One of the greatest challenges faced by those living with an undiagnosed disease is the lack of information and communication. When a patient experiences symptoms that aren’t easily classifiable or seem uncommon, they can fall through the cracks of modern medicine—leaving them feeling isolated while the true cause of their disease goes unexamined.

Genes of Interest

Here, you can learn more about some of the genes we are studying.

MyGene2 Profiles

Some UDN families have created profiles on MyGene2.org, which enables families with rare conditions to search and match with other families, researchers, and clinicians based on similar genetic findings.

Participant Pages

To help find patients with the same or similar condition, we are creating public web pages about participants in our study. Our goal is that healthcare providers, researchers, and families who know similar patients will find these pages. Connecting these patients with ours will ideally help us identify shared symptoms and diagnoses.

Participant Engagement and Empowerment Resource (PEER)

The UDN Participant Engagement and Empowerment Resource (PEER) is made up of participants and family members who have participated in the UDN. PEER members work with UDN researchers to improve the participant experience, connect families with each other, and share the UDN with others.