



UKFSHD

PATIENT REGISTRY



www.fshd-registry.org.uk



A secure, online database of patient-entered
and clinician-entered data for individuals
affected by FSHD living in the UK

SCAN ME



TO RECEIVE
INFORMATION

Why join the registry?



Share information on your symptoms, trial preferences, access to care and support etc...



Register via our secure online website and answer questionnaires on our improved registries platform



Nominate your neuromuscular consultant or other care providers to add important clinical data



Receive information about clinical trials you might want to participate in



Provide essential information to support FSHD research

