CHARGE Syndrome Foundation State Family Liaisons:

PROBLEM:

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

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:

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

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

Educational, medical and

get the answer.

NEVADA Kristin Knutson South Dakota Betsy Marsolan We live in Sioux Falls, South California Kayla and Sarah are in college Andrew is a freshman in high onan (7 years, CHARGE Syndrome) school and is currently the Victoria Criswell Who's in your family: Miles is on the spectrum, and many of the services Bill, my husband of 23 years, and therapies we've explored with Ronan have Scott Lynin Will - 19 in college in LA, Carson-18, Tyler - 16 with CHARGE/Autism, Hamish - 19 What activities do you Paul is an entrepreneur and has his own company. | |th exchange student and Bailey - our K-9 buddy. Betsy was an engineer and later advertising l love to garden, hike, Who's In Your Family? What do you want people to know about camp and study family scott and Marianne Lynn genealogy. I love opera and all kinds of music. Isaiah (5) w/CHARGE I'm involved in Boy Scout Bay Area. I have been married to an amazing, (now for special needs supportive husband for 23 years. Originally son), and working on my What do you want people to know Texas and have been in California for 25 years. I cars with my boys.

Why do you voluntee

with the Foundation

others who are going

through this amazing

strong!

journey. Together we are

have three wonderful boys and our house

Perkins School for the Blind in Boston this

always has something going on. Tyler attended

summer (2019) in their Deafblind program and

district. Additionally, I'm focusing on educating

myself on transition and what does that look

like for Deafblind adults. My son, Tyler, loves

ust as I do, and we try to make every day

loved it! I'm currently trying to auphicate that he Perkins program into my sons school, so that he

can flourish in our nome district, and working understand what i ne towards interveners being acknowledged in our be doing for my son.

PROBLEM:

Foundation workgroups need additional voluteers 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.

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?

WHAT WE DO

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.

- 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

PROBLEM:

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

> • Liliana Michel (age 2) • Katrina Michel (mom)

What do you want people to know

families, especially ones who are just

getting a diagnosis, who's world may

What activities do you like to do?

-We love hiking and traveling, both

have been difficult the last several

- Alexis loves photography, books,

and getting into EVERYTHING

podcast and various self care activity.

- Mari and Tayen love books, dancing,

need a little extra support.

feel a little upside down and may just

Matthew Jones

Alabama

(wife), David (3), Child #2 expected

interactions with the Found

always been positive. I saw

Alabama didn't have anyon

to it as a liaison, so I wanted

I've also learned, and continu

so much about CHARGE as tin

occasionally enjoy Root Beer

Ay son's favorite hobbies are

mickey mouse, and general

outside shenanigans. ©

Who's In Your Family?

Hannah (CHARGE/9)

Samantha (mom) Jacob (4)

know about your family?

We started our journey in Kansas

have it any other way. Caleb is our

genius, Hannah is our sunshine

mischievous, and Claire is the

Zoey is our excitement, Jacob is

the Foundation?

the last 10 years

educating myself

in order to be the

best advocate for my sweet Hannah. I

existing families. This journey is one that

often times starts out rather scary and

support system is one of the first steps

to finding peace among the unknown in

this vast world of CHARGE Syndrome.

I have spent

learning and

Ricky (dad)

on. I enjoy the networking as What do you want people to

What activities do you like with us recently moving back to with us recently moving back to

A little of everything. I run our hometown in Iowa. Our hearts

marathons, hiking, martial a belong to the which am blessed to civil engineer and I am blessed to

woodworking. I've been an civil engineer and be able to stay home with my five be able to stay home with my five

director for Toastmasters, an beautiful children. Our family is

the opportunity.

karily have the hearing and balance

s. My son has hearing loss,

erren's, and a couple skeletal

ound out via Whole Genome

encing, and I actually got my

de of CHARGE, I also help admin a

Dads Support Group Facebook

losis when my son did.

th, two open heart surgeries at

SOLUTION:

Alexis Ramirez-

California

CHARGE, our labradoodle Luna and

n the East Bay Area CA.

oand and I met in college,

studied sociology and my

d was studying coding and

e been in the advocacy world

are all learning ASL and our 2

out disability rights and

old currently knows more than h

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**

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

GET IN TOUCH





Contact the Family Liaison in YOUR community by clicking on your state! www.chargesyndrome.org/for-families/get-support/



