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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.
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.
Molly Martzke
Senior Program Manager
mmartzke@expectinghealth.org

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