

THE

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Special Children, Special Moms

The joys and challenges
of parenting
special needs
children.



David P. Campbell

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David Campbell was just 3 ½ when he died of an incurable mitochondrial disease called Leigh's Syndrome.



Cathy Campbell with her husband, Dan, and their sons, Danny and David.

"It's a redhead!" were the first words out of the doctor's mouth when he delivered David to Dan and Cathy (Barham) Campbell, *Maryland '81*. Seconds later, the proud parents joyfully learned that their robust infant was a boy, a little brother for their older son, Danny. But the dreams of that day took a tragic turn when David began to have problems when he was just 5 ½ months old. Cathy recalls how David's muscle weakness left him "like a floppy doll," unable to sit or crawl.

Months of testing and doctor visits (to which Cathy carried David's medical records in a rolling suitcase) were inconclusive in diagnosing what was wrong. "It was like a roller coaster," Cathy said. "David defied diagnosis. It is very hard to battle something that you don't know how to fight. I learned [from talking to others] that at some point a doctor makes a mom [going through something like this] feel crazy. But you have instincts as a mother. You know something is wrong. You must follow your instincts."

David was bright, outgoing, articulate and spirited. During one hospital stay, Cathy briefly left a sleeping David to get some much-needed rest. Upon her return, David narrowed his blue eyes and quizzed his mother in his squeaky, 3-year-old voice, "Where were you?!"

After a hopeful 12-month recovery, during which David was able to walk again with the help of a walker, his condition worsened and he became nearly paralyzed. Experimental drugs proved ineffective for little David. Leaving a host of people who loved and admired his strength of heart, David died at just 3 ½ years old.

Cathy and Dan had received David's official diagnosis just one week earlier. David had an incurable mitochondrial disease called Leigh's Syndrome. Affecting as many as one in every 2,000 babies, mitochondrial disease mutates the cell, fatally hindering the cell's ability to use life-giving energy. Research is showing that this same mutation may be the cause of better-known diseases such as Parkinson's and the underlying cause of Alzheimer's.

Cathy remembers that following David's death, "just getting off the couch was an accomplishment." But the outpouring of support by friends and family members turned out to be not only a balm for her and Dan, but a mission of hope for children everywhere in the form of the David P. Campbell Foundation for Pediatric Mitochondrial Disease Research.

"We didn't set out to start a foundation," Cathy said. "It was David's spirit that started it; we knew the money needed to be used for the kids." In just two months, family members and friends raised \$20,000. Cathy adds lovingly, "So many people remember David. The foundation helps me show my love for him. My days are productive. It helps in healing."

David's brother, Danny, now 10 years old, has his own plans too. He recently told Cathy, "When you get old, I can run the foundation. It's a way for my bro David to be with us."

Cathy is proud to report that the foundation, now in its third year, is busy raising awareness and research dollars to fight mitochondrial disease. "With new discoveries in mitochondrial medicine, therapies will help thousands of children." Cathy also reports that doctors and researchers think that a cure for this disease will be made within 10 years. "That's what keeps us going at the Wish Upon a Cure Foundation—bright smiles like Anna Grace's (see cover photo) and the hope for a better path in life for deserving kids like her and our wonderful, adorable David." (For more information on David's foundation, visit www.wishuponacure.org.)

Unlike Jack, Sarah and Matteus, David did not live very long with his disability. But in his few short years, he left a message on behalf of all special needs children...

On a sunny day in the neighborhood park, David Campbell slowly advanced up the ladder to the slide. He had never tried the slide before. The top seemed so far away. Wearing white tennis shoes and his ankle braces, David's concentration showed on his young face. Coming up from below with noisy zeal, another child began to climb behind David. Seeing the slow progress, the child blurted out impatiently, "You're too slow!" David stopped. He glanced down at the child with reproach and determination. "It's my turn. You wait!," David shouted back, his words ringing through the air.

David made it to the top and sat triumphantly. "I'm scared, Dad," he yelled to his waiting father, but then he let go and soared down the slide victoriously, overcoming his fear and the prejudice of others.

Truly, for special needs children, it's *their* turn. We must wait—and watch them fulfill their purpose in our world.