

Français, नेपाली, Soomaali, Español, Kiswahili

**Activist, poet, and novelist James Baldwin once wrote “History is not the past, it is the present. We carry our history with us. We are our history.”**

As we continue to navigate the complex medical and social issues caused by COVID-19 pandemic , we look for opportunities to support all Vermont families with a child or youth with special health needs We hope that you continue to find support from your family and your community, and want you to know that here at CSHN we are committed to building a brighter history **together**.

### Highlights:

#### **CSHN/CDC Developmental Evaluation Program updates:**

We are excited to announce the restart of our Burlington-based CSHN Developmental Evaluation Program on July 1<sup>st</sup>, 2020. We will begin offering in-person evaluations at 1 South Prospect Street in Burlington, in the Developmental and Behavioral Pediatrics (DB Peds) examination area where Dr. Beth Forbes is located. We do plan to return operations to 108 Cherry Street soon, and in the interim we see this as an ideal opportunity for additional collaboration with our UVMMC partners in DB Peds and in the Autism Assessment Clinic at VCCYF in Child Psychiatry, both of which have been ramping up their in-person evaluations in recent weeks.

Along the way, we have become experts in wearing personal protective equipment (PPE). (Clear masks, face shields, sneeze guards, goggles, and so much more!) We have benefitted greatly from coordinating our efforts with UVMMC and VDH Local Health in all phases of planning and preparation for reopening services. We do not yet have a specific date for the reopening of Child Development Clinic (CDC) at the Barre and Rutland hubs, but we expect to have more news about that in the coming weeks.

Thanks to our CDC Team for all the creative thinking, problem solving, good humor and support for each other during these challenging times, and thanks to all of you for your patience and understanding as we return to the work we know and love.

Take Care,

Nora Sabo, MSW  
Child Development Clinic Clinical Manager

### Resources:

**VT Medicaid:** provide service authorizations for Choices for Care, Traumatic Brain Injury, and Children's Personal Care COVID -19 State of Emergency extensions for up to one year. Assessments will be allowed by telephone (read more [here](#)).

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

**Talking to children about race:** Guidance from pediatricians and families can be found [here](#).

### Family Spotlight:

Hello CSHN families, we are the Briggs family. Will, Natalie and I (Amelia!) live in Shelburne with our two dogs Maverick and Cooper.



Natalie has a partial chromosomal duplication; she is the only documented case in the world with her exact duplication. Life for the past ten years has been the most challenging, stressful, heartbreaking, joyful, exciting, proud time of our lives, so when the pandemic hit we were panicked and scared, but quickly put on our "we've got this hat" and started to plan. This meant thinking outside of the box, outside of the existing world that we lived in. In our stressed, scared brains we were asking ourselves **"How are we going to manage our medically complex child's health and keep her out of harm's way? Is it safe for her to go to the hospital for weekly infusions and very frequent blood draws? Is it safe for her home care nurses to come into our home? How is she going to continue her education remotely as a Deaf/Blind child? What will happen if one or both of us get sick?"**

I had to deal with my anxiety and fear first, I stopped reading news articles, stopped reading a lot on social media and limited what news I watched. I turned to Natalie's medical team to provide us with accurate information and how it affects us, here in Vermont. We are VERY fortunate to have an amazing medical team, from her pediatrician's office to UVMCH team to her BCH team, we are surrounded by care, compassion and knowledge. We knew, like with all things medical, we could not do this alone. We needed help. Our first step was to speak with our pediatrician and go through our list of nurses to determine if their exposure risk was low enough to work with Natalie. It was! We could continue to have the much needed care and support of our nurses. Then onto the other issues. It was determined that it was safest for Natalie to remain home as

much as possible. Through many phone calls with doctors, nurses, human resources staff at my husband's work and insurance companies we were able to get weekly infusions transferred to home, however, home infusions services was not taking any new patients. Onto plan B, we would learn how to administer it ourselves. For every question we had, there were multiple phone calls and discussions to figure out how to go outside of the box, but stay close enough that insurance would continue to pay. We had to get creative, but as all of you know, we are parents of a special needs child, we've done this for ten years.

TELEHEALTH! Both a blessing and a curse. As many of you know, trying to manage a child and the technology required to have a virtual visit is nearly impossible! Thankfully our team in Boston realized this very quickly and we were able to email pictures and videos ahead of time for review so if Natalie chose not to participate, we were still able to have a successful, beneficial visit. During challenging times like these, it shows us the wonderful things that happen in our communities, but also shows us what needs to be worked on. It will take us parents/caregivers voicing our thoughts and opinions to implement change. As the state continues to open up, most of us will continue to be homebound until there is a vaccine and/or treatment. What are some things that would be beneficial to you and your family? If they are beneficial to you, they will most likely be beneficial to others. Share your voice with your providers and friends, there is always room for change!

*We are so grateful to the Briggs family for sharing their story and perspective! If you would like to share your experience of having a child or youth with special health needs, please contact CSHN's Family Partnerships Coordinator. [charlotte.safran@partner.vermont.gov](mailto:charlotte.safran@partner.vermont.gov)*



### 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 and updates at <https://www.healthvermont.gov/family/special-health-needs>