID-19 will be created to improve the general knowledge of this new disease and its evolution and prognosis in these patients.



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Registration for POs

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THANK YOU!

For inquiries, please contact
info@share4rare.org

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