



THE EVANOSKY
FOUNDATION

We Win in the End

THE EVANOSKY FOUNDATION

2009-10 Annual Report

A Message From Bob Evanosky

Dear Friends,

In the past five years that The Evanosky Foundation has been in existence, we have been able to see tremendous changes. Newborn screening for deadly diseases similar to the one that affects my boys has been legislated in three states. A housing program to support families whose children are going through the transplant process at Duke University has been established. And clinical trials have had a direct impact on my family's life as a result of John receiving a new form of transplant in July 2009 that targets specific stem cells.

We at The Evanosky Foundation are about change and making the world a better place. Our goal as a Foundation is to ultimately combine newborn screening with improved, less risky transplants to make MLD and other fatal metabolic diseases (specifically lysosomal storage disorders) a thing of the past.

We appreciate your continued support of our efforts as we work to improve children's lives. Your gifts of money, House of Hope items, and time have been critical in making that happen. We pray that in 2011 we will be able to continue to make significant progress in medical research and newborn screening legislation which will allow a better quality of life for children and families affected by life-limiting lysosomal storage disorders.

We Win In The End,

Bob Evanosky
President
The Evanosky Foundation

Accomplishments

What Did We Do?

The Evanosky Foundation put together an approach to help families and children affected by MLD and supported three key initiatives in 2009-10:

- 1. Medical Research**
- 2. Family Support**
- 3. Newborn Screening**

You can read more about these projects, along with the Foundation's financial activities, on the following pages.

Accomplishments

Medical Research

The Evanosky Foundation continued to sponsor work at Duke University in developing therapies that will treat children with leukodystrophies. In July 2009, John Evanosky became the first child in the world with a lysosomal storage disorder to successfully receive an outpatient stem cell transplant with stem cells from his father, Bob. These stem cells co-exist with John's bone marrow and blood and for the first time since he was born, he can now produce the enzyme that he has been missing and that causes MLD. Just as important, John did not have to stay in the hospital to receive this procedure—it was all done outpatient. In contrast, Jack Evanosky spent just under 40 days in an ICU transplant unit to achieve the same result in 2005. Not only is the treatment less harsh on the child, but the cost is 75 percent less than a traditional transplant. This is monumental and could potentially change the outlook from certain death to life for children with MLD and other lysosomal storage disorders.



Bob (left) and John Evanosky on transplant day, July 9,

At the time John was treated in July, the FDA only gave Duke University the approval for one patient to be included in this trial, but we are working with the doctors to get the FDA's approval so that many children suffering from lysosomal storage disorders—including John's twin, Christopher—can receive this same treatment.

This trial is a result of research that The Evanosky Foundation has funded at Duke in the past, and continues to fund research in the area of brain and nerve repair.

Family Support

Recognizing the extraordinary need for housing transplant patients and their families while receiving treatment at Duke Children's Hospital, The Evanosky Foundation opened its first House of Hope in September 2008. Because this apartment was constantly occupied and demand for additional housing was high, The Evanosky Foundation opened two additional Houses of Hope in 2009, one in April and another in July. A fourth was opened in August 2010.

All of the House of Hope apartments are professionally decorated and feature conveniences such as a high-efficiency washer and dryer, computer with wireless high-speed Internet access, flat screen televisions, DVD players, and a video gaming system. Special amenities that enable a cleaner environment and reduce dust accumulation, such as wood floors, ceiling fans and wood blinds, have also been installed. National manufacturer Flexsteel Industries provided furniture covered in a specially patented material that is both comfortable and can be easily disinfected.

Lamps, clocks, and other wall decor help give the Houses of



The volunteer crew at House of Hope 3. From left: Matt Wanzenberg; Bob Evanosky, Sr.; Bob Evanosky; Larry Vice; and Paul McDermott

Hope their welcoming atmosphere. The apartments are all in the same complex, conveniently located just minutes from the hospital and shopping.

The Evanosky Foundation is able to provide housing to families at a 55 percent discount compared to traditional corporate housing. Through the end of 2010, the House of Hope program has served 10 families.

Newborn Screening

In 2009, The Evanosky Foundation was involved with promoting and advocating for newborn screening expansion efforts in the State of Missouri. House Bill 716, the Brady Alan Cunningham Newborn Screening Act, was signed into law by Governor Jay Nixon on July 8, 2009. House Bill 716 mandates newborn screening for Krabbe, Pompe, Fabry, Niemann-Pick and Gaucher diseases — the same diseases the The Evanosky Foundation advocated for in Illinois Senate Bill 1566, which was passed in November 2007. Missouri State Representative Tom Todd (D—District 163), the key sponsor of the bill, introduced it after being contacted by the family of Brady Cunningham, for whom the bill was named. Tragically, Brady Cunningham passed away on April 6, 2009, but he and his family have left a wonderful legacy with his short life.



Missouri Gov. Jay Nixon, who signed HB 716 into law on July 8, 2009, surrounded by family members of the late Brady Alan Cunningham, who passed away as a result of Krabbe disease.



Bob Evanosky (left) with New Mexico Governor Bill Richardson and Julie Allen.

A similar victory occurred in New Mexico in 2010. On March 9, 2010, New Mexico Governor Bill Richardson made New Mexico the third state in the U.S. to screen all babies for five lysosomal storage disorders (LSDs) -- Fabry, Gaucher, Krabbe, Pompe, and Niemann-Pick diseases -- all of which are similar to metachromatic leukodystrophy. The Evanosky Foundation worked closely with Julie Allen (pictured far right - the grandmother of a child with MLD - with Bob Evanosky and Gov. Richardson), along with two other advocates and Representative Rhonda S. King, to pass this important legislation. The implementation of this law will allow approximately 28,000 babies each year to be screened for these diseases, which is especially beneficial for New Mexico since it has the highest incidence of Niemann-Pick C disease in the country.

In late 2010, the State of Illinois has begun to implement its lysosomal storage disorder screening that was but into law three years ago. Advances in technology have allowed the cost of the screening to be significantly lower than earlier projections, and The Evanosky Foundation is advocating that two additional lysosomal storage disorders be added to the screening panel.

When these states have fully implemented screening for these LSDs, approximately 12 percent of the babies born in the U.S. will be screened at birth, giving them and their families a chance at better lives.

Other Accomplishments



Jack Evanosky with his Duke hospital school teacher, October 2009

Jack's Library

The Evanosky Foundation continues to support Jack's Library, a program designed to provide books and movies to children undergoing transplant procedures.

In 2009, Pi Gamma Pi sorority based in Wheaton, Illinois, chose to donate books to Jack's Library as part of their literacy initiative. Many thanks to Anne Wanzenberg for coordinating this effort!

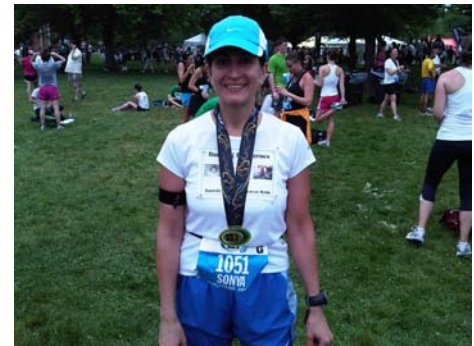
Fundraisers

2009 Rock 'n' Roll Chicago Half Marathon and Bank of America Chicago Marathon

The Evanosky Foundation was a bronze charity for the 2009 Rock 'n' Roll Chicago and a contributing charity of the 2009 Bank of America Chicago Marathon. In 2009, 13 people ran for Team Evanosky in both events and raised more than \$24,000.

2010 13.1 Chicago Half Marathon

In 2010, The Evanosky Foundation was an affiliated charity with the 13.1 Chicago Half Marathon event. We were excited to have two team members, Jeff and Matt Wriker—who came from Oklahoma and Texas respectively—travel to Chicago to compete in the 5K portion of the race. It was Matt's first 5K ever, and he did well. Additionally, Jennifer Weiner was thrilled to complete her first half marathon. We hope that Jennifer and Matt—as well as other first time and experienced runners—will continue to run with Team Evanosky in the future!



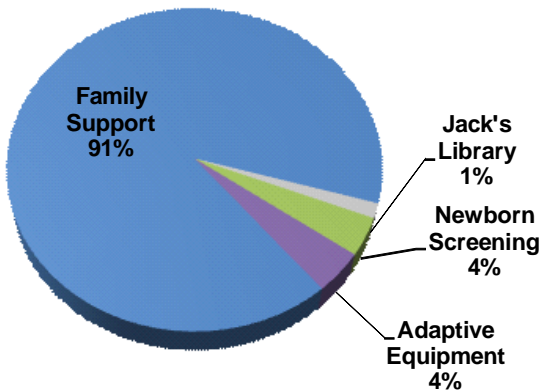
Sonya Evanosky after completing the 2010 13.1 Chicago Half Marathon



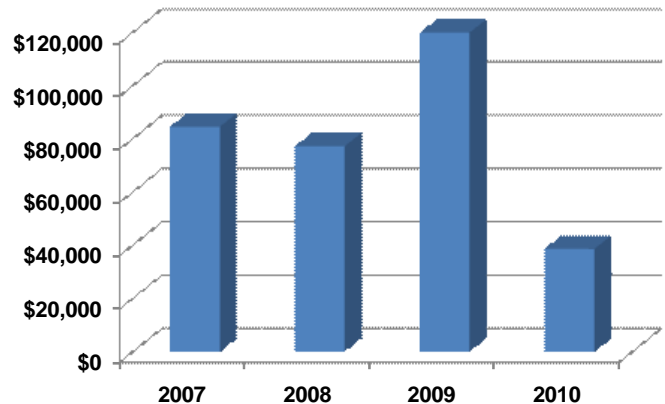
2010 13.1 Chicago Half Marathon runners near the start line. From left, Jennifer Weiner, Matt Wriker, Jeff Wriker and Ryan

Financials

The Evanosky Foundation 2009-10 Expenses by Type



The Evanosky Foundation 2007-10 Revenue



The Evanosky Foundation is recognized as a 501(c)(3) organization by the Internal Revenue Service and all donations are tax-deductible. In 2009, the Foundation received over \$121,500 in contributed support from individuals and businesses. Through mid-December 2010, slightly over \$38,700 was received. Fundraising efforts were not as successful in 2010 due to a tightening economy as well as fewer fundraising activities.

Expenses for both 2009-10 totaled \$94,600 and were primarily used to fund three projects, which included Family Support, Newborn Screening, and Jack's Library.

Projects related to Family Support received most of the funds in 2009-10. Approximately 10% or \$8,000 of the Family Support expenses were given to individual families whose children are battling a leukodystrophy to assist with payments for medical bills, housing or other necessities. The remaining costs were associated with starting and maintaining three additional Houses of Hope.

How Can I Donate?

1

Donate online by going to The Evanosky Foundation's website at www.evanoskyfoundation.org and clicking on "Donate or Help" on the left hand side. Donations can be made quickly and securely through our Paypal service.

2

Send a check to The Evanosky Foundation at P.O. Box 9234, Naperville, Illinois 60567

3

Donate a car, truck, boat, motorcycle or RV to The Evanosky Foundation through our partner, CARS, by calling (877) 537-5277. Your vehicle will be picked up and you'll receive a tax deduction!

Due to collaborative efforts with other non-profit organizations and companies, The Evanosky Foundation was able to minimize costs associated with the passage of the Missouri and New Mexico newborn screening bills, which provided for enhanced newborn screening for five fatal diseases. After the initial success with the Illinois bill, we are pleased to see that other states are following suit and passing laws to implement newborn screening for lysosomal storage disorders.

In 2009-10, fewer dollars were disseminated for Medical Research because projects that were funded in prior years required no additional funding. However, as projects reach the clinical trial stage in 2011, more funding may be needed.

Donors

The Evanosky Foundation's success is made possible by the generous contributions of its donors. Thank you! If you believe we have inadvertently overlooked your donation and not listed your name here, we apologize and encourage you contact us to be certain it was received. Please note that 2010 amounts are through December 14, 2010.

\$5,000+

Anonymous (2009, 2010)
Bob & Sonya Evanosky (2009, 2010)
Duke PBMT Family Support (2009)
HSBC Matching Gifts (2009)
Matt & Anne Wanzenberg (2009)

\$2,500 - \$4,999

Andrew & Amanda Armishaw (2009)
HSBC Matching Gifts (2010)
Tim Molek Memorial Fund (2009)
Mike & Denise Woodward (2009, 2010)

\$1,000 - \$2,499

Su Ming Chow (2009, 2010)
Melinda & Lawrence Turner (2010)
Libby Nobis (2009)
Mike & Dana Smith (2009, 2010)
Myron M. Studner Foundation (2009, 2010)
The Tatem XHIM Foundation (2009)
Elizabeth Therkelsen (2009)
Larry & Kim Vice (2009)
Ryan & Julie Willhauck (2010)

\$500 - \$999

BP Fabric of America Fund (2009)
Bob & Nancy Evanosky (2009)
David Evanosky (2009)
GE Foundation (2010)
Kaplan (2009)
Sanofi-Aventis (2009)
United Way of Central New Mexico (2010)
Winslow Leatherman (2009)
Elizabeth Therkelsen (2010)
Will & Beth Wong (2010)

\$250 - \$499

Julie Allen (2010)
Always There Concierge (2009)
Bank of America Foundation (2010)
Jan Bleeker (2009)
BP Fabric of America Fund (2010)
Community Health Charities of California (2009, 2010)
Jean Downie (2009)
Sherann Emerling (2009)
Larry & Linda Johansen (2009)
William & Olga Massart (2009, 2010)
McDonalds (2010)
Sean Rezentes (2009)
Rick Sciortino (2009)
Marna Sheftic (2009)
Pat Smith-Pierce (2009)

Michael Swinford (2010)
United Way of Central New Mexico (2009)
Jeff Wriker (2010)

\$100 - \$249

Steven Ainger (2009)
Phillip & Wendy Armstrong (2010)
Richard Barrett (2010)
Marian Bergan (2009)
Paul & Nicky Berk (2009, 2010)
Randy & Jody Berns (2009)
Ben Breslau (2010)
Daniel Brooks (2009)
Louise Buchanan (2009)
George & Susan Buck (2009)
Chevron Humankind Matching Gift Program (2009, 2010)
Steve & Dawn Clark (2009)
Patrick Coicou (2010)
Chuck & Pam Collier (2009)
Ward Collier (2009)
Cook's Piano Service (2009)
Robert Coulter (2009)
Rod Creswell (2009)
Peter Davies (2009)
Lori Dennison (2009)
Dave & Charlotte Dockstader (2009)
Joyce Doma (2009)
Jean Downie (2010)
Mike & Tammy DuVall (2009, 2010)
Rachel & Arthur Dykxhoorn (2010)
Ealliance Corporation (2010)
Todd & Amanda Eicher (2009)
Nick & Kristen Fleming-Wood (2009)
James Foster (2010)
Brenda Gonzalez (2009, 2010)
Mary Gray (2009)
Gordon & Alene Guthmiller (2009)
The Home Depot Foundation (2010)
Tim & Barb Hoskins (2009, 2010)
Ed & Joan Hurst (2009)
iGive (2009)
Anthony & Rebecca Jacob (2009)
Jean Jarman (2009)
JOH Options (2009)
Larry & Linda Johansen (2010)
Theresa Jones (2009)
Voula Kanavas (2010)
Dr. Mary Keen (2009)
Katherine & Rob Kerr (2010)
Thomas Kimble (2009)
Hyon Ko (2009)
Darrell & Tiffany Lewis (2009)
Kevin & Jean Lyons (2010)
Ann Madea (2009, 2010)

Dayton & Helen Marshall (2009)
Skip & Ruth Maynard (2009)
Paul & Holly McDermott (2009, 2010)
McDonalds (2009)
Erin McGregor (2010)
Kevin & Jennifer McKinney (2009)
Stacey & Chris Metzger (2010)
Gladys Miller (2009, 2010)
Patty Murawski (2009)
John & Bari Murphy (2010)
William Nelson (2009)
Network for Good (2010)
Gary & Mollie Niederpruem (2009)
Janet Nixon (2010)
Karen Nixon (2010)
Meghan Oatman (2009)
George & Jeanice Officer (2009)
Steve Page (2009)
Eileen Pappas (2010)
Brian & Michelle Parchem (2009, 2010)
Nilesh Patel (2009)
Brian & Jaime Phillips (2009)
Ari & Jamie Potash (2009, 2010)
Chris Randolph (2010)
Steve & Pam Reed (2009)
Rodrigo & Janaina Ribeiro (2009)
Susan Riley (2009, 2010)
Fred & Susan Rodgers (2009)
Holly & Dave Rodgers (2010)
Rick Sciortino (2010)
Paul & Johanna Sedillo (2009)
Marna Sheftic (2010)
Eric Sloan (2010)
Christian Spesia (2009, 2010)
Chris & Pat Stallter (2009, 2010)
Thomas & Myra Steininger (2009)
Don Tomsik (2009)
Stephanie Trietley (2009)
United Health Group (2010)
Matthew Van Ermen (2009, 2010)
Craig & Sherry Vesper (2009)
Samantha & David Viscomi (2010)
Sarah Voss (2009)
Carol Walker (2009)
Aaron & Jennifer Weiner (2009, 2010)
Lawrence & Judy Weiner (2009, 2010)
Ryan & Julie Willhauck (2009)
Thomas & Carolyn Wujek (2009)
Susan Yamanaka (2009)
William Zeiler (2009, 2010)
Vladimir Zeravica (2009)
Gary Zilk (2010)

\$50 - \$99

Julie Allen (2009)
Rose Babendir (2009)

Mirosława Babicz (2009)
 Matt & Saba Bando (2010)
 Lisa Benson (2009, 2010)
 Janette Bereta (2010)
 Mrs. John D. Bethay (2009)
 Jan Bleeker (2010)
 Beth Bovis (2010)
 Karen Byrd (2009)
 Albert & Concetta Cacini (2009)
 Kay Carlile (2009)
 Ron Charmoy (2009)
 Edward & Elizabeth Cheatham (2010)
 Walker Collier (2009)
 Cheryl Cooper (2009)
 John & Mary Crook (2009)
 Matt Cummins (2009)
 Joan Cundey (2010)
 Mary Janet Dahm (2010)
 Angie Dante (2009)
 Susan Davidson (2010)
 Mark & Jennifer Davis (2009, 2010)
 Mike & Heather Davison (2010)
 Bryan & Karen Duncan (2009)
 Menno & Keri Ellis (2009)
 Bruce Ellwein (2009)
 Louis Erskine (2010)
 Jamie Faber (2010)
 Jerome & Lenore Fox (2009)
 Frames & Art by Klutz (2009)
 Allen & Karen Franck (2009)
 Jeanine Gausselein (2010)
 Thomas & Kathleen Gausselein (2010)
 Jennifer Gentile (2010)
 Sue Ellen Gerchman (2010)
 Patrick Goodwin (2009)
 Berta Graham (2009)
 Don & Jody Haas (2010)
 Martyn Harris (2009)
 Pamela Harvey (2009)
 Virginie Helmus (2009)
 Steven & Sylvia Higa (2009, 2010)
 Ann Hodges (2009)
 Jeff Hoeger (2009)
 Bob & Karen Hovey (2009)
 Amy Hummel (2009)
 William Huttenbach (2010)
 iGive (2010)
 Sharon & Paul Izzo (2010)
 Janeco Enterprises (2010)
 Ellie & Stacey Johnson (2009, 2010)
 Kaplan (2010)
 Kathleen Katrenak (2009, 2010)
 Michael L. Kiser (2009)
 Dayton Kishimoto (2009)
 Patricia Lang (2009)
 Edmund Injae Lee (2009)

T.J. & Carina Lewis (2009)
 Dylan & Amy Longaker (2010)
 Claire Lunardini (2010)
 Kevin & Jean Lyons (2009)
 Jerry & Kristin McConnell (2009)
 Richard McGaughey (2009)
 Erin McGregor (2009)
 Bruce McNair (2009, 2010)
 Chris & Stacey Metzger (2009)
 Michele Minarik (2009, 2010)
 Ravin Narain (2009)
 Gina Nelson (2009)
 Jim Nelson (2009)
 Keith & Linda Nelson (2009)
 Nathan & Heather Nuss (2009)
 Robert & Jodie Oboyle (2010)
 Kathy O'Brien (2009)
 Debra Oliver (2009)
 Christine O'Reilly (2009, 2010)
 Mike & Nadezda Palumbo (2009)
 Eileen Pappas (2009)
 Chris & Renee Price (2009, 2010)
 Thomas & Amber Purpura (2009)
 Art Racek (2009)
 Mark & Karen Reed (2009)
 Dennis K. Richardson (2009)
 Luda Riebe (2009)
 Brad Robbin (2009)
 Debbie Roller (2009)
 Edwina Sampler-Wright (2009)
 Howard & Jane Schroeder (2009)
 Carmen Sever (2010)
 Colleen Sherven (2009)
 Martin & Carrie Shiring (2009)
 Pamela Sinclair (2010)
 Carlyle & Leanna Skogen (2009, 2010)
 Paula Slabinak (2009)
 Jolene & Rick Spraggins (2010)
 David Tersteeg (2009)
 Marilyn Thompson (2010)
 Michelle Tomaino (2010)
 Laura Turley (2009)
 Steve Vara (2009)
 Geraldine Vazquez (2010)
 Joseph Vitale (2009)
 Sarah Voss (2010)
 Pat Ward (2009)
 The Washington Post Company (2010)
 Peter Weiss (2009)
 Louise Whitley (2009)
 Linda Kay Wilson (2009)
 Maureen Wolfson (2010)
 Vladimir Zeravica (2009)
 Tony & Dana Zitzka (2009)

*Donations may be sent to:
 The Evanosky Foundation
 P.O. Box 9234
 Naperville, Illinois 60567*

*Donations can also be made online
 through our website at
www.evanoskyfoundation.org.*

*Many employers will match donations
 made by their employees, and The
 Evanosky Foundation has received
 matching donations from companies
 such as HSBC, Chevron, Starbucks,
 Bank of America, McDonalds, Jones
 Lang LaSalle and the Washington
 Post. Check with your human re-
 sources department to see if your gift
 can be matched!*

*Many employers -- like IBM, Chevron
 and Sacramento County, California --
 offer donations through payroll deduc-
 tion. Check with your employer to
 see if this option is available for you!*

Key Things You Should Know

1. The Evanosky Foundation is an IRS approved, 501(c)(3) nonprofit organization.
2. 100% of every donation goes to support initiatives such as medical research, family support, or newborn screening.
3. All administrative costs are paid for by the founders.
4. The Evanosky Family does not receive any direct benefits from The Evanosky Foundation

About Us

The Evanosky Family's Story

Bob and Sonya Evanosky have three sons: John and Christopher, who are identical twins, and Jack, who is 26 months younger. All three boys were diagnosed with metachromatic leukodystrophy (MLD) in early 2005.



John and Christopher were initially diagnosed with cerebral palsy, but after experiencing a rapid decline in their abilities, they were properly diagnosed with MLD in January 2005. The Evanoskys were told that John and Christopher, who were diagnosed at age three, most likely would not live past the age of six. A few weeks later, Jack also tested positive for MLD at the age of one.

The Evanoskys learned that cord blood stem cell transplants were being used to treat MLD at Duke University Medical Center in Durham, North Carolina. After an evaluation by the doctors at Duke, Jack received his stem cell transplant on April 1, 2005. During this time, friends approached the Evanoskys with a proposal to form a foundation and thus, The Evanosky Foundation was formally established

in June 2005. Since then, due to pioneering efforts at Duke, John Evanosky received a new type of transplant in July 2009 and is doing well. The Evanosky Foundation is working towards allowing this treatment to be available to Christopher Evanosky and other children.

Mission Statement

The Evanosky Foundation supports pediatric leukodystrophy research, universal newborn screening, and children and families affected by a leukodystrophy, lysosomal storage disorders, or other disabling pediatric conditions. We are a dynamic organization committed to seeing meaningful change and improvement in each of these areas.

2009-10 Board Members

- Francis "Bob" Evanosky
- Sonya Evanosky
- Michael DuVall
- Karen Fedyszyn
- Amy McKenzie



The Evanosky Foundation
P.O. Box 9234
Naperville, IL 60567
(630) 236-8039

Website: www.evanoskyfoundation.org

E-mail: evanoskyfoundation@evanoskyfoundation.org
