

Support and Engagement for Families with Children with CHARGE Syndrome

CHARGE Syndrome is a recognizable genetic syndrome with a known pattern of features. It is an extremely complex syndrome involving extensive medical and physical difficulties that differ from child to child. Most children have hearing loss, vision loss, and balance problems that delay their development and communication.



Who We Are

The CHARGE Syndrome Foundation is a national nonprofit organization. Our goals include ongoing outreach and support, increasing knowledge, promoting awareness, building networks and partnerships, and investing in cutting-edge research.



What We Do

Our Outreach and Engagement Manager is a staff member who directly engages with families. They connect parents to resources and other families in their state or with similar challenges. They collaborate with partners and professionals to spread awareness.



Family Liaisons

Family Liaisons are family members or individuals with CHARGE who volunteer to work within their state of residence and adjacent states, or unique social/cultural spheres, to build relationships, network, collaborate, and disseminate information. This program has found success in easing social isolation in families, and improving the self-efficacy of both individuals and families.



Parent-to-Parent Virtual Support Groups

Parent-to-Parent Virtual Support groups offer opportunities to connect virtually from anywhere in the world. There are different groups built according to developmental stages or other commonalities.

One example is the Birth-to-Three support group for new parents.



Other Programs and Support

Medical Travel Assistance Program



Crocker Barker Sibling Scholarships



Ethan Wolfe Recreational Assistance Program (EWRAP)



Contact Us

Info@CHARGEsyndrome.org

CHARGEsyndrome.org

