

How PPD Clinical Research Services and Matrix Clinical Trials Delivered a Patient-Centric Solution to Recruit and Retain Hard-to-Reach Patient Populations for Ultragenyx



BACKGROUND

Patient recruitment and retention in rare disease clinical trials can be particularly challenging due to widely distributed and hard-to-find patient populations, the burden of participating in a trial, often spurred by lengthy journeys to diagnosis or repeated failed clinical trials. Digital and decentralized solutions help alleviate patient burden by bringing the trial to the patient.



SITUATION

A rare disease subject's bloodwork was deemed not viable for processing and needed to be repeated. The subject expressed frustration and felt another in-home visit would be too great of a burden. Without a mobile solution, the patient would be unable to participate in the trial.



SOLUTION

By continual assessment of the protocol, PPD, part of Thermo Fisher Scientific, identified and operationalized a decentralized strategy that would enable, build and deploy a mobile site to the patient's home. Through digital and decentralized solutions' unique partnership with Matrix Clinical Trials, we quickly established and implemented the mobile site strategy along with relevant clinical resources. The patient met the clinical team at the mobile site and completed the visit without the stress and burden of having people in their home for an extended length of time.



RESULT

By utilizing digital and decentralized solutions' end-to-end offerings - from consultancy, strategy development and our established partnership - we were able to implement a patient-centric solution for Ultragenyx within three weeks of being notified of the patient's concern, directly addressing the patient's needs regarding burden. This offset the risk of potential dropout, which in rare diseases would have a significant impact. Instead of having one PI/site with a very small patient population attached to that particular site, we now are able to open enrollment to the entire country, capturing more patients. This is one example of the dynamic ability of PPD Clinical Research Services to bring the trial to the patient.

Patient burden reduced



by taking the site to the patient via a mobile health clinic

Participant dropout eliminated

by implementing a creative, patient-centric solution in place of a standard in-home visit



Patient-centric solution deployed within three weeks



of notification about patient's concern