



THE EVANOSKY  
FOUNDATION

*We Win in the End*

THE EVANOSKY FOUNDATION

# 2006 Annual Report

## *A Message From Bob Evanosky*

Dear Friends,

Sonya and I understand that life comes to us as we find it, but at the same time we recognize that we are commanded to help our fellow man and specifically children. It is our intent, through the Evanosky Foundation, to make this place a little better than we found it.

The year 2006 saw The Evanosky Foundation accomplish great things in its fight against leukodystrophies. We are committed to do what it takes to eradicate these destructive diseases and help the affected children and families that care for them. I am in constant amazement at the strength of these beautiful children warriors. As a result, I would like to dedicate The Evanosky Foundation's accomplishments during the year of 2006 to these children. We use the tenacity and toughness these children display on a daily basis as a standard by which we operate this business known as The Evanosky Foundation. May God bless these children and may God bless you, our friends and supporters.

"We wait in hope for the Lord, he is our help and our shield. In him our hearts rejoice, for we trust in his holy name. May your unfailing love rest upon us, O Lord, even as we put our hope in you." (Psalm 33:20-22)

We Win In The End,

Bob

## *Accomplishments*

### **What Did We Do?**

The Evanosky Foundation was founded by several friends of the Evanosky family in 2005. In 2006, The Evanosky Foundation developed a clear vision of attacking metachromatic leukodystrophy (MLD) on several fronts. If not treated immediately, MLD is fatal, so it is very important that this disease be detected as soon as possible, before symptoms appear. However, many families find out too late that their loved one is affected by this disease. With this in mind, in 2006 The Evanosky Foundation created five projects to find a cure for MLD, detect it at birth and help families and children affected by the disease:

- 1. Medical Research**
- 2. Newborn Screening**
- 3. Duke Laptop Project**
- 4. Jack's Library**
- 5. Family Support**

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

# Accomplishments

## Medical Research

The Evanosky Foundation spent \$67,500, or 81% of its cash contributions, on medical research. Two key initiatives were funded as a part of the Foundation's "Race Against Time" efforts.

For the first project, The Evanosky Foundation coordinated with several other foundations and families to provide funding to complete Dr. Joanne Kurtzberg's oligodendrocyte research at Duke University. Dr. Kurtzberg's project involved harvesting, isolating and growing a particular type of cell known as an oligodendrocyte from umbilical cord blood. The unique thing about this type of cell is that it has the potential to stop MLD once it is infused into the body. There is also the possibility that it can repair prior damage! Human safety trials that utilize these cells are expected to begin in 2007 or 2008. If these trials are completed successfully, it is anticipated that the study will be expanded to include additional children who are not eligible for transplant, such as John and Christopher Evanosky!



*Bob Evanosky with Dr. Joanne Kurtzberg of Duke University*



*Bob Evanosky with Dr. Maria Escolar of UNC Chapel Hill*

The second project focused on developing the initial architecture for an International MLD Registry, headed by Dr. Maria Escolar at the University of North Carolina at Chapel Hill. Dr. Escolar has collected the largest amount of data in the world on children who have been affected by MLD. The registry will collect information on the natural course of MLD if it is untreated, and this data will be used to measure the effectiveness of treatments such as bone marrow or stem cell transplants, cell replacement therapy or enzyme replacement therapy. The registry will be international and open to medical professionals to use for research. The more data researchers have, the easier it is for them to identify new and effective treatments for MLD. The Evanosky Foundation hopes to use this data to publish a paper in medical journals on the effectiveness of MLD treatment by July 2009.

## Newborn Screening

The Evanosky Foundation launched its Newborn Screening (NBS) effort in 2006, and spent \$1,753 on this initiative. Armed with the knowledge that the only way to truly stop the vicious cycle of MLD was to detect it at birth and treat the disease immediately, Bob Evanosky began reading medical journals, searching the Internet, and talking to doctors about newborn screening for MLD. This led Bob to Dr. Michael Gelb, a researcher at the University of Washington in Seattle. Dr. Gelb's team recently developed a newborn screen test, or assay, that can test for five fatal diseases which are known as lysosomal storage disorders (LSDs). MLD is also an LSD, and Dr. Gelb is working to develop a test for MLD as well.



*John Evanosky , November 2001*

Knowing that a newborn screening test for MLD would be available soon, Bob teamed up with Dr. Barbara Burton, a renowned genetics doctor at Children's Memorial Hospital in Chicago and professor at Northwestern University Medical School. With her guidance, he attended two federal newborn screening com-

mittee meetings and spent countless hours determining how the State of Illinois could implement Dr. Gelb's LSD tests, which will eventually include the test for MLD. Dr. Burton and The Evanosky Foundation partnered with Senator Dale Righter of Illinois, and legislation to screen for LSDs was introduced into the Illinois Senate as SB1566 in February 2007.

## Duke Laptop Project

In January 2006, The Evanosky Foundation forged a partnership with Hewlett-Packard (HP) Corporation and purchased 16 laptop computers at a reduced cost that were provided to each of the 16 in-patient rooms on the transplant unit, known as "5200", of Duke Children's Hospital. The Evanosky Foundation also donated three gently used laptops and HP donated a color laser printer. Additionally, The Foundation negotiated an agreement with the Hospital to provide information technology support for these laptops—a service valued at more than \$10,000 per year!

This initiative was critical, since children are not allowed to leave the 5200 unit and parents must be very close for at least 20 and possibly 50 or more days. A computer can provide a vital link to the outside world for these families and children, and let them communicate and receive messages of support from family and friends. The Family Support team has reported that the laptops are being heavily used on the unit and during Bob and Sonya's visit to 5200 in May 2006, the nurses stated that the laptops "are constantly in use, especially by the teenagers." One father told Bob, "My son uses the laptop during the day and then when he gets tired, I use it to update our CaringBridge site and do our finances." This is exactly what The Evanosky Foundation set out to achieve, and we are excited that the laptops are a positive addition to these families' lives.



From left: Jane Schroeder (Duke PBMT), Jana Campbell (HP), Bob Evanosky (The Evanosky Foundation), Mark Coen (Carotek), Dr. Suhag Parikh (Duke Children's Hospital), Barb Hoskins (The Evanosky Foundation)

## Jack's Library

Jack's Library provides books, movies, and magazines to patients in children's hospitals. In April 2006, The Evanosky Foundation donated over \$1,500 in Usborne Books to the Duke University Children's Hospital. Because of infection control requirements, books cannot be shared between patients, so the books were given to individual patients. Amber, a child life specialist, was very pleased to receive the donation. "We often do not get book donations, or when we do, we cannot use them because the books are not new or the source is unknown," Amber said. "These books will be very welcome on the unit."



Durham Public Schools Duke Children's Hospital Teachers, September 2006

The Jack's Library program also partners with teachers who are educating children going through the transplant process. This dedicated group of teachers works with children to make sure that they do not fall behind in their academic studies. In 2006, The Evanosky Foundation purchased 15 instructional media DVDs, 4 electronic dictionaries, and 5 licenses to edHelper.com to benefit the Duke University Children's Hospital—a value of over \$1,000.

## More Accomplishments

### Family Support

A portion of The Evanosky Foundation's mission statement is to provide support to families affected by a leukodystrophy or other disabling conditions. This is important because families are often under significant financial and time pressures because of their child's disability. Transplant costs are estimated at \$600,000, and parents are often required to move or quit their jobs. Additionally, equipment that can improve the quality of a child's life is often cost prohibitive and in many cases not covered by insurance.



Children and staff at the CoACH House enjoying the Love Sac

In order to address this need, in 2006, The Evanosky Foundation donated funds to families going through transplant and provided Love Sacs to the CoACH House as well as an individual family. As the CoACH House staff stated, Love Sacs are great for children with a leukodystrophy because it allows the child to be comfortable and cuddle with someone else!

In addition, The Evanosky Foundation donated over \$36,560 in adaptive equipment, which it received from Edward Hospital, to Marianjoy Rehabilitation Hospital and the CoACH Care Center.

## Fundraisers

### Silent Auction

In August 2006, The Evanosky Foundation had its first dinner and Silent Auction. The event was attended by over 100 people and raised over \$31,900 in net revenue! The event was very successful and made a significant contribution to the Race Against Time medical research initiatives!



Bob Evanosky



Whiplash playing at the Silent Auction

### LaSalle Bank Chicago Marathon

The Evanosky Foundation was an associated charity of the 2006 LaSalle Bank Chicago Marathon. Fifteen people ran for Team Evanosky and raised over \$20,200. It was the first marathon for Bob Evanosky and his sister, Kim Vice, and they both successfully finished despite bone-chilling temperatures. In 2007, The Evanosky Foundation is once again an associated charity of the LaSalle Bank Chicago Marathon, and plans to have another strong team of runners.



Kim Vice and Bob Evanosky after completing the 2006 LaSalle Bank Chicago Marathon

# Financials

## The Evanosky Foundation 2006 Income Statement

amounts in dollars

<b>Income</b>	
<b>Contributed support</b>	
Individual/business contribution	58,754
Donated professional services - GAAP	672
Gifts in kind - goods	42,370
<b>Total Contributed support</b>	<b>101,797</b>
Interest & Merchandise Sales	-311
Special events	31,734
<b>Total Income</b>	<b>133,219</b>
<b>Expense</b>	
<b>Grants &amp; Donations</b>	
Grants to other organizations	115,068
Awards & grants - individuals	852
<b>Total Grant expense</b>	<b>115,920</b>
<b>Other expenses</b>	
Credit Card fees	650
Supplies	439
Postage, shipping, printing	650
Outside computer services	409
Travel and meetings	2,381
<b>Total Other expenses</b>	<b>4,529</b>
<b>Total Expense</b>	<b>120,448</b>
<b>Net Income</b>	<b>12,771</b>

The Evanosky Foundation is recognized as a 501(c)(3) organization by the Internal Revenue Service and all donations are tax-deductible. In 2006, the Foundation received \$90,656 in individual cash contributions and special events. In addition, it received over \$43,000 in donated goods and services.

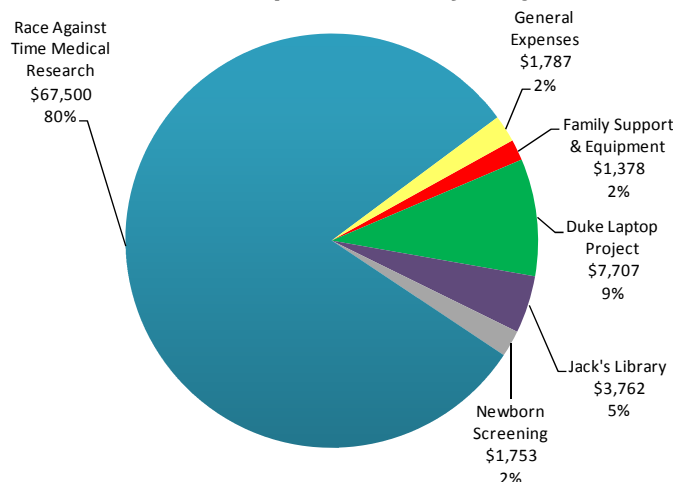
All of these contributions were used to fund the core five projects, which included Race Against Time Medical Research, Newborn Screening, the Duke Laptop Project, Jack's Library and Family Support. In addition, over \$36,560 in adaptive equipment, which The Evanosky Foundation received from Edward Hospital, was donated to Marianjoy Rehabilitation Hospital and the CoACH Care Center.

Overall, only 2% of the costs, or \$1,787, was used for general expenses such as postage and supplies, and this amount was covered by donations from Bob and Sonya Evanosky.

The Foundation believes that overhead costs should be minimized and as a result, does not have any paid staff. In addition, The Evanosky Foundation has found that it is effective to bring together non-profit organizations and companies to work together on a common goal, such as forming a coalition to fund Dr. Kurtzberg's oligodendrocyte research. This allows projects to get done quickly and at a lower cost to the Foundation.

Each year, the IRS requires the Foundation to file a tax return, known as Form 990. You may view the Foundation's 990 returns, along with returns from other nonprofit organizations, at <http://www.guidestar.org>.

## The Evanosky Foundation 2006 Cash Expenditures by Project



# Donors

*The Evanosky Foundation's success is made possible by the generous contributions of its donors. Thank you!*

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

Anonymous  
Bob & Sonya Evanosky  
HSBC Matching Gifts

## **\$2,500—\$4,999**

Ramesh Kumar & Poornima  
Nayakanti  
Tim Molek Memorial Fund  
Mike & Denise Woodward

## **\$1,000—\$2,499**

Christine & Joe Censullo  
Stephen & Bridget Folan  
Rich & Lisa Giemzik  
Melinda & Lawrence Lerner  
Stacey & Chris Metzger  
Steve & Pam Reed  
Ernesto & Denise Scollo  
Kim & Larry Vice  
Tom & Mary Whitney  
Ryan & Julie Willhauck  
Vlado Zeravica

## **\$500—\$999**

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Shawn Bolger  
Mike & Tammy DuVall  
Bob & Nancy Evanosky  
Amy & David Graffia  
Heather Horton  
LexisNexis Cares  
Jack & Marilyn Marino  
Holly & Dave Rodgers  
Paul & Johanna Sedillo  
Julie Woods

## **\$250—\$499**

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Lori & John Ebert

Menno & Keri Ellis  
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**\$50—\$99**

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Elizabeth Bateman  
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Paula Chlebowski  
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Mike Weigel  
Matt & Chris Winkle  
Stephanie Wise  
Meredith & Dave Worniak  
Beth Young

**In-Kind Donors**

*(excludes Silent Auction donations)*

Phillip & Wendy Armstrong  
Brandon & Megan Bateman  
David Benjamin  
Janice Burns  
Lorrie & Mercedes Domin  
Rachel & Arthur Dykxhoorn  
Edward Hospital  
Bob & Nancy Evanosky  
Bob & Sonya Evanosky  
Girl Scout Troop 1409  
Kandi & Ryan Horton  
Lionel & Carol Lenz  
Corbin & Debbie Lirot  
Stacey & Chris Metzger  
Mollie & Gary Niederpruem  
Richard Payne  
Prager Moving & Storage  
Michael & Dana Smith

# 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 fourteen 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 developmental abilities, the family learned that MLD was the proper diagnosis.

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.

While researching the disease, the Evanoskys learned that cord blood stem cell transplants were being used to treat a variety of illnesses, including MLD, at Duke University Medical Center in Dur-

ham, North Carolina. After an evaluation by the doctors at Duke, Jack was deemed eligible for a transplant. Because Christopher and John's symptoms had progressed too far, they were deemed ineligible. Jack received his stem cell transplant on April 1, 2005, making him the second youngest child with MLD to undergo this treatment.

During this time, friends approached the Evanoskys with a proposal to form a foundation that would fund MLD research and develop programs to enhance the overall quality of life for families affected by MLD or other leukodystrophies. Thus, The Evanosky Foundation was formally established in June 2005.

The Evanosky Family does not receive any direct benefits from The Evanosky Foundation.

## Mission Statement

The Evanosky Foundation exists for the purpose of generating funds to support two main objectives. It will support pediatric leukodystrophy research as well as assist and care for children and families affected by one of the leukodystrophies and/or other disabling conditions.

## Core Values

- We believe in each child's right to live his life to the fullest and achieve his full potential.
- We are compelled by our faith to help our fellow man during times of extreme need.
- We vow to be faithful stewards of all monies raised, and promise to respect individual donors' requests pertaining to use of their funds.
- We commit to being partners in everything we do.
- We promise to be responsive to needs and requests, and to see each of our efforts through to fruition.
- We will be proactive, seeking out those who need help.
- We pledge our lifelong commitment to this endeavor.

## 2006-2007 Board Members

- Francis "Bob" Evanosky\*
- Sonya Evanosky\*
- Michael DuVall\*
- Amy McKenzie\*
- Karen Fedyszyn\*
- Grant Gu
- Barb Hoskins

*\*current board member*



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

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

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