Requesting your genetic report

Give this paper to your/your child's doctor so that they know what you are asking for.

Your patient is registered in the Global FKRP Registry, an international registry that collects clinical and genetic information about people affected by conditions caused by mutation in the *FKRP* gene. These conditions are limb girdle muscular dystrophy type 2i (LGMD2I), congenital muscular dystrophy type 1C (MDC1C), muscle eye brain disease, and Walker-Warburg Syndrome.

The Global FKRP Registry is primarily aimed at finding patients for clinical trials and so all patients need to provide the Registry with genetic confirmation of their diagnosis, which includes details of the exact mutations.

We kindly request that you provide your patient/patient's parent with a copy of their/their child's genetic report for the Global FKRP Registry.

What should I do with the genetic report once I have it?

You can upload a copy directly to your account in the registry.

To do this you will need to scan the genetic report so that you have an electronic copy saved.

Once you have this, log into your account on the registry website (www.fkrp-registry.org) and then go to Your Genetic Report form and follow the instructions on the page.

OR

You can send a copy to the address below:

Global FKRP Registry
John Walton Muscular Dystrophy Research Centre
Institute of Genetic Medicine
Newcastle University
International Centre for Life
Newcastle upon Tyne, NE1 3BZ
United Kingdom