



# Caregiver Connections

## Family CIRCLE Progress

As we enter May we are thrilled to announce that our group has grown to over 700 families across the United States. This map indicates the various universities and hospitals involved in the study.

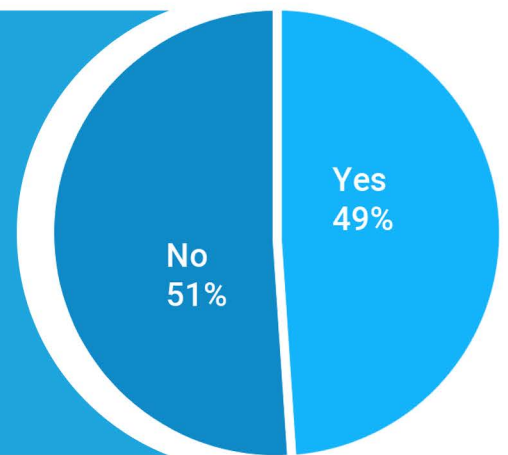
We want to extend a huge THANK YOU to all of you who have made this research possible. We have already started to learn so much about the experiences of caregivers of children and youth with special healthcare needs.



## Family Facts

**During the past 6 months, have you or other family members cut down on the hours you work because of your child's health conditions?**

So far, 1/2 caregivers from Family CIRCLE have said that they or another family member have cut down on the number of hours they work because of their child's health conditions. These employment disruptions could cause financial strain and may indicate the need for additional support services.



## Family Voices

Family Voices is an organization run by families and friends of children with special healthcare needs, with the goal of improving healthcare services and policies for children. Check out the [Bright Futures Family Pocket Guide](#), a handbook written by families for families and co-created by Family Voices. This guide contains information and advice to help families and providers work together to promote the health and wellness of children.

## Family Spotlight

Yadira, a lived experience partner collaborating with Children's Mercy, has written the following message for other caregivers involved in this project. [Click here to learn more about LEP involvement in Family CIRCLE.](#)

Being a mom and caregiver of a child with disabilities can be tough... but also not so much.

I have dedicated myself to care for my son. To be able to take him to his doctors' appointments (surgeries), Individualized Education Program's school meetings, sports, fun activities, in general to be there always. It's important to know that we are not alone. That there is always so much support, like Project Eagle, Families Together, our own families, and services and support like those at Children's Mercy. Because of that I became a volunteer, and we feel grateful. Down Syndrome Guild, where we've also received so much support, hosts so many activities and conferences. I was a leader in the Latino group there where I welcomed new families and gave them information about Down Syndrome. We keep in touch to share our doubts, questions, to share our experiences. I have met incredible, honest people because of my son. It's okay to feel overwhelmed many times, who doesn't? But also, we must set a goal and try always to accomplish what we want for our loved ones and never give up.

## Media

This month we're recommending a podcast about parents of children with rare conditions called The Rare Life. In Episode 84, hear Madeline Cheney and Carrie Holt discuss their journeys as caregivers of children with special healthcare needs here: [The Rare Life](#).