Linking families to genetics

Family Center

HRGN Annual Meeting 2023
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Program Aims

Provide culturally- and linguistically-appropriate education and resources on genetics and genetic conditions to families

Provide technical assistance to RGNs on how best to incorporate family leaders into their programs and reach underserved populations

Train individuals and families to become family leaders within the genetic health care delivery system and the Regional Genetics Networks (RGNs)

Provide support for individuals and families with, or at risk for, genetic conditions so that they can be equal partners in their health care
Our Partners
Family Center Resources

WEBSITE

PODCAST

PEER LEARNING

WEBINARS

LEADERSHIP TRAININGS
Understand Genes and Genetics

Genes are the instructions for life as we know it.

Learn More Here
INDIVIDUAL

Resources for understanding and embracing your own capacity for leadership.

Finding the Win by Sarah Jacobs

“My husband, Adam, and I have two boys, Graham (10) and Dominic (6). Dominic has Dravet Syndrome. It is a rare and severe form of epilepsy that is lifelong and drug resistant...”

Read More →

Who is a Family Leader? With Jeannette Mejias

“Honor your process. It’s okay to not be okay. Then once you go through the stages, what’s next?”

Watch The Video Here →

Who is a Family Leader?

In this interactive virtual learning module, you will: Recognize who can be a family leader and how and where they demonstrate leadership, identify leadership characteristics and describe your own leadership in the context of being a family leader.

Complete The Module Here →
Who is a Family Leader?

WELCOME

Who is a Family Leader?
Linked Together

A dynamic podcast series showcasing honest and open discussions about the issues that affect family leaders and what it means for families to drive systems change.

Linking families to genetics.
Peer-to-Peer Groups and Learning

- Family Center Workgroup on Inclusion
- Family Center Community of Practice on Diversity, Equity, and Inclusion
- Parent Leader Office Hours
Opportunities for Involvement

Inform
Stay up to date on the latest events, resources, and trainings by signing-up for updates or follow organizations on social media.

Join
Join the Family Center Community of Practice on Diversity, Equity, and Inclusion. – 4:00 – 5:00pm EST On the third Wednesday of every other month

Reach out
Reach out at mmartzke@expectinghealth.org