

# CHARGE Syndrome Foundation

## State Family Liaisons:

# Problem Solvers

### PROBLEM:

State Deaf-Blind Projects and the CHARGE Syndrome Foundation are NOT both receiving information on newly diagnosed families.

### SOLUTION:

Liaisons develop information sharing and referral agreements with each state deafblind project. This allows true connections to be forged between new families and the resources from their technical assistance programs.

### PROBLEM:

Educational, medical and therapeutic resources vary from state to state and it is difficult for the national foundation to maintain current resource lists.

### SOLUTION:

State Liaisons are connected to state-based resources. They are not expected to know all the answers - but who to call within a state or region to get the answer.

### PROBLEM:

Foundation workgroups need additional volunteers for program development, feedback and implementation.



### SOLUTION:

State Liaisons are invited to work with the Board of Directors on projects and programs as needed without any additional training or vetting. These are tried and true volunteers who understand the mission of the Foundation as well as the needs and circumstances of its members.

### PROBLEM:

2021 Conference had to be postponed due to COVID-19. Board of Directors worked to convert the program to a fully-accessible digital format.

### SOLUTION:

State Liaisons were able to be quickly trained to host, moderate and even present sessions of the 2021 Symposium. This happened on a tight schedule because of the communication already established between the Board, the Liaisons, Deafblind Network

### NICE TO MEET YOU!

Sign into our digital guest book and let us know what we can do for you!



Can we provide more information on local family to family support?

Would your organization like a presentation on CHARGE Syndrome?

Do you know of a family that would benefit from contact with their State Liaison?



Are you interested in information specifically for professionals?

### JOIN US AT OUR CONFERENCE!



**15th International CHARGE Syndrome Conference**  
"Back in CHARGE"  
held at Rosen Single Creek in Orlando, Florida  
July 20-23, 2023

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

### WHO WE ARE

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

They provide family-to-family support for newly diagnosed families and ensure connection to state deafblind projects and other vital medical, educational and language resources.

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

### WHAT WE DO

- Provide family to family support.
- Share the latest CHARGE 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 the CHARGE families in the state

### GET IN TOUCH

### FIND SUPPORT IN YOUR STATE



Contact the Family Liaison in YOUR community by clicking on your state!  
[www.chargesyndrome.org/for-families/get-support/](http://www.chargesyndrome.org/for-families/get-support/)

