

## happynewyear

The New Year gives us an opportunity to reflect on past successes as well as create a plan that will drive us into 2010 and beyond. In doing so, we must take this opportunity to thank everyone who has given generously of their energy, support and resources to help further the vision of the Loeys-Dietz Syndrome Foundation. Your dedication and contributions to the LDSF have humbled us. You have sent cards, hosted fundraising events, sent heartfelt emails, and given donations; your response to the growing needs of the LDS community is overwhelming and it motivates us to keep dreaming and moving forward in growing the LDSF to meet the ideas and desires of our community.

Your contributions continue to inspire us, and we are working harder than ever to continue to adhere to our mission. To reflect this, you will find a wonderful story from someone in our LDS community, you will read about the LDS education that is taking place, and the research opportunities available.

Your invaluable help has made our future plans possible, and we will do our best to serve you well. We look forward to much goodness and growth in 2010. Whatever the New Year brings for you, we wish you all peace and happiness

Respectfully,

*Beth Utz and Gretchen Oswald*  
President & Vice-president, co-founders

### foundationmission:

The Loeys-Dietz Syndrome Foundation (LDSF) is a 501(c)(3) non-profit organization dedicated to:

- encouraging education about LDS and related connective tissue disorders to medical professionals and lay communities in order to aid in identification, diagnosis and treatment of Loeys-Dietz syndrome
- fostering research about LDS
- providing a support network, for parents and families affected by Loeys-Dietz syndrome

## heartrenderings — Melissa Thomason, LDSF Member

One night during the summer of 2004 I stayed awake into the wee hours of the morning working on my list of "Things to Do Before I Die." I was twenty-four years old and, as far as I knew, perfectly healthy; but making the list seemed like a good idea. That night I thought of 75 things that I wanted to do before my time on Earth was over. The usual, "sky dive" made the list, as did "Meet Maya Angelou" (Number 11) and "Buy my mom a house" (Number 26). I was obsessed with seeing the world outside of my little town in North Carolina, and number one was, "See the Grand Canyon." I looked over the list when I was done and added

one more thing, (Number Zero) "Don't Die." I'm not sure why I added it, but today it is checked off and a note has been added, "10/19/08 – I did that!"

On October 19, 2008 I survived a Type I aortic dissection. I was thirty-five weeks pregnant with our first child, a little boy, and had been hospitalized for

high blood pressure just two days before. That Sunday morning felt like any other morning. Besides being very pregnant and in the hospital on bed rest, I felt just fine. With no hesitation, I stepped into the tub to take a hot shower. I leaned my head back and into the stream of water. Then, suddenly, a pain hit me. It wasn't in my chest, as I certainly would have expected it to be, but in my teeth. Everything went black for a second, and I remember thinking that my teeth were going to crack into a million pieces. I felt too hot and faint. My jaw tightened and then I felt like I couldn't breathe. I grabbed onto the side of the tub and screamed my husband's name.

I had no idea what was wrong with me, but I did insist, to my husband, the nurse, and then the doctor, that something was indeed wrong. Doctors decided to deliver the baby via an emergency C-section. Our seven pound beautiful little boy was born just minutes later. I was elated but still felt "like a bulldozer was sitting on my chest." Chest X-rays came back clean,

but finally, a CT scan revealed the huge dissection, originating in the ascending aorta and extending to beyond my kidneys. I kissed my little boy goodbye and was loaded onto a helicopter bound for the nearest trauma center and my second surgery of the day.

That moment was the hardest moment of my life, and the weeks that followed were some of the most difficult I've ever experienced as complications continued to arise. I was completely overjoyed when I finally returned home six weeks later. Doctors suspected that I may have a connective tissue disorder, and I was officially diagnosed with Loeys-Dietz syndrome in May 2009. My geneticist called me at my home and in her strong Turkish accent told me that my LDS test came back positive. "Now, it all makes sense," I thought to myself: "the pectus excavatum I was born with, the hypermobile joints, and the dissection." I cried as I told my husband. Though I knew I shouldn't be, I was ashamed. I was "genetically flawed." I wasn't who he'd thought I was. We'd always planned to

[continued on back](#)



Melissa & Nathanael,  
Nov. 2009

# contributions

The Loey's-Dietz Syndrome Foundation is greatly impacted by its members, families, and friends who have made donations to help further our cause. These donations are much appreciated and support our mission of raising awareness, education and research efforts for those affected by Loey's-Dietz Syndrome and related connective tissue disorders.

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## upcoming events

### LDSF Weekend

June 25th & 26th  
Baltimore, Maryland

Join with other LDSF families and learn from some experts at Johns Hopkins. Visit [www.loeysdietz.org](http://www.loeysdietz.org) for more information.

## researchopportunity

Children and adolescents with LDS that have previously had cardiac surgery are invited to participate in a pilot research study that is being conducted by Gretchen Oswald & Laura Hutchins, a genetic counseling student from the University of Maryland.

This study aims to directly survey children and adolescents with LDS that have already had preventative cardiac surgery to begin compiling information about their experiences and feelings about the surgery and hospitalization afterwards. With the information we gather from this study, written preparatory materials will be developed for children and adolescents that are scheduled for the surgery, in order to better prepare them and their families.

The study consists of an online survey which will take approximately 60 to 90 minutes for each child or adolescent to complete, at his or her convenience. Questions focus on asking participants to share their thoughts and feelings on challenges, experiences, and positive aspects of their surgical preparation and hospitalization. The survey will be open through March 1, 2010.

In order to be eligible for the study, you or your child must have a confirmed diagnosis of LDS and must have undergone the cardiac surgery between the ages of 5 and 18.

If you, or your child, is interested in participating or have any questions about the study, please contact either Gretchen or Laura for more information.

We very much look forward to beginning the study and hearing from you and your children! Thank you!

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## heartrenderingscont.

have a big family, and now I would never be able to give him that. I buried my head in his chest and cried, "I have it. I'm so sorry." He, of course, smiled at my foolishness and wiped my tears away. I never could have made it through all of this without him.

In fact, I never could have made it through all of this without the help of most of my family. In June '09, just nine months after my dissection, a follow-up CT scan revealed a 6.2 cm aneurysm near the top of my descending aorta. Only the ascending aorta had been repaired during my first surgery and, now the entire aorta, weak and dissected, needed to be replaced. Dr. Chad Hughes of Duke University Medical Center replaced my entire descending aorta in July 2009. The thoraco-abdominal incision begins near the top of my left shoulder blade and wraps underneath my arm, around my rib cage, and down into my lower abdomen. That surgery was, by far, the most painful thing I've ever lived through. I recovered for only three months, and then on October 22 of the same year underwent my third surgery: a valve-sparing root replacement and aortic debranching procedure, which prepared my aortic arch for a less invasive stent.

Now, after three surgeries in just one year, I am home and awaiting that final stent procedure. I spend my days making up for lost time with my son, Nathanael, who is now just over one year old and thriving. He loves to laugh and has a smile that is absolutely infectious. I also have long conversations with my mom, who has been here to help me every day since it all began. She spends her days with me now and nights with my dad, who is here every chance he gets. I spend my nights enjoying my little family. My husband and I love being parents! We have not decided yet if we will ever have more children, but for now, it is enough to be here and be together, just the three of us.

Skydiving doesn't seem as important as it once did. In fact, although I would still love to meet Maya Angelou and buy my mom a house, my list of "Things to do Before I Die," now seems unquestionably empty. I am sure the Grand Canyon is breathtakingly beautiful, but I am more concerned now with seeing the beauty that surrounds me every day. Life is the here and now. It is in my son's eyes when he awakes in the morning and in my husband's when we kiss goodnight. Life is what is beautiful. I know that now.