What we do

The UDN Participant Engagement and Empowerment Resource (PEER) is made up of patients 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. A primary goal of the PEER group is to provide resources and support for UDN patients and families across the country. If you are a current UDN patient or family member, consider joining our UDN Patients and Families Facebook group or follow us on Twitter and Instagram.

Contact us

We are here for you! If you have questions, concerns, or comments, or just want to connect with other UDN patients and families, please reach out to us by email at UDNpeer@gmail.com.

Newsletter

The UDN PEER group publishes a quarterly newsletter for patients and families in the UDN. The newsletter includes patient and family stories, updates on the PEER activities and the UDN network, and resources tailored to the UDN community’s needs. Check out our most recent version here or our archive of previous newsletters here.

Events

Upcoming

UDN PEER “Tell Me More” Lecture Series: Sanath Kumar Ramesh

Past

UDN PEER Presents: The Genome Odyssey Book Launch with Dr. Euan Ashley

UDN PEER “Tell Me More” Lecture Series: Dr. Matthew Might

Radio Health Journal: Undiagnosed Mystery Diseases
Meghan Halley (PEER Co-Chair) lives in Menlo Park, CA with her three children, ages 7, 6 and 3. Her middle son, Philip, is a patient in the UDN, though he remains undiagnosed at this point.

Troy Evans (PEER Co-Chair) lives in Draper, UT. He entered the UDN as a patient in 2018 by visiting the UCLA site. Although a diagnosis has not yet been made, he is confident the UDN will be able to help him like it has so many others.

Sarah Marshall lives in Eden Prairie, MN with her four daughters; her youngest, Phoebe who is 12 years old, is a UDN participant. As an experienced mom with an advanced degree in social work, she spends a great deal of her personal and professional time doing advocacy work.

Brian Broadbent lives in Dallas, TX with his wife and two daughters. His youngest daughter Emma, age 4, was a UDN participant and diagnosed by a collaborative team as having a deletion of CHASERR, a lncRNA gene.

Luke Shantz lives half the year on Whidbey Island just outside of Seattle, WA and the other half of the year in Colombia South America. He was first seen by NIH in 2016 and after years of research was diagnosed with a rare neurological movement disease.

Jessica Regele lives in Middleton, WI with her husband and 4 children. She was a UDN participant and was diagnosed after genome sequencing revealed she was a carrier for the FLG mutation. This discovery, additional testing and medical recommendations through
UDN have been life altering. She believes in a perfect world every individual with an undiagnosed disease would have the opportunity to be a participant of UDN.

Kara Anderson lives in Charlottesville, VA. She is very grateful to the UDN. After being undiagnosed for years, she was given a conclusive diagnosis at the Duke site in 2018. She looks forward to celebrating with present and future UDN participants who get closer to and achieve a diagnosis through this instrumental program.

Christin Siscoe lives in Clemmons, NC. Registered nurse by trade, Mom to Ayden and Cooper, and wife to Shay. Her son Cooper was accepted in the UDN and visited the Duke site. He is still waiting on a full diagnosis but Hereditary Pancreatitis was diagnosed in December 2020 from the network. She hopes that one day everyone searching for a diagnosis will find their answers and treatment through the collaboration of science and the UDN.