

# Kennesaw mom, son perform concert to raise awareness for mitochondrial disease

By Stacey L. Evans



Reid Traylor

Susan Schreer Davis and her son Sam at their Kennesaw home. The two will be performing a concert at The Daily Grind on Sept. 23 at 7:30 p.m. to raise awareness for mitochondrial disease. Both were diagnosed with the disorder just over a year ago. Schreer Davis, a musician who teaches voice and piano lessons at the Murray Arts Center at Mount Paran Christian School, said she finds strength in her faith, her writing and her son. "There are plenty of times he's been strong for me when I really didn't have it. That's really been helpful to me," she said.

store and I thought 'look at me, I'm doing better' and then the third day my whole leg feels like it can snap off. I used to be the person who was in charge [of church committees, volunteering], ... now you feel like you're always the person who has to say no. I have difficulty picking up my grandchildren. It's those things that are different. ... Sometimes I think, 'who is this person I'm living in?'"

She struggles most with the limitations it places on what she can do as a mother.

"I have a son at UGA. For me to make that drive up to Athens... I can't just get in the car and drive that far in one day because I'll pay for it the next week," said Schreer Davis. "I'm constantly trying to figure out how to juggle, how to live life and keep family life normal."

Part of making life normal is coming to terms with the disease, which Schreer Davis says she's finally accepted a year after the diagnosis. "I knew the disease didn't go away but I thought I could live in front of it and it would be behind me somehow. But through the year it sinks in this isn't going away. I'm accepting that it's kind of all around me and if I try to break free I'm going to hurt myself more."

What's more difficult to accept is knowing Sam, now 17 and an avid swimmer, may face the same obstacles she does.

"He's very nonchalant about it. There are limitations and as a teenager you don't want limitations. He looks really built and he's trying to stretch himself. He wants to do what other kids do but his body has a lot of limitations. The hardest part as a mom is for me trying to be big through this, knowing he has been diagnosed with what I have, that he could end up like me."

With acceptance comes dealing with the disease in small ways.

"I had this black ugly cane, so I went to Wal-Mart and bought butterfly stickers to make something more fun out of it," she said. "As you accept and embrace, you can live with it and still have a lot of life there."

She also began writing again, which has been therapeutic for her. She writes about her daily struggles on her blog at [www.susanschreerdavis.com](http://www.susanschreerdavis.com), and she has written a song, "Hope Flies", about her battle with mitochondrial disease. The song was written in conjunction with the Foundation for Mitochondrial Medicine, for which Schreer Davis is an ambassador. Through sharing her story with the foundation and her writing, Schreer Davis hopes to raise awareness about the disease.

"If it were more well known it wouldn't have taken me five years to be diagnosed. Maybe I wouldn't have fallen and be 42 with such a damaged leg. Bottom line is we are trying to raise awareness. This probably affects more people than realize. Twenty years from now a lot more people will be aware and more connections to other diseases will be realized."

Currently there is no cure for mitochondrial disease, and no effective treatments. It's believed the disease is linked to Autism, Alzheimer's, Muscular Dystrophy and Parkinson's, and a cure for mitochondrial disease could help cure other disorders.

Schreer Davis and Sam will be performing Sept. 23 at The Daily Grind at 3960 Mary Eliza Trace in Marietta at 7:30 p.m. The concert aims to

Susan Schreer Davis thought the fatigue she felt for years after her husband died from a brain tumor was perhaps a form of grief that would not let go.

Widowed at 27, the Kennesaw resident strived to go on after such an immeasurable loss, and adjust to life as single mother of two young boys. But when Schreer Davis, a musician who teaches piano lessons, started noticing she had trouble with her hands in her early 30s, she began to wonder if the all the pain and exhaustion she felt were signs of an illness. The symptoms progressed until, by age 37, she often relied on a cane to walk and had frequent, intense pain in her feet. She had test after test done by various doctors, but it would take five years, and a diagnosis of her son, Sam Schreer, before she would finally get answers.

Sam was a robust eighth-grader when he began experiencing aches in his shoulders, ankles and hips. The pain progressed to the point he started seeing a physical therapist to alleviate the soreness, but it wasn't working.

"[The physical therapist] would tell him 'you're not trying hard enough' and he would say to me 'mom, I'm really trying.' Doctors would say it was just growing pains. He said to me one day that his hands shake quite a bit, and the next day I pushed for him to see a neurologist," said Schreer Davis.

After scores of doctors over those two years, it was the pediatric neurologist, Dr. Edward Goldstein, who agreed with Schreer Davis that there was likely a link between her and Sam's condition. A thorough examination and EMG concluded they both had muscle weakness, and so he referred the mother and son to Dr. John Shoffner, a neurogeneticist.

Finally, someone was listening.

"Dr. Goldstein was frustrated I had been ignored so long," said Schreer Davis. "He was a godsend."

Dr. Shoffner ordered a muscle biopsy, which confirmed Sam suffered from mitochondrial disease. Schreer Davis, who during this time required back and ankle ligament surgeries after falling, was diagnosed shortly thereafter. It was also found that Schreer Davis' body wasn't properly metabolizing folic acid, which is often a complication for those with mitochondrial disease. She began taking medicine for the folate deficiency which helped her ability to walk, but after a nearly four month reprieve she's back to relying on a cane most days.

"If I don't use a cane, by the end of the day I'm in too much pain," Schreer Davis said.

Almost all cells in the body have mitochondria, which are tiny "power plants" that produce a body's essential energy. Mitochondrial disease means the power plants in cells don't function properly. When that happens, some functions in the body don't work normally. The disease affects the brain, muscles and heart in varying degrees. Some with the disease may have occasional trouble thinking, remembering, and moving and more severe cases have serious handicaps. All struggle with fatigue and muscle weakness, and many also have diabetes. There are good days and bad days.

People who aren't familiar with mitochondrial disease don't understand the limitations it puts on a person, said Schreer Davis. The person may appear "normal," but any amount of physical movement, even a trip to the grocery store, can cause the person to be in extreme pain the next day.

"The grocery store is your Mt. Everest," said Schreer Davis, who remarried several years ago. She and her husband Don Davis, own the Go Fish! store on the Marietta Square.

"Some days when you are rested you can go more, but if you use energy today, then the next two days are going to be a lot harder. It's funny the mind games that go on. Recently I went two days in a row to the grocery

store and I thought 'look at me, I'm doing better' and then the third day my whole leg feels like it can snap off. I used to be the person who was in charge [of church committees, volunteering], ... now you feel like you're always the person who has to say no. I have difficulty picking up my grandchildren. It's those things that are different. ... Sometimes I think, 'who is this person I'm living in?'"

She struggles most with the limitations it places on what she can do as a mother.

"I have a son at UGA. For me to make that drive up to Athens... I can't just get in the car and drive that far in one day because I'll pay for it the next week," said Schreer Davis. "I'm constantly trying to figure out how to juggle, how to live life and keep family life normal."

Part of making life normal is coming to terms with the disease, which Schreer Davis says she's finally accepted a year after the diagnosis. "I knew the disease didn't go away but I thought I could live in front of it and it would be behind me somehow. But through the year it sinks in this isn't going away. I'm accepting that it's kind of all around me and if I try to break free I'm going to hurt myself more."

What's more difficult to accept is knowing Sam, now 17 and an avid swimmer, may face the same obstacles she does.

"He's very nonchalant about it. There are limitations and as a teenager you don't want limitations. He looks really built and he's trying to stretch himself. He wants to do what other kids do but his body has a lot of limitations. The hardest part as a mom is for me trying to be big through this, knowing he has been diagnosed with what I have, that he could end up like me."

With acceptance comes dealing with the disease in small ways.

"I had this black ugly cane, so I went to Wal-Mart and bought butterfly stickers to make something more fun out of it," she said. "As you accept and embrace, you can live with it and still have a lot of life there."

She also began writing again, which has been therapeutic for her. She writes about her daily struggles on her blog at [www.susanschreerdavis.com](http://www.susanschreerdavis.com), and she has written a song, "Hope Flies", about her battle with mitochondrial disease. The song was written in conjunction with the Foundation for Mitochondrial Medicine, for which Schreer Davis is an ambassador. Through sharing her story with the foundation and her writing, Schreer Davis hopes to raise awareness about the disease.

"If it were more well known it wouldn't have taken me five years to be diagnosed. Maybe I wouldn't have fallen and be 42 with such a damaged leg. Bottom line is we are trying to raise awareness. This probably affects more people than realize. Twenty years from now a lot more people will be aware and more connections to other diseases will be realized."

Currently there is no cure for mitochondrial disease, and no effective treatments. It's believed the disease is linked to Autism, Alzheimer's, Muscular Dystrophy and Parkinson's, and a cure for mitochondrial disease could help cure other disorders.

Schreer Davis and Sam will be performing Sept. 23 at The Daily Grind at 3960 Mary Eliza Trace in Marietta at 7:30 p.m. The concert aims to

raise awareness about mitochondrial disease, and is the first time Schreer Davis will do a full-length concert in five years.

"Before I didn't think I could go out and sing with wobbly legs, when I didn't know why they were wobbly," said Schreer Davis.

But her faith has kept her standing strong.

"Faith and God. That's what's gotten me through all of this," she said. "My songs have been about my journey, my hope, lessons I've learned. Every one of them are connected to a time God touched me and helped me get through to the next place."

### **Hope Flies fundraiser**

Hope Flies, the annual fundraiser for the Foundation for Mitochondrial Medicine, is November 5, from 7:30 p.m. to midnight at the Terminus 200 building, 3280 Peachtree Road. The event will feature dance music from Band X, a live auction, raffles, an open bar and hors d'oeuvres.

Individual tickets to the event are \$150 and all proceeds benefit the Foundation for Mitochondrial Disease.

For more event information or to buy tickets, visit [www.hopeflies.org](http://www.hopeflies.org).

For more information on the Foundation, visit [www.foundmm.org](http://www.foundmm.org).

---

Copyright ©2011 Cobb Life, all rights reserved.