



Wish Upon a Cure™

David P. Campbell Foundation  
for Pediatric Mitochondrial Disease Research

Spring 2004

## ★ Thanks To Everyone Helping Fight Mitochondrial Disease! ★

This past year was our most successful ever! Many new people joined the fight against mitochondrial disease. Welcome to the 535 new donors from 17 states who joined us in this worthy cause!

In 2003, our major fund-raising event was the Wish Upon A Cure breakfast at the Hilton Hotel in Irvine, Calif. We received more than \$72,000 in donations, including future pledges from our Multiple-Year Givers. Special thanks to our wonderful sponsors, Secure Horizons from PacifiCare and Golden State Funding, for making the event possible.

We raised more than \$82,000 for mitochondrial disease research and awareness in 2003. Several events in California and Arizona helped us surpass the previous year's level.

**Mitochondrial Disease Awareness Events**  
Wish Upon a Cure was named the designated charity for the local ATA Taekwondo Family Center in Mission Viejo, Calif. The ATA Center put the Foundation in the spotlight as it hosted 1,000 competitors at the Anaheim Convention Center in November.

At the tournament, Chief Instructor Toshon Gilbert paid tribute to David Campbell, known in ATA circles as "Little Dragon."

Also, honorary black belts were bestowed upon Dr. William Nyhan and Dr. Robert Naviaux, physicians from the University of San Diego's School of Medicine and the University of California, San Diego's Mitochondrial and Metabolic Disease Center. The ATA Family Center of Mission Viejo raised close to \$4,000 during 2003, its third year of raising funds for mitochondrial disease research. Thank you to Mr. Gilbert and Julia Reed, chief tournament producer.

The Foundation also was named a recipient charity of the Chandler, Ariz., Jaycees' first Fore Kidz Charity Golf Tournament, held in October. The tournament and subsequent silent auction netted more than \$1,000 for the fight against mitochondrial disease. A big thank you goes to Kris Preston, president of the Chandler Jaycees, for perfect weather, a sellout golf tournament and contributions to the Foundation.

We sent an awareness mailing to approximately 22,000 people across the country, giving many people their first glimpse into mitochondrial disease. Many returned generous donations -- we garnered over \$5,000 and we welcome them to the Wish Upon a Cure family.

We are now only \$150,000 away from our goal of establishing the first ever fellowship into mitochondrial disease research!

### **Wish Upon a Cure Presents First Grant to Help Fight Mitochondrial Disease**

We were so pleased to distribute the first grant of \$35,000 from the David Campbell Foundation during 2003. The recipient was Dr. Robert K. Naviaux, co-director of the Mitochondrial and Metabolic Disease Center at the University of California, San Diego. Dr. Naviaux, a gifted physician and researcher who helped care for David in his final days, worked at a frenetic pace during the grant period to advance the body of knowledge in the scientific world. He was published as the lead scientific article in the latest edition of *Mitochondrial and Metabolic Disorders – A Primary Care Physician's Guide* with his work on the spectrum of mitochondrial disease.

### **Momentum for 2004**

Thanks to your generosity, 2003 was a very productive year for informing many people about mitochondrial disease. However, much work is still to be done. Join us in 2004 as we reach our goal of doubling contributions to further awareness and research of these orphan diseases.

## Mito Spotlight

*An excerpt from the Cumberland Times-News, Cumberland, Md. Sunday, September 14, 2003*

### **FAMILY RAISES AWARENESS OF DAUGHTER'S DISEASE**

*Maria D. Martirano Times-News staff writer*

LAVALE – Anna Grace McMullen loves the free-fall feeling of a roller coaster ride and has been known to cry when she's taken off one.

The naturally curly blonde with big, bright eyes and a quick smile also is a fan of the outdoors and swimming. She's naturally curious and very social — especially with other children.

The daughter of Bethany and John McMullen, Anna Grace, 3, was diagnosed in 2001 with Leigh's syndrome, a mitochondrial disease that has prevented her from sitting, walking, crawling or talking. She communicates through facial expressions and verbal sounds and has started to use sign language.

"The prognosis isn't good for Leigh's," Bethany, a stay-at-home mom, said.

Mitochondria are part of every cell in the

body that contain genetic material and are responsible for processing oxygen and converting substances from the food eaten into energy. Basically, mitochondria is the "energy" for a person's body, and when those cells don't work correctly, neither does the body.

Mitochondrial disease is believed to affect 40,000 to 70,000 people nationally. In 1999, when the family was living in Charlotte, N.C., Bethany says her pregnancy was "completely normal." Anna Grace and her twin, Palmer,

were born full term Oct. 20, but the difference between the siblings was apparent from the beginning.

Palmer came in at 6 pounds, 11 ounces with Anna Grace at 5 pounds, 3 ounces.

"She was a lot more fussy than he was and her sucking was very, very poor," Bethany said.

They were told to take their only daughter, who still did not have full head control, to a neurologist and to have an MRI completed. The test results showed Anna Grace had a mitochondrial disease.

"We'd never heard of it," Bethany said.

With so few mitochondrial disease specialists in the country, the McMullens relied on the Internet for much of their information.

Anna Grace had a muscle biopsy to determine the exact diagnosis which indicated Leigh's syndrome – one of the more deadly mitochondrial diseases.

"I don't think either one of us ever was in denial that something was wrong," John said. But for Bethany it was "like taking a brick and throwing it in my face" because they already knew what the outcome could be.

Bethany's best friend just happens to be the cousin of Cathy Campbell, a California mother whose son, David, died July 1, 2001, at 3 1/2. They didn't know their son had Leigh's Syndrome until a week before his death.

The McMullens don't know how much time they will have with Anna Grace, but they've done things and taken their trips to gather their memories and share experiences with her. Last summer, they went to Disney World through the Make a Wish Foundation. The Allegany County League for Crippled Children also has helped the family.

Anna Grace attends preschool three days a week and is one-on-one with an aide.

Bethany said her daughters' progress has continued albeit slow.

"She never lost any of her skills," she said. John said she's very aware of her surroundings and the people around her.

"For me, that's always been one of the bright spots," he said.

**Update:** Since this article was published, Bethany reports that Anna Grace, now 4, is able to crawl – a big step for a beautiful girl.

## What is Mitochondrial Disease?

Every cell in our body contains mitochondria. Mitochondria are the "energy factories" that produce the energy used by our bodies.

When mitochondria fail, a person could have one of many symptoms, including seizures, sudden infant death syndrome (SIDS), low blood counts, muscle spasms, blindness, deafness, dementia, stumbling or tremors, cerebral palsy, heart failure, stroke, or progressive muscle weakness. Often, three or more organ systems are affected in sequence.

Once thought to be rare, these diseases are now known to be nearly as common as childhood cancer. Nearly 5,000 people will be diagnosed this year in the United States. Many more children will be gravely affected before a diagnosis can be reached. Currently, the diagnosis of Mitochondrial Disease is often missed because sensitive tests to accurately diagnose all of the possible defects have not yet been developed.

## PHILANTHROPY STARTS EARLY: Meet our Young Donors Club

When a group of children in Mission Viejo, Calif., began having lemonade stands to benefit the Wish Upon A Cure Foundation, it was clear something special was happening. They became the first inductees into the Young Donors Club, children up to age 16 who have become donors in their own right. This group includes boys who mow lawns, teenagers who sponsor high school events and, of course, the lemonade stand kids. More than 30 Young Donors have raised over \$1,000 in the last two years. Kids, interested in becoming a member? Just send donations, letters and pictures to the Foundation. Attn: Young Donors Club.



Young Donors (from L to R): Jordan Rice, Nicholas Cotta, Courtney Garbe, Connor Timmons, Cayia Leffel, Clay Eggeman, James Thomas, Amanda Thomas, Kelsey Garbe, Danny Campbell, Alexis Cotta.

## WISH UPON A CURE SOCIETY ESTABLISHED

At the October breakfast in southern California, we launched the Wish Upon A Cure Society for supporters committed to helping us fight mitochondrial disease. These supporters were invited to pledge their financial support to the Foundation over a number of years. For example, we welcomed a number of donors who agreed to pledge \$1,000 a year for five years. We were delighted to welcome approximately 30 donors who have promised to give their ongoing support for a number of years.

For the Foundation, having donors who are willing to commit to making a gift not just for one year, but also for a number of years, means we can plan into the future. We know that we have supporters who are helping us find a cure. To each of the members of our Wish Upon a Cure Society, welcome and thank you.

If you are interested in adding the David P. Campbell Foundation to your annual giving plan and would like to become a multiple-year giver, please contact [Cathy Campbell at \(949\) 462-0307](mailto:Cathy.Campbell@orangeccf.org) or [Jane Lehmann Shafron at \(949\) 770-2755](mailto:Jane.Lehmann@orangeccf.org).

## THE ORANGE COUNTY COMMUNITY FOUNDATION

The David Campbell Foundation is a fund of the OCCF and through them we receive our nonprofit status. Teaming with the Orange County Community Foundation provides the administrative support and legal framework that enables our foundation to operate as a nonprofit organization and with minimal overhead. We truly value the support of the OCCF and in particular our mentor, Todd Hanson, vice president of Donor Relations and Community Partnerships.

## Our Mission

The Foundation's mission is to:

- A** Raise national **Awareness** of this orphan disease class so that appropriate
- R** **Research** and funding will come to mitochondrial diseases, with the goal of finding a
- C** **Cure** in our lifetime.

Wish Upon A Cure™ fundraising services is dedicated to raising funds for the David P. Campbell Foundation for Pediatric Mitochondrial Disease Research.

Wish Upon a Cure™ is a trademark of Cathy Campbell. The David P. Campbell Foundation is a fund of and receives charity status through the Orange County Community Foundation (Tax ID # 33-0378778).

Design and creative services generously donated by Dava Romaniello Designs (949) 493-4692  
Printing and mailing services generously donated by Dave Robinson, RR Donnelley.



John and Bethany McMullen sit with their daughter, Anna Grace, at their home in LaVale. (Photo Credit: John A. Bone/Times-News Sept. '03)

