

## HEALTHY KATY FAMILIES

Tom and Joy Roeh and their daughters Reagan, Rebecca, and Riley relocated to Katy to be closer to medical services and treatment for mitochondrial disease





# Managing Mitochondrial Disease

Written by Jody Lane | Select Photography by Suzi Issa

To an outside observer, the Pohlas may seem like any other Katy family. Melody and Doug Pohla's three sons, Nicholas, Nathan, and Daniel are all bright, active boys who love to swim and practice tae kwon do. But what isn't seen is Nicholas' feeding tube, inserted at 15 months of age, which needs protection when he spars, or the times Nathan is hospitalized because he's caught the latest stomach bug and needs fluids, or the oxygen masks the boys wear every night. The Pohlas' three sons are all battling mitochondrial disease.

## Signs and Symptoms

The Pohlas are not alone in their fight and are joined by several other Katy families striving to help their children overcome mitochondrial disease and live happy, healthy lives. Mitochondrial disease is a genetic disease that occurs when mitochondria, the powerhouses of the cell, fail to convert food into energy. When cells don't have enough energy to perform their functions, organs begin to fail. This disease can affect any system of the body, and the combination of symptoms is unique to each patient.

## Focusing on the Positive Side

Over the past three years, since the boys' mitochondrial diagnosis was confirmed, Melody and Doug Pohla have learned how much of a tightrope walk this journey can be. "Children with this disease don't follow the manual for other kids," shares Melody. "We must be especially careful when they're sick and careful in the extreme heat or cold."

The Pohlas believe in teaching their sons that everyone has their own challenges. "One person might have to wear glasses, [while] another needs oxygen," says Melody. She strives to stay strong and positive for her family. "It's all about perspective," she shares, adding, "Yes, Nicholas has mito, but he's also a black belt in karate! There's a lot to be proud of."

## Creating Opportunities

Tom and Joy Roeh relocated to Katy in June 2011 with three girls, twins Riley and Reagan, 6, and Rebecca, 4. The decision was forced by the 20 mitochondrial-related trips made to Houston in 2010 for one daughter or another. "Our normal is so normal to us, that I forget how abnormal it truly is," says Joy. Between charging batteries, ordering supplies, and making sure meds are filled and the equipment is working, their days are busy.

Joy works at creating opportunities for the girls. One week in June, Rebecca was at a science camp, pushing her portable oxygenator around in a baby stroller. Her feeding

pump, which runs 24 hours a day, was tucked inside the backpack she wore. Their home itself is accommodating, too: Two swings hang inside the house for recreation and a 50-foot line on the oxygen tanks allows Rebecca to run around the house.

"These kids are still kids," Joy says. "They want to have fun and do everything they're able to do." She adds, "Our lives are filled with a lot of joy, and I think there's a misconception that once you get this diagnosis, it's just grim and gray." For a personal perspective on living with mitochondrial disease, visit Joy's family blog at [roehfamily.blogspot.com](http://roehfamily.blogspot.com).

Despite having a genetic disease, Riley, Rebecca, and Reagan Roeh enjoy living life to the fullest



Photo by Haley B Photography

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Missy Knight's son Samuel lost his battle with mitochondrial disease when he was only 4 years old

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### *Fighting to Stay Healthy*

Madison Andrews, the daughter of John and Beth Andrews, began experiencing mitochondrial symptoms in the fourth grade. Now 14 years old, her first symptoms were uncontrollable migraines, with gastrointestinal and heart issues later following. Her twin brother TJ also suffers from mitochondrial disease and was long ago diagnosed with atypical cerebral palsy, as well.

For Madison, one of the most difficult parts of dealing with this disease is the lack of understanding from others. "If you look at a child in a wheelchair, you can physically see what's wrong," she explains. "If you look at me, you probably couldn't tell I have a daily battle - it's a little battle, but a battle just the same. It can be a lonely place."

### *Searching for a Cure*

Research efforts relating to mitochondrial disease remain in their early stages. There may be a better understanding of the disease now, but there is still no cure or good way to treat it, according to Dr. Mary Kay Koenig, director of the University of Texas Mitochondrial Center of Excellence and one of the few mitochondrial disease specialists in the world.

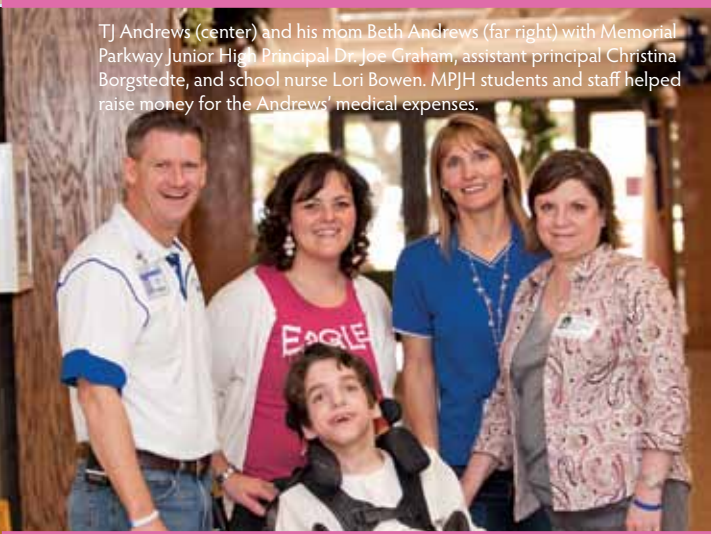
"I equate mitochondrial disease to something like diabetes, which used to be a life-threatening disease," says Dr. Koenig. "It still can't be cured, but it can be managed and people can live healthy lives."  
KM

JODY LANE is a freelance writer, who is passionate about spreading awareness of conditions like mitochondrial disease.





Nathan, Daniel, and Nicholas Pohla all suffer from mitochondrial disease, but still enjoy sports like tae kwon do and karate



TJ Andrews (center) and his mom Beth Andrews (far right) with Memorial Parkway Junior High Principal Dr. Joe Graham, assistant principal Christina Borgstedte, and school nurse Lori Bowen. MPJH students and staff helped raise money for the Andrews' medical expenses.

## Diagnosing the Disease



Mitochondrial disease specialist  
Dr. Mary Kay Koenig

### Side Effects and Symptoms:

- Learning disabilities and autism
- Suffering seizures and strokes
- Suffering from cardiomyopathy or heart attacks
- Renal failure
- Diagnosed with hepatitis or liver failure
- Respiratory failure
- Muscle weakness or fatigue

Source: memorialhermann.org/mitoclinic

### Learn More

UMDF Houston Chapter

713-568-1045

houstonchapter@umdf.org

Offers support groups for family, siblings, and teens, as well as monthly meetings and seminars

Help raise funds for mitochondrial disease research with a benefit night for the United Mitochondrial Disease Foundation on Saturday, Jan. 28, 2012 at Chic-fil-A Cinco Ranch. Call Melody Pobla at 281-395-8573.



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