



# THE CHARGE SYNDROME FOUNDATION Liaisons

# Local Support &

# National Strength



## WHO WE ARE

### Local:

Liaisons are adults with a family member diagnosed with CHARGE syndrome who volunteer to work within their state of residence and adjacent states or special social/cultural sphere to build relationships, network, collaborate and disseminate information.

### National:

The Family Engagement Workgroup (FEW) oversees the liaison program. The FEW is headed by the Outreach and Engagement Manager and is composed of Regional Facilitators, members of the Foundation's Board of Directors and Special Advisors to the Board. The FEW recruits, trains and supports liaisons to work directly with families.

This program is volunteer based and has found success in easing social isolation of families and improving the self-efficacy of both liaisons and referred families.

## WHAT WE DO

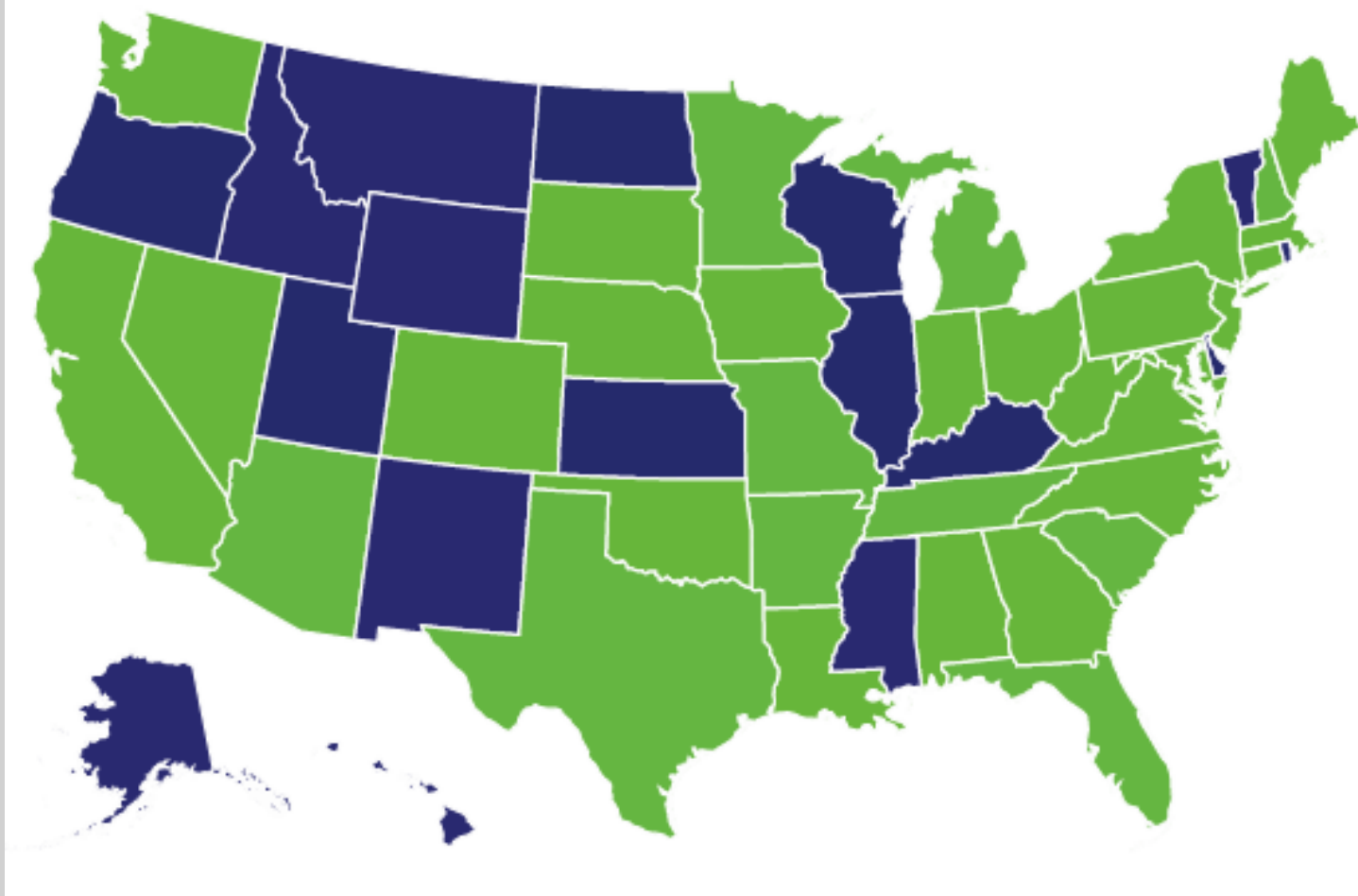
- Provide support for families with a new diagnosis and ensure connection to state deafblind projects and other vital medical, educational and language resources
- Share the latest CHARGE Syndrome Foundation resources with the State Deaf-Blind Projects and the families
- Assist in helping both the Foundation and the State Projects in identifying families
- Promote connections among families with a member who has CHARGE syndrome
- Plan one local family meet-up annually in coordination with the annual Walk & Roll for CHARGE
- Prepare and maintain a State Resource List to help in medical, educational and social systems' navigation
- Gather virtually for quarterly training meetings

Liaisons can connect families with these programs:



Do you know a family that could benefit from a connection to state and local resources?

## FIND SUPPORT IN YOUR STATE



Contact the liaison in YOUR community by visiting [www.chargesyndrome.org/for-families/get-support/](http://www.chargesyndrome.org/for-families/get-support/)



## NICE TO MEET YOU!

Sign up for the CHARGE Syndrome Foundation eNews to receive e-mail announcements highlighting upcoming events, research, webinars, conference information, and more!



## JOIN US AT OUR CONFERENCE!



15th International CHARGE Syndrome Conference "Back in CHARGE" Orlando, Florida July 20-23, 2023

Individuals with CHARGE syndrome receive FREE conference registration.

16th International CHARGE Syndrome Conference "The Grand Adventure" Phoenix, Arizona July 24-27, 2025

Conference is a unique opportunity to learn from experts in the field and connect with families throughout the weekend. Professionals learn as much from families as families do from them. Scholarships are available by the generous donations of our members and partners.