The John Walton Muscular Dystrophy Research Centre

Newcastle University

GLOBAL FKRP REGISTRY

The online research database for individuals with limb girdle muscular dystrophy R9 (2I)

Are you registered?

www.fkrp-registry.org

fkrpregistry@newcastle.ac.uk

Patient & doctor-reported genetic & clinical data of individuals with mutation in the **f**u**k**utin-**r**elated **p**rotein gene (FKRP)

Who can register?

GLOBAL FKRP REGISTRY

- Patients with an FKRP-associated condition from around the world:
  - Limb girdle muscular dystrophy type R9 (LGMDR9, also called LGMD2I)
  - Congenital muscular dystrophy type 1C (MDC1C)
  - Muscle Eye Brain disease (MEB)
  - Walker-Warburg syndrome
- All ages welcome - patients under 18 years must be registered by their parents or guardian (16 years in the UK)

Why register?

- Receive details of clinical trials & research studies and FKRP-relevant information
- Patient data improves our understanding of the natural history of FKRP-related muscular dystrophies & assists clinical trial planning

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