

THE EVANOSKY  
FOUNDATION

*We Win in the End*

THE EVANOSKY FOUNDATION

# 2008 Annual Report

## *A Message From Bob Evanosky*

On January 3, 2003, a young man named Ryan Patrick Kishbaugh finally lost his fight against cancer. He was 18 years old when he died and from what people tell me, he was a brilliant individual. I first learned about Ryan when I read one of his personal journal entries that was reproduced, framed and currently resides on the walls of "5200" at Duke University Children's Hospital. One of the entries has deeply affected me and I would like to share it with all of you:

I know there is no answer to what I am asking, but then tell me, if we can't change this world, what are we here for? If I can't make someone love herself, what am I here for? If I can't help, what use am I? I know the answers are there, I know I will never be able to understand them, so just try and see it from my eyes for a moment. We are supposed to go on believing that everything will get better, that we will make a difference, but when we are gone, does anything ever change? Do people ever change? Cultures? Nations? DO the wars ever stop? Does the hatred ever end? Where? When? And can I make a difference, with such opposition, can I do anything to help? Can I do what nobody else is able to, can I make them see? Can I open their eyes? The world wasn't created to be perfect, but if we all believed it could be, could it actually happen? Would you ever let it? Would we ever let it? Use your life to make a difference. Each person we help, it is a small step in making the world a better place. Open your eyes to that, and to the beauty of life. Don't waste it. You'll never get a second chance. None of us do.

These words written by Ryan have had a profound impact upon me since I first read them back in 2005 when The Evanosky Foundation was being created. For those reading this who have never contemplated the question of whether one person can make a difference, or for those who still seek to have it answered, I echo Ryan's words: "use your life to make a difference. Each person we help, it is a small step in making the world a better place. Open your eyes to that, and to the beauty of life. Don't waste it. You'll never get a second chance. None of us do."

In a large way, The Evanosky Foundation, along with its volunteers and supporters, works daily to honor Ryan's request. We invite you to come along with us on this journey of making the world a better place.

We Win In The End,

Bob Evanosky

# Accomplishments

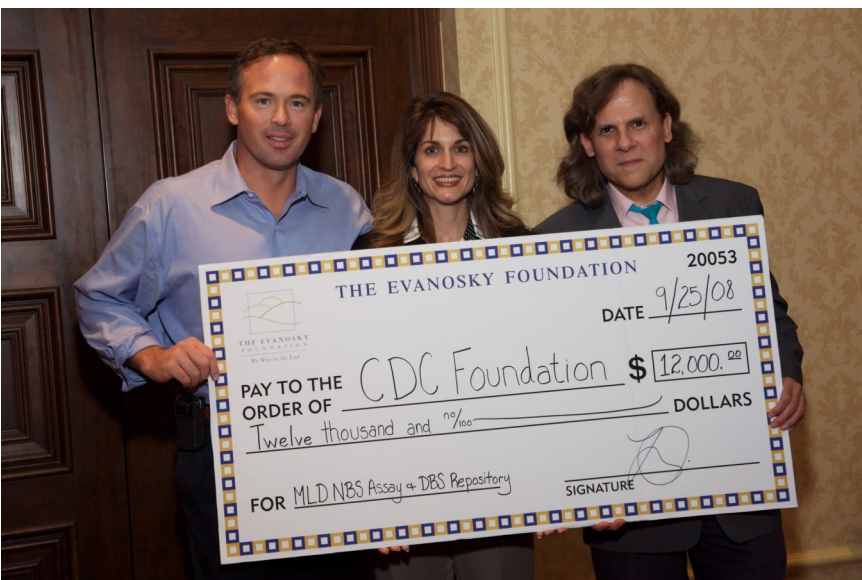
## Treatment and Research Funds

In June 2008, The Evanosky Foundation announced the formation of The John, Christopher, and Jack Evanosky MLD Treatment Fund at the University of North Carolina - Chapel Hill. The fund will be used solely to provide assistance to families with children diagnosed with metachromatic leukodystrophy who are seeking treatment from Dr. Maria Escobar, who provides pre- and post-transplant developmental evaluations at the University of North Carolina Center for Development and Learning. The fund, currently valued at \$10,000, will be a “last resort” source of funding when all other forms of financial support have been exhausted or denied. The money may be used for travel and lodging expenses, medical evaluations and testing, parking fees, or other items that will help MLD families receive care and treatment from Dr. Escobar. The establishment of this fund supports The Evanosky Foundation’s mission of assisting and caring for children and families affected by MLD.



*Bob Evanosky (right) presents Dr. Maria Escobar a check in establishment of The John, Christopher, and Jack Evanosky MLD Treatment Fund.*

In late September 2008, The Evanosky Foundation revealed a collaborative relationship with the CDC (Centers for Disease Control and Prevention) Foundation’s Newborn Screening Translational Research Initiative (NSTRI). As a result of this relationship, The Evanosky Foundation created a fund with the CDC Foundation to accomplish two very important objectives:



*Bob Evanosky (left) and Sonya Evanosky present Dr. Robert Voght of the CDC Foundation with a check to establish the Newborn Screen Assay and Dried Blood Spot Repository Fund*

1. It will create a dried blood spot (DBS) card repository, which will collect blood samples from people who are carriers or have been affected by MLD or other lysosomal storage disorders. In doing so, researchers throughout the world can use this information to help identify the criteria for “normal” and “abnormal” test results.
2. It will focus on developing and implementing tests to screen all newborn babies for MLD and other lysosomal storage disorders (LSDs) in a public health environment. In the future, this will give each state the ability to test every baby for these diseases at birth.

The initial focus of this collaborative relationship will include not only the CDC, but transplant programs from various hospitals and universities throughout the United States.

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## House of Hope

The Evanosky Foundation's first apartment for families receiving medical treatment in the Durham, North Carolina area opened on September 17, 2008. The professionally decorated luxury apartment is designed to be a home away from home for families while their children are receiving stem cell transplants at Duke Children's Hospital.

The House of Hope features conveniences such as a high-efficiency washer and dryer, laptop computer with wireless high-speed Internet access, flatscreen televisions, DVD players, and a video gaming system.

In mid-September 2008, The Evanosky Foundation welcomed a family whose child had MLD and was recovering from a stem cell transplant received at Duke Children's Hospital. When that family "graduated" and headed home in November, the apartment underwent major renovations, including the installation of wood floors, ceiling fans, customized window treatments, and specially upholstered furniture provided by Flexsteel Industries. All of these amenities are critical for children who have compromised immune systems and require a clean, allergen-free environment. Unlike most apartments, the House of Hope is professionally decorated, with all walls featuring warm paint colors, crown moulding, and decorator art and accessories (provided by Uttermost).



*The child's bedroom in the House of Hope features gender neutral colors and fabrics and flooring that are durable and easy to clean.*

Not only is the House of Hope fully furnished, but all household items such as sheets, towels, and a fully-equipped kitchen are included. Many household items for the House of Hope were donated by supporters of The Evanosky Foundation from registries at retailers Bed Bath & Beyond, Target, and Amazon.com.



*MLD patient Tyler McAdams, of New Mexico, and his family Julie, Robert, and Robert Allen with Bob Evanosky in the House of Hope - December 2008.*

Julie Allen and her family moved into the renovated House of Hope in December 2008 with her grandson, Tyler. Tyler has MLD and lives in New Mexico, and Duke provided the best options for Tyler's treatment. "We arrived at House of Hope on December 5th. What an incredible apartment. First, it was just wonderful not having to be in the hospital any longer. The completely furnished apartment was so inviting. There are so many amenities (we don't even have some of this stuff at home). Tyler liked using the Xbox, watching his dad play Guitar Hero, and having the wireless computer available made communication easier. It is our goal to continue to support The Evanosky Foundation for all the support and kindness we received in Durham."

The Evanosky Foundation plans to open two additional Houses of Hope in 2009.

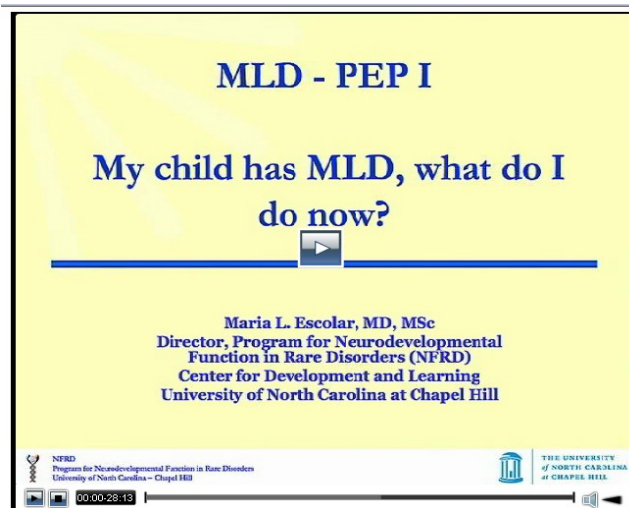
## Other Accomplishments

### MLD Parent Education Program (MLD PEP)

In November 2008, The Evanosky Foundation debuted its new MLD Parent Education Program (PEP), designed to inform parents and healthcare providers about MLD. The Foundation teamed with Dr. Maria Escolar of the University of North Carolina - Chapel Hill's Program for Neurodevelopmental Function in Rare Disorders (NFRD) to produce a web-based video in which Dr. Escolar, a well-known researcher and clinician, discusses MLD, its symptoms, treatments, and current research. The 28-minute professionally produced episode is posted online and is available at The Evanosky Foundation's website ([www.evanoskyfoundation.org/25101.html](http://www.evanoskyfoundation.org/25101.html)) as well as the NFRD website ([www.nfrd.cdl.unc.edu/mld-pep/session-1](http://www.nfrd.cdl.unc.edu/mld-pep/session-1)).

Dr. Maria Escolar is one of the foremost experts in the world on MLD and its progression and treatment. As the disease is rare, many parents and healthcare practitioners are unfamiliar with the disease, and this video provides accurate, fact-based information that is accessible to anyone with a computer and an internet connection.

The Evanosky Foundation plans to continue to expand this program to include more educational videos in the future.



## Fundraisers

### Chicago Distance Classic Half Marathon and Bank of America Chicago Marathon



*Will Wong (back left), Jack and Bob Evanosky, and Beth Wong (back right) along with Christopher (front left) and John Evanosky the day before the 2008 Bank of America Chicago Marathon in October 2008. Will and Bob both ran the marathon on behalf of Team Evanosky and crossed the finish line together!*

In 2008, The Evanosky Foundation added another running event, The Chicago Distance Classic Half Marathon, as part of its annual fundraising activities. The half marathon attracted more runners—including Sonya Evanosky and her mother, Linda Johansen, who both completed their first half marathon!

For the third consecutive year, The Evanosky Foundation was also an official associated charity of the Bank of America Chicago Marathon which took place in October.

A total of thirteen runners participated in these events and collectively they raised over \$35,000 for The Evanosky Foundation!



*Sonya Evanosky (left) and Linda Johansen after completion of the 2008 Chicago Distance Classic in August 2008.*

# Financials

The Evanosky Foundation is recognized as a 501(c)(3) organization by the Internal Revenue Service and all donations are tax-deductible. In 2008, the Foundation received \$77,292 from individuals and businesses.

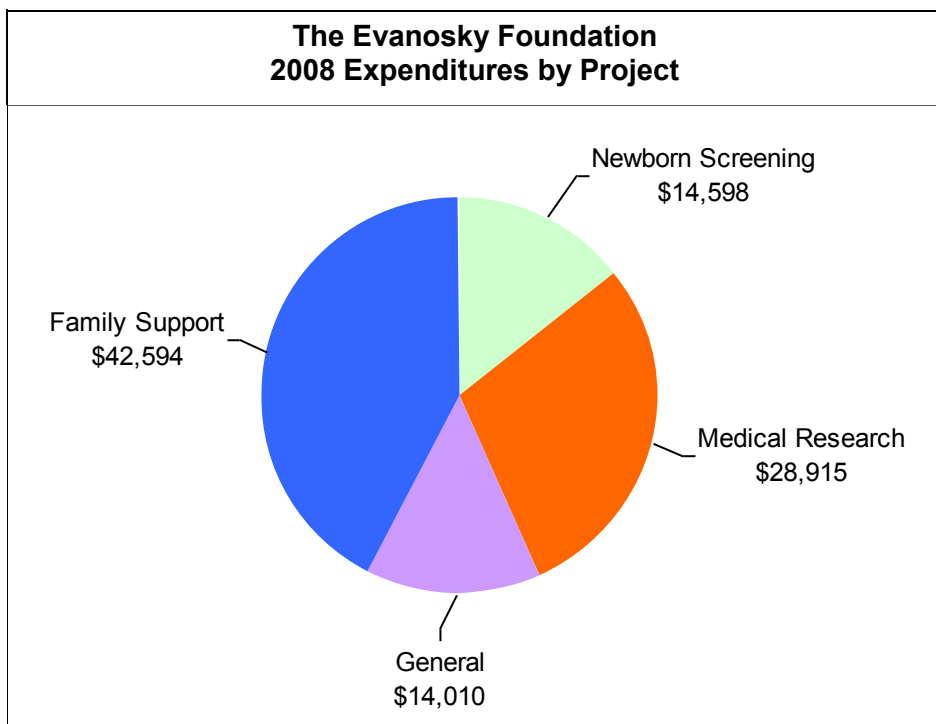
Expenses totaled \$100,117 and were primarily used to fund three major projects in the areas of Newborn Screening, Medical Research and Family Support.

Family Support, which includes Jack's Library and the House of Hope program, commanded the largest allocation of funds in 2008. In this area, The Evanosky Foundation established the John, Christopher and Jack Evanosky MLD Treatment Fund at the University of North Carolina (see page 2 for more details). Additionally, The Evanosky Foundation partnered with Dr. Maria Escolar to create the first MLD Parent Education Program (PEP) entitled "My Child Has MLD, What Do I Do Now?" which is available as a free, authoritative online resource for both doctors and families (see page 4 for more details). The Evanosky Foundation also contributed \$2,500 to the purchase of new washer and dryer units on the Duke University Children's Hospital transplant ward ("5200"). Finally, over \$15,000 was spent for rent and living expenses associated with the House of Hope program (see page 3 for more details).

From a medical research perspective, \$25,000 was donated to the Duke Pediatric Bone & Marrow Transplant Program to further studies in MLD treatment and nerve repair. Remaining funds were spent to complete the initial development of an online, international MLD registry through the University of North Carolina.

For Newborn Screening, The Evanosky Foundation worked closely with the Centers for Disease Control (CDC) Foundation and donated \$12,000 to establish the Newborn Screening Assay and Dried Blood Spot Repository fund (see page 2 for more details).

General and fundraising expenses accounted for \$14,010, which was covered by donations from the Evanosky family.



## 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.

## How Can I Donate?

1. You can donate online by going to The Evanosky Foundation's website at [www.evanoskyfoundation.org](http://www.evanoskyfoundation.org) and clicking on "Make a Donation" on the left hand side
2. If you prefer to send a check, you may send it to The Evanosky Foundation at P.O. Box 9234, Naperville, Illinois 60567

# 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.*

## **\$5,000+**

Anonymous  
Bob & Sonya Evanosky  
HSBC Matching Gifts

## **\$2,500 - \$4,999**

Sui Ming Chow  
Wood Dale Bowl

## **\$1,000 - \$2,499**

Simon Boag & Yasmin Keshavjee  
Deutsche Bank Americas Foundation  
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Larry & Kim Vice  
Mike & Denise Woodward

## **\$500 - \$999**

Vincent Kam Ki Chan  
Mike & Heather Davison  
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Gary & Mollie Niederpruem  
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Sarah Voss  
Dennis Ward  
Glenn & Renee Westra  
Miriam Wong Tsao

**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](http://www.evanoskyfoundation.org).

Many employers -- like IBM and  
Sacramento County, California --  
allow donations to The Evanosky  
Foundation through payroll de-  
duction. Check with your em-  
ployer to see if this option is  
available for you!

# 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.



## Mission Statement

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

## 2008 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

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**E-mail:** [evanoskyfoundation@evanoskyfoundation.org](mailto:evanoskyfoundation@evanoskyfoundation.org)