

COMPASS

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SMA Care Center Network: Connecting Families to Comprehensive Care

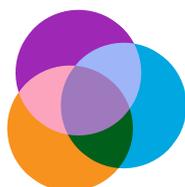
This year, Cure SMA launched the SMA Care Center Network, a collection of specialized clinics across the nation that will help ensure that all those living with spinal muscular atrophy (SMA) are able to receive high-quality, multidisciplinary care. The SMA Care Center Network is a diverse set of hospitals that share clinical data on SMA patients by connecting their electronic medical records to our registry. This will allow us to investigate the impact treatments and care have on SMA, create benchmarks, and certify centers of excellence in the future.

By connecting SMA Care Centers to one another and utilizing a united registry to collect data, healthcare providers, including neurologists, pulmonologists, physical and occupational therapists, nutritionists, and orthopedists, will be able to work together to provide complete and comprehensive treatment. Because SMA is a medically complex disease, these clinical teams must take a multi-faceted approach to treat SMA, and Cure SMA is taking a multi-faceted approach to improve care, as well.

Over the next three years, Cure SMA will invest \$9.1 million in the development of the SMA Care Center Network. The goal of the Network is to create an evidence-based standard of care to improve the lives of people with SMA. Cure SMA has developed several characteristics to identify SMA Care Centers to be a part of this network. Most importantly, SMA Care Centers must demonstrate a desire to improve SMA care both locally and nationally and offer the following:



Geographical diversity



An interdisciplinary care model



Pediatric and adult care team partnerships



The capacity to provide FDA-approved therapies for SMA



An Information Technology (IT) team to support the integration of electronic health records (EHRs)

How the SMA Care Center Network Benefits Families

Dany Sun is the mother of a 7-year old girl living with SMA type 3. Doctors originally diagnosed Dany's daughter with SMA type 2. Her family was given a packet of information and told that someone would follow up at a later date.

The night of her daughter's diagnosis, Dany connected online with other families impacted by SMA through the Cure SMA website. Dany received critical information which helped her to understand her daughter's complex medical needs and get connected with a multidisciplinary care team. Her daughter's diagnosis was eventually corrected to SMA type 3 and she was able to receive the appropriate comprehensive care that she needed.

"The stress when we were first diagnosed of physicians not knowing what SMA meant for my child was crippling. I couldn't trust them," Dany described. "Once we were connected to a center that understood SMA, I had normal worries for my kids, but I'm not worried about their wellbeing. I'm not worried the people caring for them don't understand SMA care. That should be available for everyone."

For more information, visit cureSMA.org/carecenternetwork

