What we do

UDN Participant Engagement and Empowerment Resource (PEER) is made up of patients and family members who have participated in the UDN. 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 UDN 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 peerudn@gmail.com.

Newsletter

Sign up for the newsletter here.

The UDN PEER group publishes a quarterly newsletter for patients and families in the UDN. The newsletter includes patient and family stories, updates on UDN PEER activities and the UDN, 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 events

TBA

Join our mailing list for event reminders!

Past events

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

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

UDN PEER “Tell Me More” Lecture Series: Dr. Anastasia Wise

UDN PEER “Tell Me More” Lecture Series: Dr. Eric Green

About us

Meghan Halley (co-chair)
Sarah Marshall (co-chair)
Troy Evans
Luke Shantz
Kara Anderson
Christin Siscoe
Tia Hopkins
Erika Cox
Meghan Halley (UDN 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.

Sarah Marshall (UDN PEER co-chair) resides in Minnesota with her four daughters, her youngest finally received a diagnosis in June 2021 after a 10+ year diagnostic odyssey. Outside of personal and professional advocacy, she likes to run, kayak and adventure outdoors.

Troy Evans 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.

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.

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. A 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.

Tia Hopkins and her son, Terren (pictured), are from Maumee, Ohio. Terren has been a part of UDN for a couple of years. They finally had the opportunity to travel to Maryland this past July, and though don’t yet have a diagnosis, Tia says, “we learned a lot about how special he is.”

Erika Cox lives in El Paso, TX with her husband and two daughters. Her youngest daughter Ava, age 7, was a UDN participant and diagnosed by a collaborative team as having TBCK. Ava’s condition is de novo which makes her more rare but extra special to her family.

John Peltier lives in Calgary, Alberta, Canada with his two daughters. His youngest daughter has been a UDN participant since late 2017, working with the UCLA site. A diagnosis has not yet been determined; however, the work of the UDN has advanced a number of promising leads and enhanced the understanding of his daughter’s underlying condition.

Pazhani Sundar Murukesan lives in Austin, TX with his wife and daughter. His second baby, Atharv (son), was born in 2018 and lived for 7 months before passing away in 2018 due to intractable epilepsy. His third baby, Akshita (daughter), was born in 2020 and lived for 5+ months before passing away in 2020 due to intractable epilepsy, the same condition as his son. Akshita was enrolled in the UDN and visited Baylor Genetics in Houston. Both of his kids remain undiagnosed. Even though his kids are deceased, he hopes the UDN will be able to help find the diagnosis with their DNA materials and blood samples & muscle biopsy samples.

Stephanie Tomlinson has advocated for her son and others like him for over 20 years. She has been certified in the program Partners in Policymaking and seated on numerous committees surrounding early childhood special education and early detection. Recently, Stephanie was the Patient Support Coordinator for MitoAction. As the first call for help, Stephanie answered calls from patients, caregivers, and care providers looking for support and resources regarding Mitochondrial Disease. She hosts a bi-weekly podcast, Energy in Action, which focuses on the storytelling of patients with rare diseases, and experts in the field discussing their research. She is passionate about people having a voice in their care and strongly urges people to use their voices. It is the experience of those who are battling the disease that holds the answers to a treatment.