

Family Virtually Visits Officials to Advocate for Children

For Family Advocacy Week, they will ask Congress to prioritize the use of telemedicine



Jacksonville, Fla. (August 3, 2020) – Nemours Children's Health System, a multistate leader in the health of children with complex care cases, will participate in Family Advocacy Week, an event organized by the Children's Hospital Association. Each year, this event gives families the opportunity to meet with and educate lawmakers about their experiences and the care that they receive from

children's health providers, whose role was made even more difficult by the pandemic.

One of Nemours' patient families, the Chergis, will meet members of Congress virtually this year, due to the pandemic. Technology such as telemedicine has helped families like them see specialists remotely from home, and avoid risk of COVID-19 exposure. The Chergis are scheduled to meet Rep. John Rutherford (FL-04), Rep. Michael Waltz (FL-06), and staff of Rep Al Lawson (FL-05), on August 5 to share their health journey, and urge the elected officials to invest in the future of children.

At birth, Cassidy had a "code pink" cardiac emergency, couldn't breathe, and spent her first 3 months of life in the NICU awaiting the diagnosis of a very rare issue. Congenital Central Hypoventilation Syndrome (CCHS) affects less than 1,200 in the world. Cassidy has a trach and must have a ventilator with her at all times- for the rest of her life.

With all her medical challenges, the spunky 11 year old and her mom, Marne, have found ways to thrive, thanks to their medical providers, such as those at Nemours Children's Specialty Care and Wolfson Children's Hospital, and to the private duty nursing help she needs around the clock. Her medical care is expensive, and there are barriers to qualifying for Medicaid.

"We have a child on life support," says mom, Marne Harvich-Chergi. "In essence, our home is a NICU. We have ventilators and oxygen and all of this equipment that resembles an intensive care unit in our home. [Though I have tried,] I can't stay awake 24 hours a day, seven days a week to care for her."

That is why Marne, a small business owner, advocates for the needs of Florida's children who are medically fragile.

"Family advocates like Mrs. Chergi help connect policymakers with parents and patients to illustrate the complex and highly specialized care that is needed from specialists like ours," said Robert Bridges, Nemours Children's Health System Enterprise Executive Vice President and Chief Executive of Florida Operations.

"Technology is what is allowing this visit to take place virtually this year, due to the pandemic, instead of in the nation's capital, and it is also what helps support families like the Chergis access" said Daniella Gratale Director, of the Office of Child Health Policy and Advocacy at Nemours.

When she can, Cassidy likes to play violin and ukulele, loves computer coding and wants to be a Disney Imagineer.

"I'm teaching my child to go to college, I'm teaching my child to work hard, I'm teaching my child to care for herself, and I'm teaching my child that nothing will get in her way," Marne says.

In addition to understanding the importance of having access to high quality medicine, the family is advocating for telemedicine, because for patients like Cassidy, it is an uncomplicated -- and safer -- way to see her specialists. "There are no germs in telemedicine," says Marne.

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About Nemours Children's Health System

[Nemours](#) is an internationally recognized children's health system that owns and operates the two free-standing children's hospitals: the Nemours/Alfred I. duPont Hospital for Children in Wilmington, Del., and Nemours Children's Hospital in Orlando, Fla., along with outpatient facilities in five states, delivering pediatric primary, specialty and urgent care. Nemours also powers the world's most-visited website for information on the health of children and teens, [KidsHealth.org](#), and offers on-demand, online video patient visits through Nemours [CareConnect](#). [Nemours ReadingBrightstart.org](#) is a program dedicated to preventing reading failure in young children, grounded in Nemours' understanding that child health and learning are

inextricably linked, and that reading level is a strong predictor of adult health.

Established as [The Nemours Foundation](#) through the legacy and philanthropy of Alfred I. duPont, Nemours provides pediatric clinical care, research, education, advocacy and prevention programs to families in the communities it serves.

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