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## *In her memory*



Sarah and Peter Cunningham establish CeCe Cares foundation to help with pediatric epilepsy, Page 5

Twin sisters Cecelia Cunningham (left) and Reese Cunningham are pictured in an old family photo. Cecilia passed in 2010, inspired the creation of CeCe Cares, a pediatric epilepsy foundation. PHOTO SUBMITTED

Reese Cunningham, 4, hugs a CeCe bear, a bear she designed in memory of her twin sister Cecelia, who passed away unexpectedly in 2010 as the result of Dravet Syndrome, a catastrophic form of pediatric epilepsy.

LAUREN FINKLER/22ND CENTURY MEDIA



# Granting wishes and relief

Cecilia Cunningham honored, remembered through CeCe Cares charity foundation

LAUREN FINKLER, Editor

Sarah and Peter Cunningham have been through every parent's worst nightmare.

Their daughter Cecilia, or CeCe, had her first seizure just before her first birthday and was diagnosed with Dravet Syndrome, a catastrophic form of pediatric epilepsy. For the most part, the seizures were under control and her case was not considered to be severe.

Then, in 2010, Cecilia passed away in her sleep as the result of sudden unexplained death in epilepsy.

This June, the Cunninghams decided to make a difference for families going through the same struggles, establishing CeCe Cares, a 501(c)(3) public charity.

Through donations, CeCe Cares alleviates the financial strain that comes with each hospital bill, providing grants for kids with epilepsy.

The grants sponsor items that insurance won't cover such as cooling vests, iPads with customized software, strollers for kids who can't walk and medication.

This year, they provided six grants and next year they aim to provide 18-20.

One of the grants allowed a child with pediatric epilepsy to have a cooling vest, making it possible for him to join a baseball team and enjoy some of the normal things children should, explained Sarah.

"The whole ordeal of having to deal with a child who is ill is hard enough because you're constantly in a state of terror that something is going to happen," Sarah said. "For so many families to be concerned about your child and about how you're going to pay for medication is overwhelming for a lot of families.

"I think that epilepsy is a very misunderstood disease."

To date, CeCe Cares has raised "just north of \$50,000," the family said, and about two-thirds of the funds go to grants.

The remainder of the funds go to CeCe Bears, a teddy bear designed by Cecilia's 4-year-old twin sister Reese in conjunction with the North American Bear Company.

For many kids, a teddy bear is an item of comfort, but to Reese this bear is her sister. The bear has her sister's big eyes and is adorned with bandages like her sister used to wear as if they were stickers.

This month, 2,000 bears will go out to children in treatment centers at 10 different hospitals which the Cunningham's foundation supports. The bears can be sponsored for \$39.99 and will provide comfort to children as they are undergoing treatment for epilepsy.

The Cunninghams have included 10 hospitals in their outreach efforts, including local hospitals such as Comer Children's Hospital, Children's Memorial Hospital and Rush Children's Hospital. By 2012, they hope to expand to work with pediatric epilepsy care centers in 25 national and local hospitals.



The Cunningham family presents the first CeCe bear to their daughter's doctor, Dr. Sookyong Koh at a benefit for CeCe Cares at Children's Memorial Hospital in Chicago on Nov. 30. PHOTOS SUBMITTED



The Cunninghams in family photo with twin daughters Reese (right) and Cecilia, who passed away in 2010.

"There's definitely days that are hard, but at the same time we have to help because we know that it's the right thing to do," Sarah said.

For more information about CeCe Cares, visit [cececares.org](http://cececares.org).