

February 15, 2009

Dear Friends of the Foundation,

The first part of the year is a time when many of us give thanks for our blessings and renew our focus on how to share these blessings with others. Sharing our blessings is certainly not a new idea, but is especially poignant this year as many families face new challenges. Such challenges cause us all to take a look at our priorities, to imagine ourselves in someone else's shoes and to wonder just where this life is leading us.

We are not at all surprised at how fast and strong our community has grown within the Loeys-Dietz Syndrome Foundation. As we continue to support each other and our community, we can see how we have pulled together. Some have chosen to support our community by joining the online forum and offering emotional support.

Others have supported our community by doing a fundraiser. Some have bought pins, bracelets or note cards. Some have tried the unique new way of donating online through JustGive.org. Others have donated in honor or in memory of a loved one. Your steadfast support has helped us make a difference in 2008.

In addition, we thank our board members who have supported the Foundation in a myriad of ways and donated countless hours to help ensure that we continue to follow our mission and the needs of our community.

Having said that, we are very pleased with our accomplishments this past year (our first year!) and that they are in line with our mission, which continues to emphasize education and awareness about Loeys-Dietz syndrome. This past year we have worked hard to collaborate with the National Marfan Foundation (NMF) on educational materials specific to Loeys-Dietz syndrome, in addition to funding specialists at their annual conference in Boston this past summer. We look forward to continued collaboration.

We also had the wonderful opportunity for design student Megan Golden to give us a "face lift" which provided our Foundation with an updated style incorporated into our website, print materials, and overall appearance that gives us the professional appearance we needed! We are so very pleased at her hard efforts!

We also had our first Texas style fundraiser complete with a crawfest and golfing event organized with the Bilbow's. As well, a quest that gained the hearts of many around the world through Quentin's Quest. These initial fundraising efforts reminded us how our members can make a difference in our community and have lasting benefits for all.

In 2008 we welcomed 187 members into our community. Sadly, we said good bye to three amazing individuals, including Robert Hogan, Kayleigh Palmer, and Erin Ramsey. They will be fondly remembered and greatly missed, and our well wishes go out to the families and friends of the Hogans, Palmers, and Ramseys.

After a very busy first year, we still have goals for the organization that extend into 2009 and beyond. Some of these future goals include:

- Create additional educational Loeys-Dietz syndrome fact sheets specific to gastrointestinal, allergy, cervical spine instability, and vascular concerns
 - Continue to explore opportunities for collaboration with organizations with common visions and goals such as the National Marfan Foundation and Ehlers Danlos National Foundation
 - Promote membership growth and involvement
 - Recognize the scope and needs of our community to better assist donors to plan their philanthropic involvement more effectively
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It has been a rewarding year; we have had many happy times and sad times. We have enjoyed meeting so many of you personally, be it through the LDSF forum, fundraising, conference, emails, or FaceBook. We are thankful that you are part of our community, and look forward to working with you to build on these achievements in this new year. We hope you find comfort in knowing that together we have helped many families.

If you haven't already, we encourage you to consider a donation. Your generosity will truly make a difference. For those of you who have, we thank you in the following pages.

Thank you again for your support and best wishes to you and yours for a happy 2009.

Sincerely,

Beth Utz
President, co-founder

Gretchen Oswald
Vice-president, co-founder



CONTRIBUTIONS

The Loeys-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 Loeys-Dietz Syndrome and related connective tissue disorders.

In Memory of Robert Hogan:

Arthur Allerman
Elmo and Darlene Amundson
Darrell and Christine Anderson
Rev. Robert and Elizabeth Baugh
Joyce Bjur
Cynthia Blades
in the name of Marla Hogan
Eric & Sherrie Boone
Nancy Borgstrom
Melissa Brady in the name of Marla
John & Karen Brill
in the name of Marla Hogan
Terry & Lisa Brill
in the name of Marla Hogan
Gerald & MarLou Brytowski
Laurette Buswell
Amy Carr
in the name of Denise Hogan
Brigita Celms
Louise Chalfant
in the name of Kevin & Jana Hogan
Mark & Brenda Chuba
Elmer & Mildred Clair
Eileen & John Clifford
Sonja Dauphin
Pat Decker & Family
Joseph DeTucci
Dan & Treasure Eiden
Ed & Annette Foertsch & Family
Pamela Forte
Eric Fyksen
Louise Goede

Gotzian's Inc.
in the name of Michael F. Hogan Family
Roland & Jan Gregoire
Jolie Griffin
David Hackenmueller
Christina Hansen
Kevin Hogan
Michael Hogan
Cheryl Hoksbergen
Michael & Debbi Johnson
Ruth Johnson
in the name of Michael Hogan
Paul & Mary Kester
Joseph & Darlene Kinning
Kevin & Karen Kleist
Daniel & Therese Kosch
Luella Larson
Michael & Sandra Laughlin
Laurette F. Buswell Living Trust
Ralph & Judy Lichliter
Robert & Sharon Lien
Andrea Livingston
Charlie Lombard
John & Myrna Mahoney
Gloria McDonald
in the name of Brian Hogan
Lucille Muth
Dennis & Sharon Nelson
Gerald & Sandra Nelson
Greg, Sarah, & Noah Nelson
Richard & Lucinda Nelson
Linda Nesbitt

Audrey Olsen
Jack & Kathy Ostvig
Phyllis Peabody
Haso Peljto
in the name of Michael F. Hogan
Dan Peters
in the name of Marla G Hogan
Range Systems
Lucinda Redd
in the name of Marla and Brian
Howard & Audrey Ridgeway
Jack & Lola Savering
Laura Schaller
Mark Schiller
Judy Seibert
Brad & Linda Seiwert
Mark & Sara Shonka
Cindy Smith
Ed & Marge Smith
Carter & Tammy Stenberg
Esther Stohl
Jim & Marlene Strege
Lynn Strosnider
Loren & Judy Thompson
Kay Trapp
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in the name of Landon, Jen & Britton Trost
Zdenek & Solvig Urban
Barbara Vanderheyden
Tim and Kathy Wahlers
Walter & Frances Wentz
Terrie Wheeler
in the name of Michael Hogan

In Memory of Deborah A. Ports and Lisabeth Moore:

Lauren Appelt

In Honor Of:

Emersyn Ray Aurich by Robert & Dana Aurich & Family

Emersyn Ray Aurich by Pence Engineering, LLC

Jylian Bilbow by John & Kendall & Family

Gabi Guaipatin by Malu Gomes & Antonio Pereira

Hawthorne Family by William Boffa Jr.

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Quentin Waid 'Quentin's Quest' by:

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Lynn Green

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Linda Haluska

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Mary Rowe Vanzandt

Sheila Waid & Family

Alexander Utz by:

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Campbell Family

Children's Charity Walk

Mona DiCesare

Fostoria Lions Club

Dallas & Kathy Fultz

Dr. Thomas & Holly Guernsey

Key Bank Foundation

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Mimi Schaffner

Steve Snyder

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Rick & Rebecca Utz

Gloria & Phillip Warrington

Nancy Zeulzke

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A-1 Wrecker Service, LLC

Acme Brick Company

Linda & E. Wayne Alderman

Alexis Arteaga

Donna Bailey

Steven & Amy Ballard

Theresa Barry

John C. Bartels

Dr. Rosmary Batanjski

Tom Beecher

in the name of Ethan Wilson

Dr. Tim & Jill Beidelschies

John & Kendall Bilbow

Dr. Aaron & Cristin Brescia

in the name of Anthony Brescia

Bonnie Bower-Dennis

Thomas & Lorna Cahill

Margaret Cain

William & Kris Carter

Chrylser Heaven, Inc.

John & Lori Cook

Corrie Churchill

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Elaine & Richard Coren

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Mary Demet

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Thomas & Tamara Gordon

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Mesch McBride & Evans LLP

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Sarah Moore

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Barb Peterson

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Richard & Kathryn Sankovitz

Nancy Schmitz

Eileen Scott

Lenora Sheahan

Sandra Simpson

Nancy Slater

Speed Fab-Crete

Kori Staab

Christine Stefaniak

Kari & Justin Stephens

Kelly Toohey

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Dr. Derik & Beth Utz

Jim & Sheila Waid

Nancy Ware

Ruth Wiesmann

Gary Wilhite

Steven Winokur

Randy & Deborah Wolter

Louis & Wilhelmina Yaeger

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