THE EVANOSKY
FOUNDATION

We Win in the End

THE EVANOSKY FOUNDATION

2007 Annual Report

A Message From Bob Evanosky

Dear Friends,
The great NBA basketball player Michael Jordan once said, “Obstacles don't have to stop you. If you run into a wall, don't turn around and give up. Figure out how to climb it, go through it, or work around it.” Here at The Evanosky Foundation, we look upon our responsibility to combat MLD and other lysosomal storage disorders in the same way.

The year 2007 afforded us the ability to punch through that wall with a number of opportunities, most importantly in the creation of Illinois Senate Bill 1566. After almost a year of hard work, a coalition of agencies, led by The Evanosky Foundation, worked with the Illinois legislature and the Governor to transform IL SB1566 into a state law requiring that the State screen all babies for five lysosomal storage disorders which are fatal if left untreated. This was a historic first within our country.

The year 2007 also allowed for The Evanosky Foundation to lay the groundwork for new research related to brain or nervous system repair for children who suffer from neurological damage. In addition, we also continued to support the oligodendrocyte research, which is focused on curing MLD, that we funded in 2006. My personal hope is that in 2008 we will have human trials using stem cell therapies that will benefit both children and adults suffering from metachromatic leukodystrophy along with other leukodystrophies.

I look back to 2007 as a year of accomplishment, as a year that puts us one step closer to protecting our future children from numerous terminal illnesses and at the same time rescuing children like my three sons from the damage that has wreaked havoc on their physical bodies.

I want to thank all of you who have had a hand in making 2007 the year it was; I am proud to be a part of the team of supporters that make up this organization.

We Win In The End,
Bob

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 2007:

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

Dr. Maria Escolar with John (left), Jack (front) and Christopher Evanosky

The year 2007 was a year in which considerable effort was invested in developing projects that The Evanosky Foundation will be involved in for the next several years.

The Evanosky Foundation continued to sponsor preclinical work at Duke University in developing cellular therapies that will treat children with leukodystrophies. We expect to see the beginning of Phase I clinical trials that will administer cells intrathecally (into the spinal fluid) for children with advanced leukodystrophies. Individuals or organizations who are interested in funding this or other research should contact Bob Evanosky at The Evanosky Foundation at evanoskyfoundation@evanoskyfoundation.org.

Beginning in 2006 and continuing throughout 2007, The Evanosky Foundation worked with The Trimper Children's Fund, Athena's Hope Foundation, The Stennis Foundation and key individuals to provide the funding needed to complete Dr. Joanne Kurtzberg's oligodendrocyte research at Duke University. Dr. Kurtzberg's project involves harvesting, isolating and growing a particular type of cell that mimics an oligodendrocyte from umbilical cord blood. The unique thing about an oligodendrocyte is that it has the potential to stop the degenerative effects of MLD once it is administered into the body. There is also the possibility that it can repair prior nerve damage. Human safety trials that utilize these cells are expected to begin soon.

The final project, which was funded in late 2006 and largely completed in 2007, focused on developing the initial architecture for an MLD Physician & Family Registry. This project was headed by Dr. Maria Escolar at the University of North Carolina at Chapel Hill. Dr. Escolar is a world renowned MLD doctor and holds a vast collection of data pertaining to children who suffer from MLD. One of the many purposes of this registry will be to collect information on the natural course of MLD if it is untreated, which 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 a global, web-based registry open to medical professionals 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 that this data will be used to publish a paper in medical journals on the effectiveness of early MLD treatment by July 2009.

Family Support

Christopher Luna, August 2007

We at The Evanosky Foundation recognize that we must possess the compassion and caring needed to care for individual families affected by leukodystrophies, not only in the United States but abroad as well. In 2007, we came in contact with a little boy named Christopher "Junior" Luna who lives in the Dominican Republic. Junior has a leukodystrophy, and we worked with two missionaries who befriended Junior's family to make sure that Junior receives proper treatment. We have provided medical supplies, a wheelchair, clothing and books. We have also paid for Junior's medical care when necessary, since hospitals in the Dominican Republic will discharge a patient regardless of his condition if he does not have the ability to pay. This is what The Evanosky Foundation is all about—making a difference so that other families do not have to experience the same pain and challenges that we have faced. To read more about Junior's story, please go to www.caringbridge.org/visit/cristopherluna and click on "Read Story" in the "My Story" section.

In addition, in 2007, The Evanosky Foundation worked with the Boy Scouts of America to manufacture physical therapy equipment for children. Boy Scouts who want to attain the rank of Eagle Scout must participate in an Eagle Scout project that has a significant benefit and/or impact on the community, so Troop 81 Eagle Scout candidates teamed up with The Evanosky Foundation to manufacture various pieces of physical therapy equipment with a total retail value of nearly $30,000. The Evanosky Foundation will provide this equipment to families whose children need this equipment. Since physical therapy devices are often very expensive, this equipment will be appreciated! The Evanosky Foundation has underwritten the cost of most of the raw materials necessary for this work.

Boy Scouts from Troop 81 delivering equipment made to benefit disabled children

Newborn Screening

Beginning in 2006 and throughout 2007, The Evanosky Foundation worked to expand newborn screening to include lysosomal storage disorders (LSDs) in Illinois. Lysosomes are contained within human cells and have enzymes that break food down into its basic elements so it can be used by the body. Individuals who do not have one of these enzymes, such as people with MLD, have a lysosomal storage disorder. The Evanosky Foundation partnered with a variety of groups and individuals to file Illinois Senate Bill 1566 on February 9, 2007. The bi-partisan bill, authored by Senator Dale Righter (R), provided for screening of all Illinois babies for five LSDs, which included Pompe, Krabbe, Gaucher, Niemann-Pick, and Fabry diseases. Like MLD, treatment for these diseases is only effective if started before symptoms appear, so newborn screening is essential to early treatment. After numerous discussions, e-mails, and trips to Springfield, Governor Rod Blagojevich signed SB1566 into law on November 5, 2007, making Illinois the first state in the country to screen for these five LSDs. This date was of particular significance to Bob and Sonya Evanosky since it was John and Christopher Evanosky's sixth birthday. It is The Evanosky Foundation's hope that other states will follow Illinois' example so that all children in the United States can be screened for these diseases.

Following on the successful passage of Illinois Senate Bill 1566, The Evanosky Foundation will continue to advocate for newborn screening for MLD, as well as other lysosomal storage disorders, here in the United States. Researchers are currently developing a newborn screen test, or assay, for MLD that can leverage the existing LSD tests. In late 2007, The Evanosky Foundation began to formulate a plan to create a depository to house dried blood spot cards, also known as "DBSs", of individuals affected by MLD. How this works is that at birth, a baby's heel is pricked and its blood is blotted onto a dried blood spot card. That card is then submitted to the State public health lab and various tests are done to determine if the baby is affected by a disease. If researchers want to develop a test to screen for a disease, they must have existing dried blood spot cards from individuals who are already affected by the disease in order to make sure that the screening process is correct and effective. Knowing that newborn screening for MLD is in the near future, The Evanosky Foundation is in the process of developing partnerships with various universities as well as certain select government agencies to develop a process to collect dried blood spot cards from individuals who have MLD. We anticipate being able to actually collect samples in the fall/winter of 2008. By doing this, researchers who are working on a newborn screening assay for MLD will be able to immediately determine the accuracy of their test. We promise that once a valid newborn screening test is available for MLD, that we will work with both federal and state public health authorities to screen for MLD in all states.

In addition, in 2007 we developed a working relationship with the Centers for Disease Control (CDC) Newborn Screening Quality Assurance Program (NSQAP) and are assisting them with their newborn screening program for lysosomal storage disorders (LSDs). At present, the NSQAP supports 73 domestic laboratories as well as an additional 53 international newborn screening laboratories. NSQAP assists newborn screening laboratories in maintaining and enhancing the quality of their tests. By identifying children affected by an LSD at birth, The Evanosky Foundation knows that a family will have more treatment options available, like cord blood stem cell transplants and/or enzyme replacement therapy. As the newborn screening test for MLD becomes a reality, we will assist the NSQAP program to assure proper quality standards are developed.

Other Accomplishments

Jack's Library

Jack's Library provides books, movies, magazines, computers and audio/visual equipment to patients in children's hospitals. In September 2007, The Evanosky Foundation once again teamed up with Kandi Horton and Usborne Books to conduct a book drive to benefit Jack's Library, which raised over $1,800. On December 12, 2007, Bob and Jack Evanosky presented the Children's Memorial Hospital transplant team with over $700 in Usborne Books along with four DVD/VCR combination units and mounting brackets. The books were distributed to children undergoing stem cell transplants while the DVD/VCR units were installed in the stem cell transplant unit's day clinic so children can watch movies during their multi-hour transfusions. Additional donations to Duke Children's Hospital were made in May 2008.


Jack and Bob Evanosky, December 2007

Along with the book drive donations, other books and movies were donated to Duke Children's and Children's Memorial Hospital throughout the year. You can make a donation to Jack's Library at www.evanoskyfoundation.org, send in a check, or purchase an item online at the Jack's Library wish list on Amazon.com!

Fundraisers

Texas Hold 'Em Poker Tournament

On Friday, March 9, 2007, the Friends of The Evanosky Foundation hosted a Texas Hold 'Em Poker Tournament at the Oakhurst Clubhouse in Aurora, Illinois. The tournament and silent auction raised $8,700 for The Evanosky Foundation! The winner, Kevin Kochman, walked away with a 27" flat screen HDTV. We appreciate everyone who organized and participated in this event!

LaSalle Bank Chicago Marathon

Once again, The Evanosky Foundation was an associated charity of the 2007 LaSalle Bank Chicago Marathon. Over 20 people ran for Team Evanosky and raised more than $38,000—nearly double the amount from 2006! Chicago experienced record-breaking heat on marathon day, and the team persevered until the race was cut short early. In 2008, The Evanosky Foundation is an associated charity of the Bank of America Chicago Marathon and a participating charity in the Chicago Distance Classic Half Marathon.


Holly Rodgers and Bob Evanosky running for Team Evanosky at the 2007 LaSalle Bank Chicago Marathon!

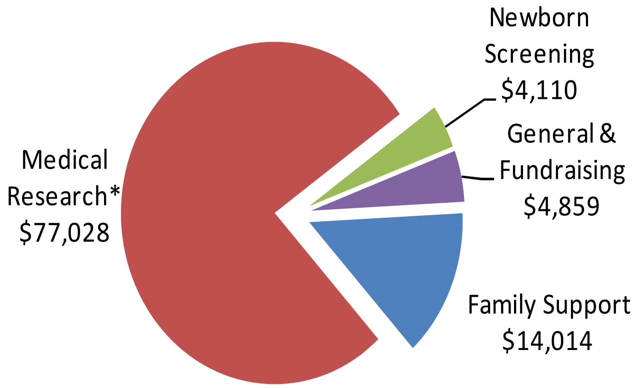
Financials

The Evanosky Foundation is recognized as a 501(c)(3) organization by the Internal Revenue Service and all donations are tax-deductible. In 2007, the Foundation received $82,893 from individuals and businesses.

Expenses totaled $25,011 and were primarily used to fund four projects, which included Newborn Screening, Medical Research, Family Support, and Jack's Library.

Due to collaborative efforts with other non-profit organizations and companies, The Evanosky Foundation was able to minimize costs associated with the passage of Illinois Senate Bill 1566, which provided for enhanced newborn screening for five fatal diseases. This bill made Illinois the first state in the US to test for these diseases, and is serving as a model for other states.

The Evanosky Foundation
2007 Expenditures by Project



**includes $75,000 of funds committed for 2008 projects*

In 2007, fewer dollars were disseminated for Medical Research because projects that were funded in prior years required no additional funding. However, doctors were brought together to discuss two new research projects that will be moving forward and requiring funds in 2008. Early estimates put the cost of these projects at approximately $3.1 million. The Evanosky Foundation will work with both private and public entities to ensure that this research is financially supported. At present, The Evanosky Foundation has obligated $75,000, most of which was raised in 2007, to these two projects.

During 2007, the Family Support program provided over $14,000 to assist families and children who are battling a leukodystrophy. As part of this, the Jack's Library program gave movies and books to Children's Memorial Hospital in Chicago, with the remainder targeted for Duke University Children's Hospital. In addition, The Evanosky Foundation worked with the Boy Scouts of America to build adaptive therapy equipment.

General and fundraising expenses accounted for $4,859, which was covered by donations from Bob and Sonya Evanosky.

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 and clicking on "Make a Donation" on the left hand side
2. If you don't want to donate online, you can send a check 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.

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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 -- like IBM and Sacramento County, California -- allow donations to The Evanosky Foundation through payroll deduction. Check with your employer 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 exists for the purpose of generating funds to support three main objectives. It will support pediatric leukodystrophy research, universal newborn screening, as well as provide assistance to families affected by one of the leukodystrophies, lysosomal storage disorders, or other disabling pediatric conditions.

2007 Board Members

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

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