

# matters of heart

issue2volume3 summer2011

A publication for people affected by Loews-Dietz syndrome, but not defined by it.

## boardnotes



Special thanks to everyone who answered our call for photos, including 12-year-old Trey Price who has LDS and is pictured here with his sister Tori.

Our Board enjoyed a summer of working and dreaming for the Foundation and also sadly mourning the loss of one of our own. With great sadness we mourned the passing of Daniel Moyer, a beloved friend and LDSF Board member who shared his story in our last newsletter. With his quick wit and incredible message of hope to our younger members, Daniel was an encouragement to us all. Daniel's passing reminds us of the great responsibility the LDSF has to support our families and to continue to learn more about LDS, it's treatment and manifestations, in order to help continue to improve quality of life.

As a Board we are continuing on the adventure and challenge of strategic planning and dreaming big for the future of the LDSF. We met over the summer to continue our progress and focus on our desire is to grow fundraising efforts to support things like new research initiatives, our 2012 conference and future staff development.

From our meeting it became clear that we are in need of more volunteers to help us accomplish these goals and further our mission. So, take a minute, consider your skill sets and get ready to step up and become involved with the LDSF!

First, we're looking to grow a **Fundraising committee**. This committee will be developing materials to support our volunteer fundraising efforts and supporting our fundraisers. We are pleased to announce that Sarah Griffith, of Pins For Peyton fame, has agreed to help head this committee. Sarah has tremendous

experience with grass roots fundraising and corporate sponsorship. We are excited for her leadership to help develop fundraising efforts for our LDSF members. We are looking for several individuals to join Sarah on this committee. For more information, email us at [fundraising@loeysdietz.org](mailto:fundraising@loeysdietz.org).

Next, we're looking for volunteers to serve on a **Thank You committee**. We desire to truly thank and honor those who have made generous donations to the LDSF. If you would be willing to write personal notes of thanks on a regular basis, this committee is for you! For more information, email [thanks@loeysdietz.org](mailto:thanks@loeysdietz.org).

We're also looking for a committed group to help us serve on our **Conference 2012 committee**. We so enjoyed meeting families, providing resources and furthering our mission with our first conference that we know it's time to start planning to do it again! Volunteers are needed to help with everything from coordinating and staffing the conference to planning kid and teen programs to working out registration and event logistics. For more information, email [conference@loeysdietz.org](mailto:conference@loeysdietz.org).

Other opportunities to get involve exist or if you have your own ideas, we'd love to hear from you! Wherever you are located, we can use skill sets, talents, passions and resources. Email us at [volunteer@loeysdietz.org](mailto:volunteer@loeysdietz.org) to find out more or share your ideas.

We are so excited to be at this place of growth and development. We are grateful for your never-ending support and encouragement and we look forward to working with you as you volunteer with the LDSF!

*Until next time,  
The LDSF Board of Directors*

## inthisissue:

- Board Notes
- Heart Renderings
- In Loving Memory
- Pins For Peyton Recap
- Celebrate Life 5K Recap
- BlogRoll
- Conference Updates
- Bananas For Bodhi Recap
- Congratulations
- Upcoming Events
- Quentin's Quest 3
- Raise Funds
- Ben & Jerry's Festival Recap
- Matching Gifts
- Volunteers Needed
- Contributions

## foundationmission:

The Loews-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 Loews-Dietz syndrome
- fostering research about LDS
- providing a support network, for parents and families affected by Loews-Dietz syndrome

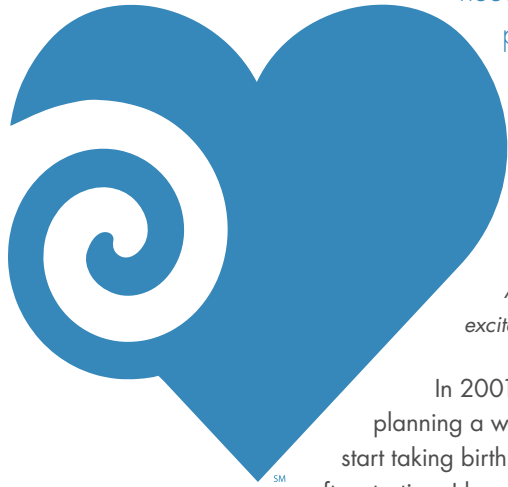
## mattersofheartmission:

To provide an outlet for members of the LDSF community to connect and stay informed with accurate, relevant and timely information.

**Loeys·Dietz**   
Syndrome Foundation

“It’s an incredible opportunity and pleasure to get to work with our LDS families. The kids, especially, are so full of spirit and teach me every day about facing life with a cheerful and can-do attitude. It is truly an honor that so many families let me into their lives and share with me the ups and downs. I love getting the phone calls, good and bad, when someone needs to talk. I love getting the email updates. I love the Christmas cards and news about pregnancies, vacations, new jobs, and college decisions. I love getting to be part of both the fears and triumphs over life’s moments with my families.”

- Gretchen Oswald, Genetic Counselor and LDSF President



## heartrenderings

*Anne Accardo, age 36, lives in New Orleans, LA. She was diagnosed with Loeys Dietz syndrome in 2008 and is the excited to be living her life to the fullest with LDS and helping to raise funds for the LDSF.*

In 2001, I got engaged, was planning a wedding and decided to start taking birth control pills. A few months after starting, I began hemorrhaging – to the point of death. I had never had a problem before, so my doctor put me on huge doses of the pill and hormones to control the bleeding. It helped for short amounts of time, but then I would be hospitalized again. I was able to get married in May 2002, but six months later, as a last resort, I had a hysterectomy. I was tested for every bleeding disorder and Marfan syndrome had been ruled out. Loeys-Dietz hadn’t been identified yet.

So, I had no answers, but I picked up and moved on. Then, in 2005, Hurricane Katrina hit. My husband and I lived a few blocks from where one of the levees broke. I left town with my parents, but my husband, who was a police officer, had to stay. When it was through, I lost both my house and my husband in the storm. It took time, but I picked up the pieces, found a new home and went back to work.

By 2008, things were going great. I was in the best shape of my life, running, going to the gym and eating healthy. Work was stressful, but I was happy there. On June 26th, after a two mile run the day before and a day of packing and moving heavy boxes at work, I went to dinner with a friend to relax. As we were waiting to be seated I started to have an excruciating pain in my jaw that moved down the to middle of my chest. I told my friend that I thought I was having a heart attack. I began sweating profusely and my entire body started to hurt, so instead of dinner he took me to the emergency room.

My EKG came back normal and the X-ray didn’t find anything. It was a CT scan that showed that my entire aorta had dissected and that I had a large aneurysm right above my heart. After consults with various medical teams and a recommendation to get treatment in Houston, I decided to follow the advice and move hospitals. The problem was the weather was too bad to helicopter me in and the drive may have been too long. My parents chartered an air med plane and got me to Houston. My pain started around 8 p.m. and I was on the operating table by 11 a.m. the next morning. All of the right decisions were made to save my life. I spent a couple of weeks in the hospital in Houston and then headed home to New Orleans.

It was during my recovery that I was correctly diagnosed with Loeys-Dietz syndrome. There was hope that medication would control my blood pressure and I wouldn’t need a second surgery to repair the aneurysm in

the descending portion of my aorta, but my six-month check up and CT scanned showed it was time for the second surgery. I checked back into Memorial Hermann in Houston at the end of January 2009, prepared for a pretty easy surgery and recovery. That wasn’t the case.

The surgery was tougher than we expected and they ended up replacing my aorta completely, even the arteries! But the hard part was my bleeding. I needed over 65 units of blood, plus other products. They couldn’t stop the bleeding and had to leave me open for a day to just watch. I pulled through fine and was starting to come back around when my lung collapsed. I don’t remember much and was basically out for almost two weeks. I woke up with a trach, feeding tube, IV’s everywhere, restraints... I had a seizure and had to have a hernia repaired. It was hell.

But I woke up and realized I was still alive and that it was time to fight. So, with the help of an amazing medical team, and friends, family and God, that’s what I did. It took 4 weeks in the ICU and 2 weeks in a rehab clinic, but I was finally released and returned to New Orleans.

I moved in with my parents until May and then returned to my own house. I’ve been on disability, but am finally ready to start thinking about working again. I’ve had a few snags since the second surgery – an incisional hernia, an aneurysm in my mammary artery and in July 2010 my yearly MRI showed I had two small aneurysms that mirrored each other in my brain in the artery leading to my eyes. I had surgery in October 2010 to repair the right side and January 2011 to repair the left.

The best news came in February 2011 when I went for my follow ups in Houston and everything was stable! I feel like I have been able to get back to some normalcy in life. I’m working again, this time within my limitations, and having fun. I still have an aneurysm in my arch, so I will go back for my CT scan in the fall. I always pray for the best, but I am at total peace with whatever the outcome may be.

Life is so short and I have faith that this journey I have been on is for a reason! I believe we can live a pretty fantastic life with LDS and when the limitations get to you, you just have to stay optimistic!



Anne Accardo is putting on a fundraiser for the LDSF in her hometown of New Orleans on Wednesday, August 24th.

# inlovingmemory

## Daniel Moyer

October 30, 1981- July 1, 2011 - York, Pennsylvania

Daniel was an eagle scout and a graduate of Hershey High School, Millersville University, and earned his Masters degree in Rehabilitation Counseling from Virginia Commonwealth University. He was a Certified Rehabilitation Counselor with the York District Office of Vocational Rehabilitation and served on the board of the Loey-Dietz Syndrome Foundation. Contributions can be made in Daniel's memory to the Loey-Dietz Syndrome Foundation, P.O. Box 22468, Baltimore, Maryland, 21203.

*Our fondest thoughts and well wishes go out to the Moyer family and friends.*



## pinsforpeytonandgracietoo

Portage, IN; May 15

Pins for Peyton and Gracie too, held their third annual fundraiser for LDSF in May at Camelot Lanes in Portage, Indiana from 6 to 10 p.m. With approximately 350 people in attendance, more than \$20,000 was raised for the LDSF!

A silent auction took place and included Chicago Bulls autographs, Chicago Wolves tickets, Indianapolis Colts autographs, as well as a package deal to a day spa and an over night hotel stay, to name a few.

The Griffith family gathered the support of over 100 different sponsors, from TNT trees to Walgreens and BP. Food for all attendees of the night's event was provided by Subway and JJ's Pizza, with beverages provided by Pepsi. Snacks for the event were donated by Hostess and Vitner's Snacks. For each \$30 bowling ticket, the attendee received free shoe rental and unlimited bowling for the duration of the event. For those choosing not to bowl, \$15 non-bowl tickets were purchased for attendance.

A DJ cranked out music so that if anyone got bored with their bowling activities, they could dance the night away. For comic relief, a "beat the man" game was provided, set aside in one of the lanes. Attendees could make a \$5 dollar donation to play for a chance to "beat the man" or at least his score in bowling, "the man" being Randy Griffith (grandfather of Peyton and Grace, an avid bowler). If "the Man" lost the frame of bowling, he would be required to dress in costume attire, chosen by the winner. He had to layer the clothing/costumes as the night progressed. It was quite funny!

There were more than 30 volunteers for the day of the event. Special thanks to Polly & Randy Griffith, Jane & Joe Clemmons, Cindy Hoonick, Jody & Erik Schneider, Jen Rachau, & Jennifer Nicksich for volunteering as committee members. All your hard work was a huge help and the event could not have been success without them. And special thanks to Sarah, Randy, Peyton and Gracie for hosting another wonderful event and raising much needed funds for the LDSF! Thank you to all!



## celebratelife5k

Bedminster, NJ; Sunday, April 10

Step Ahead Weight Loss Center held it's first annual Celebrate Life 5K to benefit the Loey-Dietz Syndrome Foundation. The event attracted close to 200 people who came together to support the Olszyk's, a local family that has been tragically afflicted with the rare Loey-Dietz syndrome. Joan Olszyk spoke to the crowd regarding her perseverance with her family's struggles with the disease and the support from her family and friends that have helped her survive and find hope. Her son Jason, who has recently undergone surgery for LDS issues, was able to walk the 5K with the participants, a true triumph of individual strength and courage. The event successfully met its goal to raise funds as well as awareness for the Loey-Dietz Foundation and to help bring awareness to the community regarding this rare cardiovascular condition.

Special thanks to Erica Neiman, Dr. Deborah Neiman, the Step Ahead NJ Weight Loss Center and Joan and Jason Olszyk for all of their time and efforts to create a successful fundraiser for the LDSF.

## blogroll

Thanks to our members who answered our call to share their blogs! Feel free to follow along with them on their LDS journey.

Learn about Stephanie's LDS adventures:  
<http://sbrandt1.wordpress.com/>

Follow Heather's story she started just before open heart surgery in March:  
<http://myjourneywithloeydietz.myblogsite.com>

Keep up with 2-year-old Scout:  
<http://shoutoutforscout.com>

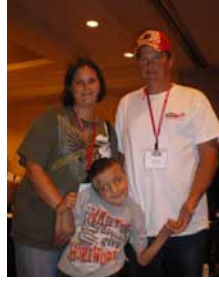
Got a blog to share? Email Megan the URL at [megan.ldsf@gmail.com](mailto:megan.ldsf@gmail.com)!

# conferenceupdates

## NMF Conference

Portland, OR; July 14-17

Families impacted by LDS could attend special LDS sessions at the National Marfan Foundation conference. Sessions were led by cardiologists Dr. Mark Lindsay (Johns Hopkins), Dr. Tim Bradley (Toronto Sick Kids), Dr. Joshua Spin (Stanford) and cardiothoracic surgeon Dr. Duke Cameron (Johns Hopkins). Patient questions about genetic testing, cardiac surgery timing, and individualized surveillance plans were discussed. In the coping with LDS session, families were also able to come together to support one another in the roller-coaster of emotions that goes along with new diagnoses, dealing with surgeries, and future uncertainties. Thank you to everyone who shared stories, experiences and support. And, thank you to the NMF for all of their support for individuals with related connective tissue disorders.



The Lewis Family from Kansas attend the NMF conference sessions about LDS

## Pediatric Orthopaedic Society of North America (POSNA)

Montreal, QC, Canada; May 11-14

Members of our newly formed LDSF-Canada attended the POSNA conference to raise awareness in the medical community on behalf of both Foundations. At the conference, 62 one-on-one presentations were made to orthopedic surgeons and 125 kits including a medical presentation and fact sheets were distributed.

Our Canadian representatives also made presentations at the Pediatric Orthopedic Professionals (POP) seminar the Foundation where they had a booth and distributed 50 kits comprised of a medical presentation, a "Head-to-Toe" checklist and fact sheets. And at the University of Toronto's Genetic seminar where they distributed over 100 medical kits.



The LDSF - Canada made presentations and distributed materials at several medical conferences in Canada.

## American College of Medical Genetics (ACMG)

Vancouver, BC, Canada; March 16 -20

Poster: Loeys Dietz syndrome and skeletal fragility. Dr. Ben Amor (Quebec, Canada) and Dr Roschger (Vienna, Austria) reported on the bone manifestations of Loeys Dietz syndrome. They studied bone biopsies on two patients and found high bone turnover and osteopenia or osteoporosis. High bone turnover can contribute to increased fracture risk.

## gobananasforbodhi

As her first LDSF fundraiser, Michelle Swindle decided to create wristbands for her son Bodhi's 1-1/2 birthday bash and family reunion held on July 3rd. Bodhi is a Christmas baby and doesn't always get the full on celebration so Michelle thought this would be a fun way to make his birthday special and meaningful. The wristbands were personalized with the tagline "Go Bananas For Bodhi" and "loeydsdietz.org" and though there was a suggested donation of \$2 per band, many people donated more. "The bands were a hit at the party and it was cool to see everyone wearing them," says Michelle "I was happy to spread awareness about LDS to my family, many of whom had no idea Bodhi had such a thing. Thanks to the support and generosity of my family, we raised a total of \$403, with all proceeds going to the LDSF in Bodhi's honor."

Special thanks to Michelle and her family for supporting Bodhi and the LDSF!



Bodhi & Michelle celebrate with family (and a clown) and raised funds for the LDSF.

# congratulations

Congratulations to Dr. Pamela Frischmeyer-Guerrero, MD PhD who was awarded the 2011 ARTrust Faculty Development Award by the American Academy of Allergy, Asthma and Immunology at their 2011 Conference in March in San Francisco CA. It is a 3 year, \$300,000 grant through the James Hilton Manning and Emma Austin Manning Foundation to support faculty development. Dr. Frischmeyer-Guerrero is a faculty member at the Johns Hopkins School of Medicine who sees pediatric LDS patients impacted by Allergic disease. Her research project is entitled "Role of Transforming Growth Factor Beta in Allergic Disease"

"The ARTrust Faculty Development Award will be instrumental in providing me with the necessary funding, support, and confidence to establish my research program and achieve my goals of becoming an independent investigator," said Frischmeyer-Guerrero. "I am extremely grateful to the ART and its donors for their commitment to academic research and the careers of new investigators in the field of allergy and immunology."



## upcomingevents

### LIVE! for the LDSF

New Orleans, LA; August 24

LDSF member Anne Accardo will host the first annual LIVE! For the LDSF on Wednesday, August 24th at the 12 Bar on Fulton in New Orleans from 6 to 8:30 p.m. Food, drinks and prizes, plus live music will be provided by the Brass-A-Holics for a cover charge of \$20. For more information, visit our web site at [loeydsdietz.org/events](http://loeydsdietz.org/events).

*Interested in planning an event to help raise funds for the LDSF? Have an idea? Contact us at [info@loeydsdietz.org](mailto:info@loeydsdietz.org) and let us help you start an event or check out the Event Request form on our web site ([www.loeydsdietz.org/events](http://www.loeydsdietz.org/events)) to get started.*

## don't forget

Our 2012 Conference survey is out! If you haven't taken a minute to fill it out, please do so this week! We value your feedback and look forward to making our next conference invaluable to you. If you did not receive a survey, please email [info@loeydsdietz.org](mailto:info@loeydsdietz.org)

Also, don't forget about our Bone Health Research study taking place. For more information visit [www.loeydsdietz.org/research](http://www.loeydsdietz.org/research).

## quentin's quest 3

Quentin is back with a brand new Quest and he's looking for help in all 50 states to help him raise \$10,000 for the LDSF by the end of November.

After watching his brothers save their change, take it to the bank to be counted and then come home with \$50 to \$100 each, Quentin decided that money could be put to good use and help the LDSF. So, he created his third Quest.

"I'm asking you to collect your change for four months," says Quentin. "From now until the end of November (the season of giving and being thankful!) and then, count up the change (or let the bank do it) and mail me a check made out to the Loeyes-Dietz Syndrome Foundation. You can do this easily in your house and I'm asking you to ask others to do it as well – maybe at work or church or school or even in your neighborhood."

Check out Quentin's web site – [quentinsquest.us](http://quentinsquest.us) – for more details and updates or to let him know you're on the Quest with him. To download a label to put on your own collection jar, visit [loeysdietz.org/quentin](http://loeysdietz.org/quentin) to find the PDF and make your own change jar. And feel free to send him checks (and pictures of you and your team of collectors) made out the LDSF whenever your container gets full.

Thanks Quentin for another great idea and for support the LDSF! We can't wait to see how much change you can collect!

## raisefunds

LDSF heart pins by artist Terri Kerchner continue to be available and make great gifts for Mother's day, Teacher gifts or any occasion! Pins are \$15, plus shipping and handling. Please email [Kate.Jurgens@loeysdietz.org](mailto:Kate.Jurgens@loeysdietz.org) for more information.

We now offer cut-out LDSF TakeHeart hearts that can be used in multiple ways to help generate heartfelt monies. Hearts can be used for a "hang-a-heart" type campaign where for a specific donation amount an individual can write their name on a heart and have it displayed on the wall at a school, store, church, or wherever! Create your own campaign to help us raise money and awareness for the LDSF. Please email at [info@loeysdietz.org](mailto:info@loeysdietz.org) to request hearts for your own campaign.

*The LDSF is a registered non-profit corporation and is exempt from the United States Federal Income Taxes under section 501(c)(3) of the Internal Revenue System. All gifts are tax-deductible. We thank you in advance for your kind assistance and support.*



## icecream&calligraphy

This year at the Ben and Jerry's 9th annual winter festival at their factory in Waterbury, Vermont, Marla Hogan, a Ben & Jerry's employee, decided to raise awareness and funds for the LDSF. With snow sculptures, free samples, free tours and music to enjoy and draw people to the event, it was suggested by Marla's sister that their dad create people's names in calligraphy for a donation for the LDSF. "After losing my husband to Loeyes-Dietz syndrome two and a half years ago, I have been trying to find ways to do fundraisers for the Foundation," says Marla. "It was a good way to get the LDSF name out there and to inform people." Marla and her family raised just under \$1,000 by doing the calligraphy and afterwards Marla filled out the paperwork so that donation would be matched through a grant program from Ben & Jerry's! Thank you Marla and family and Ben & Jerry's for your support of the LDSF!



## matchinggifts

Many employers offer matching gifts programs to encourage employees to contribute to the efforts of nonprofit organizations like the LDSF. Most of these programs match contributions dollar for dollar, and some will even double or triple the amount of your gift! Consider doing a fundraiser for the LDSF and checking with your employer, your spouse's employer, your parent's employers, etc and see if any of them offer matching gifts programs to instantly increase your fundraising efforts.

## contributions

The Loeyes-Dietz Syndrome Foundation is able to continue to Take Heart thanks to the generous support of individual donors. We welcome all levels of donation, whether it's a one time gift, a monthly donation, or the establishment of a matching gifts program. The Loeyes-Dietz Syndrome Foundation is grateful to its members and friends who have made generous contributions in memory of or in honor of their loved ones. These donations are fully appreciated and support our mission. All those who gave generously will be acknowledged at the end of the year.

## volunteers

We love our volunteers at the LDSF and know that we could never be doing what we are doing without each of you!

We are now looking to grow some volunteer teams that can assist with ongoing operations. We are currently in need of volunteers to serve on and/or lead the following committees:

**Fundraising** (host your own event and help support others running events)

**Conference 2012** (help with planning, prep and implementation of various aspects of our upcoming conference)

**Thank You** (write personal notes to our donors and volunteers)

**Newsletter** (help write story blurbs and edit our newsletter)

If you're interested in becoming a volunteer or have more questions, email Megan at [volunteer@loeysdietz.org](mailto:volunteer@loeysdietz.org). Thank you for your time and dedication in helping to further our mission!

