Garvan Institute of Medical Research | GENOMICS OF RARE DISEASE REGISTRY

An opportunity to connect to new Fibrodysplasia Ossificans Progressiva (FOP) research

FOP is one of thousands of known or suspected monogenic diseases benefiting from major advances in genomic medicine. These advances now give us the power to better diagnose, predict, and treat genetic disease.

One of the primary challenges in bringing these advances to individuals with **Fibrodysplasia Ossificans Progressiva** and other conditions is a lack of research infrastructure. To help address this gap, researchers at the Garvan Institute of Medical Research have developed the Genomics of Rare Disease (GRD) Registry: a study supporting research across all known or suspected monogenic conditions.

The GRD Registry focuses on assembling data and samples from Australians with a known or suspected monogenic disease, with the overarching goal of improving the understanding, identification, and management of these conditions. Through this initiative, families can be connected directly with emerging research opportunities, including studies that can assist with finding a genetic diagnosis. Building this research-ready community can also make Australia a more attractive destination for FOP clinical trials.

To learn more about the GRD Registry study, please visit grdregistry.org.au for more information, expressing your interest to join the Registry, or contact us on gid@garvan.org.au if you have any further questions.

Genomics of Rare Disease Website

Participant Expression of Interest Form