

“I can do things you cannot. You can do things I cannot. Together, we can do great things.”

Nobel Peace Prize winner Mother Theresa, through her tireless support of children and families, knew the power of teamwork. We want to continue to improve the health and wellbeing of Vermonters. -- **especially with those with a child or youth with special health needs.** The staff at CSHN will support our families as Governor Phil Scott, Health Commissioner Mark Levine, and other leaders plan for the safe re-opening of Vermont’s business and health care services.

Highlights

- Please take the time to complete this [survey](#) and share your experiences with **care coordination**. We will use the results of the survey to help us improve our systems.
- Consider our invitation to become a Family Partner (found in the survey) and sign up.
- We are also thrilled to launch our **Family Spotlight** feature, an opportunity for families’ experiences to be highlighted, seen, and shared. Check out the Jakubiak family on page 2!

Resources

Vermont Family Network: Our partners at Vermont Family Network are hosting [virtual chats](#) for families. Tune in, listen, talk, and know that you are not alone.

Meal Distribution for Those in Need: Meals will be distributed to those in need throughout the month of May. Food will include FEMA meal boxes, along with produce, chicken, and dairy products. Click [here](#) for the distribution schedule.

Family Voices: Information on civil rights, disability bias, and family-centered care can all be found on the Family Voices [website](#).

Talk to Us

The staff at [CSHN](#) is committed to keeping you informed about resources and updates to services that may apply to your family. Even though in-person visits are on hold right now, we are just a call or email away. Go to our website to find your local [CSHN Care Coordinator](#) or call us at 802-863-7338.

Find information all of our updates at www.healthvermont.gov/family/special-health-needs

Family Spotlight

The Jakubiak Family



My name is Irene Jakubiak, and my husband Chris and I have a 13 year old son named Reilly who has a very rare gene mutation. This mutation is known as *KCTD7*, and Reilly is one of eight cases in the United States. There are less than 30 cases worldwide.

During this surreal time of the Covid 19 pandemic, we have gone from a house that always had people coming in and out to a zoom/technology house.

Prior to Covid, we had a nurse or caregiver for Reilly 5-6 days a week. Reilly received occupational, speech and physical therapy twice a week and had school five days a week. Reilly has had all home-based services for the past six years.

We have gone from me going out and doing errands to ordering everything online, including groceries! Every weekend we go for a ride to (with no particular destination!) so Reilly and I can get out of the house. I try to do some parent groups on zoom, but it has been hard to go from being a social person to a very isolated person. Chris has continued to work for Green Mountain Power. As you can imagine, our family has gone to great lengths to keep Reilly safe when Chris comes home.

The hardest part for me is not knowing when this will end. If we are getting a blizzard we all know when it's going to end but with this I feel like there is no end in sight.

To be featured in our *Family Spotlight*, please contact charlotte.safran@partner.vermont.gov

