



Connections

LOEYS-DIETZ SYNDROME FOUNDATION

2012 ANNUAL REPORT

JANUARY 1 TO DECEMBER 31, 2012



our mission:

to bring greater awareness to Loeys-Dietz syndrome (LDS) by encouraging education, fostering research and providing support for those impacted by LDS



dear friends

As I think back over 2012, the emerging theme of the Loeys-Dietz Syndrome Foundation was *connections*. We connected with our physician-researcher champions, creating a Medical Advisory Board that will guide, oversee and help move our medical education and information initiatives forward. We connected with our families at Conference, making relationships, providing support and getting your feedback to help drive us forward. We connected with the research community, providing funding to encourage a young investigator in his LDS-related research. We connected with our overseas communities, trying to engage and encourage a global LDS community.

And, most importantly, we were witness to our families connecting with one another, supporting each other through the hardships and triumphs of life. We are simultaneously humbled and overjoyed at all of the connections forged through the LDSF in 2012.

Our existence and success is dependent on the generous volunteers, partners and donors who give of their time, talents and finances to further our mission. Our Board of Directors is continuously amazed by the graciousness and dedication of not only our LDS families, but of their circles of community who come together to support our mission and vision. As we have reviewed our 2012 accomplishments, we know that we would not have met any of our goals without your generosity.

In 2013, we hope to keep the connections going. Check out our web site (www.loeysdietz.org), where we hope you'll join our network and connect with others in the LDSF community, sign up for our eBlasts and keep up-to-date on all things LDSF.

Thank you for taking heart — for being confident in us and having the courage to walk with us through this journey!

take heart,



Gretchen Oswald

Gretchen Oswald
LDSF President

our organization

In 2012, the Loeys-Dietz Syndrome Foundation continued to engage its various communities to create a solid foundation for the LDSF's operations in Baltimore, Maryland. Streamlining our processes allowed us to dedicate more funding towards research and support initiatives. We continue to operate under a volunteer-led Board of Directors, with the goal of funding and recruiting additional staff.

Select accomplishments this year include:

- Expansion of our Board of Directors
- Creation of a Medical Advisory Council (MAC) that has global representation under the leadership of Hal Dietz, MD
- Continued partnership with LDSF-Canada
- Mentioned in media outlets: Consumer Digest, Perez Hilton, Huffington Post, PR Newswire, ESPN. Com, GoMarquette.com, NBC and FOX affiliates in Milwaukee, CBS news and various affiliates
- Average open rate of 30% for eBlasts*
- Facebook posts seen by visitors in more than 15 countries and with 35,121 reaches**

**non-profit industry average 22%*

***number of unique people who saw post within 28 days*

our goals

- Hire a part-time data-entry contract employee
- Strategically plan and fundraise for hiring staff
- Plan for smooth transition of Board of Directors leadership
- Increase identification of and applications for grant funding

encouraging education

We continued to recognize diverse educational needs of our community. As more and more individuals were diagnosed with LDS, the spectrum of the condition and the questions posed by both patients and physicians broadened. In 2012, we spent a lot of time behind the scenes reviewing our medical information for updates and additions to help our growing community.

Select accomplishments this year include:

- Attended the Pediatric Orthopedic Society of North America (POSNA) conference to raise awareness and distribute educational material to pediatric orthopedic surgeons in attendance
- Offered educational lectures and Q-and-A sessions with leading LDS specialists at 2012 conference, including Drs. Dietz and Loeys (genetics/cardiology), Dr. Sponseller (orthopedics) and Dr. Black (vascular surgery)
- Assisted volunteers in putting on 3 major fundraising events where LDS information was shared with friends, family and community members
- Provided medical information to physicians and medical specialists giving presentations to their home institutions across the United States
- Addressed all medical inquiries from individuals and medical specialists coming into info@loeydietz.org
- Gave a medical and LDSF-vision presentation at University of Pavia, Italy to approximately 250 medical professionals and patients
- Created a Roadmap initiative and developed teams for future resource development

our goals

- Release updated medical fact sheets, a redesigned web site and materials translated into additional languages
- Develop strategy for medical professional education
- Produce medical guidelines for care of individuals with LDS

fosteringresearch

We continued to place a high priority on facilitating research that informs and guides our ability to better take care of individuals with LDS. Whether it is basic science or clinical research, any information gained about Loey's-Dietz syndrome is valuable and can be translated to improve the quality of life of patients.

Select accomplishments this year include:

- Saw a new LDS gene identified — TGFB2
- Gave a \$20,000 research funding grant to Juan Calderón, a young investigator in the Dietz lab
- Continued to support the NIH-funded GENTAC (Genetically Triggered Aortic Aneurysm Consortium) whose recruitment includes individuals with LDS
- Saw approximately 24 new medical journal articles published on LDS

our goals

- Increase financial support of LDS research
- Identify a "LDS Registry" champion

providingsupport

In 2012, we supported our community through regular eBlasts, Facebook posts, and most importantly through our 2012 Conference where 110 attendees came together to learn from our medical specialists and from each other. But, perhaps as equally important as the information relayed was the connections forged during a weekend together. We think your words show this accomplishment best...

"The best part about attending the conference is meeting other families impacted by Loey's-Dietz. In two days, we went from feeling alone and isolated to having a network of friends who could truly understand what we've been through."

"Thank you to all who worked so hard to make this conference possible, from both sides of the border. It was a wonderful time for learning and for the understanding of others who truly get where you are with life."

"The LDSF Conference is a place where fears were dampened, hopes were raised, the future was made brighter, new friends were made, old friendships were renewed and the kids smiles shined above all else!"

oursupporters

The Loey's-Dietz Syndrome Foundation is supported by private contributions from corporations, foundations and individuals. From the bottom of our hearts, we say thanks to these supporters who enabled our accomplishments in 2012.

memorialgifts

Bernard & Gladys Brady:

Clark, Colleen

Betsy Cates:

Little, Lisabeth

Aileen Cheng:

Nelson-Cheng, Carol

Dane Everhart:

Anonymous Donors
Allen, Peggy
Bedsole, Michele
Cherry, Rebecca
Gregory, Willie
Hall, Phyllis
Hester, Lauren
Hudson Bay Seafood Restaurant
Moehrke, Hannah
Morrison, Johnsie
Nichols, Jerry
Parks, Shirley
Powers, Barbara
Radi, Kimberly
Tittus, Courtney
Astrakhan, Elena
Barlup, Donna

Andrew Hoien:

Williams, Melissa

Debbie Ports:

Little, Lisabeth

Erin Ramsey:

Ramsey, Jodie

James Rutchik:

Rutchik, Mary

Florabelle Thompson:

Schultz, Barbara

Tyson & Olivia Wallis:

Arms, Patricia & Geoff
Carlton, Jan
Coonrod, Bev
Deaton, Mary
Dewhirst, Christi
Edgin, Janice
Ellis, Pamela
Hertel, Paula
Kearney, Kathleen
Lange, Jessica
Lankin-Koel, Claire
McAdams, Jonathan
Porter, Patricia
Springle, Joyce
Timmins, Sherrie
Tylka, Debbie
Beck, Lauren
Deaton, Mary
Dewhirst, Christi
Ellis, Pamela
Hertel, Paula
Kearney, Kathleen
McAdams, Jonathan
Meeseey, Mandy

Elizabeth Zegar:

Anonymous Donors
Alexander, Graham
Bonner, Arlene
Camp, Frank
Citco Corporate Services, Inc.
Edelman, Ari
Germek, Mary Jane
Gray, June
Griffin, Sheila
Healy, Mark & Lorraine
Kistulinec, William & Elizabeth
Kohmer, Janice
Lawrence, Ken
Lawrence, Sue
Meola, Mary
Miele, Lisa
Miller, Cheryl
Mulkerin, John & Patricia
Paparteys, Frank
Pfluger, Scott
Polanco, Griselda & Manuel
Rodriguez, Herbert & Alison
Savchek, Mary
Smith, Maureen
Steitz, Thomas
Tomczak, Sarah
Zagarella, Mary
Zegar, Gerald
Zegar, Gladys

Kathleen Zegar:
Anonymous Donors
Arakelian, Kenneth
Carluccio, Dan
De La Pena, Carolyn
Flanagan, Audrey
Kistulinec, Elizabeth & William
Lawrence, Ken
Marsillo, Nancy
Miele, Lisa
Mikson, Rudolph & Rosemarie
Miller, Cheryl
Paparteys, Frank
Pfluger, Scott
Polanco, Griselda & Manuel
Pollard, James & Kara
Riley, Tammy
Rodriguez, Herbert & Alison
Smith, Marueen
Steitz, Thomas
Toothill, Diane
Yates, Walter & Agnes

honorgifts

Belensee Elementary School**Ms. Scott & Ms. Lemon:**

Erwin, Dianne

Shannon Brenner:

Rivera, Blanca

Richard Coren:

Coren, Elaine
Winokur, Steven & Harriet

D&R First Family Foundation:

Martin, Jonathan

Joseph Galli:

Morley, Marie-Claire

Peyton & Grace Griffith:

Echols, Brandi

Labus, Denise

Gabi Guaipatin:

Gomes, Malu

Lisabeth Little:

Clingerman, Rachel

Sandy Meinholz:

Brescia, Dee & Michael

Xavier Metrovich:

Bill Batemans Bistro
Freeman, Tracy
Metrovich, Nicholas & Crystal
Padgette, Connie
Wertz, Asmonda & Maria
Wesley United Methodist Church
Wilson, Julie

Hannah Moehrke:

Small, David

Wyatt Moser:

Anonymous Donors
Bastin, Margie
Conner, Christina
Freeman, Karen
Howard, Patricia
King, Kylie
Kirkland, Maria
Parton, Jamie
Woody, James & Marsha

Casey Nelson:

Essig, Holly
Rice, Joyce & Robyn Gloster

Cody Newman:

Block, Patrick

Casey Niles:

Anonymous Donor

Steve Novak:

NBTY Helping Hands Charity, Inc.

Joan Olszyk Family:

Leasor, Christopher

Gretchen Oswald:

Toohey, Kelly

Emily Rauschenbach:

Haskins, Nathan

Nicole Reiner:

Faggen, Ivan & Marsha
The Marilyn & Mitchell Sabin Family Fund

Elizabeth Sammon:

Morgan, Thomas & Julie
Sammon, Diane & Aldon

honorgiftscont.

Aryn Schwartz:

Schwartz-Weitz, Dorene

Nia Tauer:

Wedding Guests

Connor Wilson:

Ask, Jeneen
Aul, Michael
Brauch, Robert & Barbara
Hines, Tim
Loveland Sweets
Masters, Melissa
Missioni, Rebecca
R.E. Saxon Jeweler
Rector, Denise
Wells, Wanda
Wiersbicki, Linda
Wilson, Julie
Winter, Thomas & Karyn



thank you

The LDSF has worked hard to prepare a complete list of 2012 donors. Despite our best efforts to avoid errors and omissions, these can occur. If you contributed as a donor and your name was inadvertently omitted, listed in the wrong place or misspelled, please accept our sincere apologies and contact us at megan.rhee@loeysdietz.org, and advise us of the mistake so that we may correct our records.

donors

Affiliated Ankle & Foot Podiatry Clinic
Alleman, Robyn
Allen, Jeff
Alliance ENT & Hearing Center, SC
Anderson, Kerry
Arduino, Noreen Frankie
Associated Pediatricians
Atlas Bus Sales, Inc.
Augustana Lutheran Church Foundation
Aurich, Barbara
Badran, Souheil & Lisa
Bange, Albert & Joan
Bange, Jeffrey & Stephanie
Bange, Steven & Jeannette
Baran, Mark & Pamela
Battlefield, Gary & Petra
Bellcourt, Tim
Ben & Jerry's Foundation
Bennett, June
Bergner, Brandon
Bernard, Steven
Blaauw, Heino & Karen
Bodacious
Boilermakers Local 374
Bolas, Rui
Bradley, Murchison, Kelly & Sheal LLC
Brandt, Kenneth
Brauer, Margaret
Brauer, Molly
Breitzke, Gregory & Jenene
Broeker, Mike
Brown, Carrie
Brown, Jill
Brown, Lynn
Burns, Matthew
Burt, Billy & Teddi
Burton, Brian & Candice
Butcher, Barbara
Byrne, Timothy & Sharlene
Callanan, Susan
Campo, Kelly
Canino Electric Co.
Carey, Kathy
Carlisle Hobart South Restaurant
Carper, Forrest & Arlene
Carrall-Jeter, Penny
Casbon, Chad & Beth
Cedrone, Dave
Cesarz, Thomas
Chang, Kuang-Yu
Chavez, Christi
Children's Hospital of Wisconsin
Churilla, Daniel & Laura
Ciupak, Gregory & Teresa
Clemmons, Jane & Joseph
Collopy, John & Grace
Craft, Sandra
Craig, June
Cromer, A.
Curtis, Ronald
Dan Cain Construction
Darden, Jo
Dennis, Richard & Darlene
Dobson, Sharon
Dodds, John
Dos Bonitas, LLC
Double M Cattle LLC
Dr. D.R. Turbeville
Drehobl, Kristina & Michael
Dual Energy
Dupies, Donald & Margaret

Earp, Wayne & Rebecca
Echols, Brandi
Erickson, Carly
Erwin, Michael
Fanno, Dean & Brenda
Farmer, Gerda
Featherstone, Lisa
Feducia, Walter & Beatrice
Feibel, Darla
First United Methodist Church of Bossier
Fitzgerald, John & Janice
Foran, David & Donna Rae
Fornier, Robert
Forrester, Francine
Fox, Matthew
Frank, Lynn
Franke, Gabrielle & John
Fraternal Order of Eagles - Eagle Riders
Free Moore, Jerry
Freese, Barbara & Jean
Fritz, David & Maria
Fuller, Avis
Fuller, Peggy
Garlin, Jacquenette
Geary Dentistry
Gehling, Martin & Sarah
Gehrig, Gary & Jean
Gleason, Marie
Gold's Gym Ad Program
Gomes, Raquel
Gonzalez, Gloria
Gorecki, Susan
Gray, Margaret
Greenwell, Elizabeth & Joseph
Gridley, Clark & Kathy
Griffith, Polly & Randall
Griffith, Randall & Sarah
Guenveur, Paul & Kathy
Gumbo to Geaux
Gutierrez, Juan & Sara
Haase, Howard & Pamela
Hall, Casey & Kelly
Harpertech Specialty Equipment Repair
Hart, Holly
Hart, Michael
Hartman, David & Jeanne
Hartman, Martha
Hartt, Allyce
Harwood, Sara & James
Haug, Charlene
Hayden, Ryan
Hayes, Thos & Mary
Hays, Debbie
Hays, James
Hays, Keith & Barbara
Helms, Barbara
Helms, Marion
Herrin, James
Herron, Paulette
Hershey, Julie
Hietpas, Matthew & Amy
Highland Elks Lodge 981
Hobart Tiger Sharks Swim Team
Hofman, Kathryn & Thomas
Hogan, Marla
Holbrook, Perri
Holt, Heather
Horne, Linda & David
Houlihan Madison Most
Hudak, Patricia
Hughes, Ralph & Mary
J & K Brown Farms, LLC
Jagemann, Sue & Charles

James & Beatrice Salah Charitable Trust
Joan Martin Elementary PTO
Johnson, Ted & Nancy
Jones Lang LaSalle
Jurgens, Brian & Kate
Jurgens, Inez
Jurgens, Kristin
Jurgens, Michael
Jurgens, Raymond & Beverly
Kaye, Amanda
Keen, Marc & Michelle
Kelly's Chicagoland Law Tigers
Kielbasa, Edward & Sherri
Kirchner, Lois
Kirchner, Therese
Klister, Caitlin & Andrew
Knesek, Julie
Koster, Robert
Koszuta, Marie
Kroneberg, Cindi
Ksenak, Ashley & Kevin
Kussy, Maria
L & L Family Investment LLC
Lach, Steven
Lagacy, Rachel
Lang, Linda
Lanphere, Bonnie Lawrence
Law Office of Ronald G. Tays
Law Office of Thomas Hayes
Le Mense, Sam
Leahy, Joshua & Emily
Leahy, Terry & Paula
Legrand, Jacques
Line Avenue Pharmacy
Linn, Jim & Jean
Linn, Matthew & Patricia
Linn, Olive
Linn, Paul
Linn, Thomas
Liquidspace Inc
Liskey, Raymond & Cassandra
Little, William & Denise
Liu, Kathy
Lollar, Joshua & Shaela
Lott, Carrie
Lucas, Sarah & Jason
Luken, Jan
Luna, Jennifer & Nelson
M&M Wheel Alignment
Macdonell, Matthew & Jennifer
Machnikowski, Thomas & Nancy
Mackowski, Kimberly
MacMillan, Donald & Lois
Manista, Ray
Manous, Connie
Marinkovich, Nathan & Ginger
Masters, Bradley
Mathews, Margaret
Mathews, Richard
McClanahan, Morris & Geraldine
McCullough, Mark & Linda
McGinnis, Tim & Mary Jane
McGuire, Steve & Ruth
McKellar, Sandy
Meagher, John
Melancon, Curtis
Mercier & Associates, Inc.
Meza, Jose & Laura
Miller, John
Miller, Michael & Peggy
Millet, Kellie
Mitchell, David
Moore-Built Construction & Restoration

Moore, Belinda
Moore, Brian
Moore, Elly
Moore, George
Moore, Kenneth & Heidi
Moore, Melba
Moore, Ryan
Morales, Julia
Morgan, Denise
Muller, Mary Beth & Timothy
Murray, Lucinda
Nall, Amanda
Nassif, Kamal
Naul, Bernie & Gail
Naul, Wesley & Ashley
Neal, Bert
Nestich, Tamara & Stephen
Nikalich, Aleks
Niksch, Jennifer & Thomas
North Louisiana Veterinary Center
Northwest Indiana Cardiovascular
Physicians Management
Northwest LA Plant Food, Inc.
Novak, Steve & Christina
O'Connell, John
O'Connell, Timothy
O'Malley, Ann
Ognar, Tricia
Olson, Brian & Kathryn
Orthopaedic Pediatric & Spine Institute
Oswald, Jim & Lois
Owens, Frederick
Page, Edward
Pandl, Julia
Paul's Farm and Garden Supply
Pickett, L.G.
Pircon, Richard
Pityos, Inc - DBA Bright Spot Restaurant
Porter Hospital
Price, Tony
PS Capital Partners
Randolph, Betty & William
Reeder's Auto Services
Rees Funeral Home
Regional Insurance Services Company
Reilly, Dennis
Rhee, Megan
Richardson, Ashley
Rigg, Timothy & Angela
Riley, Francis & Deborah
Riverside Roofing Materials
Robert Adley For Senate
Rodriguez, Wilfredo & Jessica
Rogers, Stephanie
Rosen, Nicole & Richard
Salitore, Michael & Kathryn
Sanchez-Talavera, Nancy
Sandrock, Tina
Sands, Leslie
Sankovitz, James & Margaret
Schaefer, Zach
Schell, Steve & Mary
Schneider, Nancy
Schueller, Michael & Ann
Schumacher, Michael
Schwab, Rell
Seider, Alice
Seles, Tamara & Nathan
Seljan, Michael & Virginia
Setmayer, Barbara
Shelton, Mary
Siatczynski, John
Simaga, Adam & Natalie

Simon, Alison
Smith, Betty
Smith, Candice
Smith, Ronald & Judy
Snider, Nancy
Snyder, Margaret & Courtney
Solid Platforms
South Gateway Tire Co.
Spearman, Robert & Agnes
Sportspectrum Race Management
State Farm Insurance
Stewart, Alex & Michelle
Stewart, Carisa
Synergy Pest Control Systems
Tango Transport
Teamsters Union Local No. 142
Theatre School of Dance
Thompson, Michele & Jason
Thompson, Mona
Tiberi, Michael
Timms, Jane & Michael
Tomich, Damian & Laura
Toporski, Cassandra
Treadwell, Peyton & Toney
True, Steve
Tucker, Susan
Unilever
Uskert, Kathryn
Vance, Mary Ann
Vawter, Richard
Vestal, Judith
Vitali, Vincent
Wagner, Mark & Yvonne
Waid, Sheila
Walgreens
Wallace, Wendy
Ward, Stephen & Suzanne
Wargo, Lisa
Warner, Susan & Mark
Watson, Cindy
Weaver, Jimmy & Brenda
Weber, Eden
West, Kathryn
Whelpy, Ronald & Kiersten
Whiteman, Julianne
Wilkerson, Ernest
Wilson, Billy & Janet
Winokur, Harriet
Wirth, Donald & Joan
Wisconsin Health & Educational
Facilities Authority
Wise, Andy & Lydia
Wissing, Robert & Colleen
Withrow, Mary & Daniel
Withrow, Tom
Wood, Don & Jenine
Wozniak, Lorraine
Wucherer, Amy
Wyatt, Patricia
Zemburski, Kelly
Zimmermann, Dorothy & William
Zormier, Mallory
Zorn, Timothy & Janis

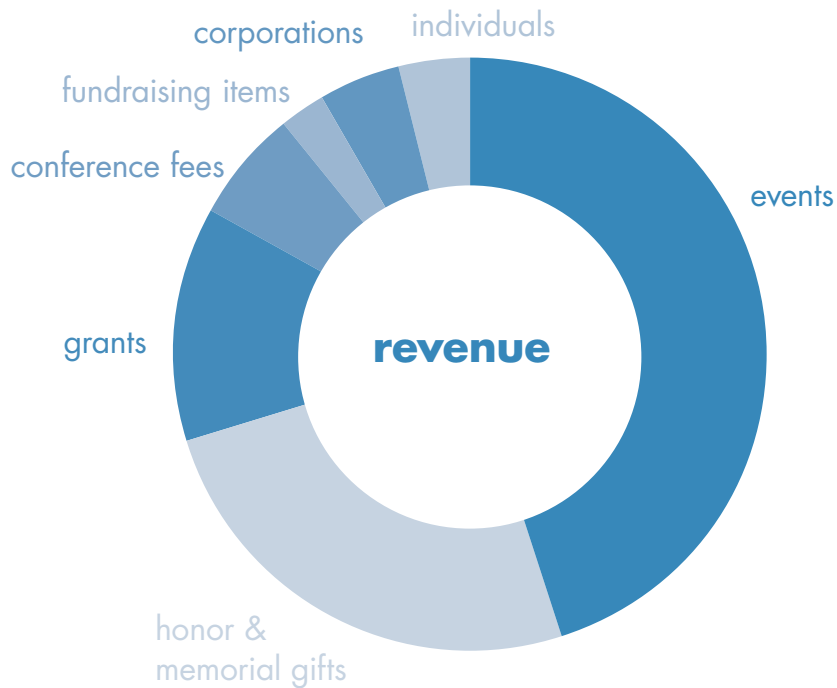


our financials

december 31, 2012

STATEMENT OF FINANCIAL POSITION

income	\$156,621. ²⁰
expenses	\$115,496. ⁵⁵
NET INCOME	\$37,103.³⁵
TOTAL NET ASSETS	\$184,695.⁷⁸



our future

Every day individuals impacted by LDS take heart and make their way through another surgery, another doctor's appointment, another personal success. You can take heart in knowing that donations provide these individuals with the support and resources they need to take heart for another day.

We hope you'll help encourage education, foster research and provide support for those impacted by LDS in 2013.

Donate online (www.loeysdietz.org/donation) or by mail (P.O. Box 22468, Baltimore, MD 21203) and help the LDS community take heart.

We thank you, from the bottom of our hearts, for your continued support.





PO Box 22468 • Baltimore, MD 21203

www.loeysdietz.org