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Our Mission

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

Come One, Come All to The Evanosky Foundation's First Annual Silent Auction!

This year's Silent Auction will be held in the evening on Friday, August 4 in Naperville, Illinois at the White Eagle Owners Clubhouse. This will be a significant fundraiser in the Foundation's Race Against Time efforts for 2006. The Silent Auction will be an adults-only event with the opportunity to bid on some great items while enjoying great food and beverages.

Tickets for the Silent Auction are \$50 a person and will be limited to 180 tickets. We anticipate a quick sellout so we recommend you purchase your tickets soon! You can purchase your tickets online at The Evanosky Foundation website—go to "How Can I Help" and then click on "Silent Auction". All monies raised from the Silent Auction will go towards the Dr. Joanne Kurtzberg's Pediatric Pediatric Blood and Marrow Transplant Research Fund at Duke University and will support her research in cell replacement therapy for MLD (Metachromatic Leukodystrophy) and Krabbe's Disease (a related leukodystrophy).



If you are interested in helping with the Silent Auction, we need help in the following areas:

- Donate gift cards or gift certificates
- Provide tickets to movies, sporting events, concerts, zoos and attractions
- Contribute purchased or handmade products
- Offer services, such as landscaping, construction, handyman, etc.
- Put together a themed gift basket
- Provide a DJ or master of ceremonies
- Offer assistance with decorations and food
- Contact local businesses about donating items

Anyone interested in helping can contact Barb Hoskins directly at 630.236.8039 or by e-mail at barb@evanoskyfoundation.org. We look forward to having you all there to help The Evanosky Foundation in reaching our goal to find a cure for individuals with MLD. Stay tuned for more about the Silent Auction at www.evanoskyfoundation.org!

Foundation Obtains Official Nonprofit Status From IRS

Recently, The Evanosky Foundation received its nonprofit status from the Internal Revenue Service, allowing all contributions since March 15, 2005 to be tax deductible. In addition, as an official 501(c)(3) nonprofit organization donations can be matched by almost all company matching gift programs!

First Donation of Jack’s Library Books Goes to the Pediatric Transplant Unit at Duke University

“These books will be very welcome on the unit.”

During Jack Evanosky’s one-year post-transplant tests at Duke University in April 2006, Jack and his parents presented the “5200” pediatric stem cell transplant unit at Duke Children’s Hospital with the first book donations to Jack’s Library. Because of infection control requirements, books cannot be shared between patients, so The Evanosky Foundation donated the books to the unit to be given to individual patients. Amber, one of the Child Life Specialists, 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.” One of the children who was present during the book donation spotted a few books she would like as well as her “neighbor” on the unit. In addition to paper books, the Foundation is now also purchasing books on CD. Because the CDs can be wiped free of germs, these audio books will serve as true library books. Finally, the Foundation also purchased a variety of magazine subscriptions for the unit that appeal to all age groups, including parents. Your donations are making a difference!



Amber and Jack — April 5, 2006



If you are interested in helping the Jack’s Library effort, the Foundation has compiled a Wish List on Amazon.com. Simply go to www.evanoskyfoundation.org and click on the Amazon logo on the main page. When the Amazon logo appears, click it again and you will go to Amazon.com—doing this will ensure that the Foundation gets 4% of your purchase price from Amazon! Then click on Your Lists (top right) and in the Wish List section, search for The Evanosky Foundation. You can then choose a product from the list, and purchase it! This allows you to make a direct gift of books and books on CD that have been specifically requested by the 5200 unit.

Foundation Obtains Support for Laptops

The Evanosky Foundation recently reached an agreement with Duke University Children’s Hospital for the Hospital to provide information technology support for the laptops that the Foundation recently donated to the pediatric blood and marrow transplant unit at Duke University. Karen Fedyszyn, a Foundation board member, was instrumental in obtaining the support. Previously, the computers were serviced by volunteers in their free time. Now, families using the computers will receive consistent support from trained IT professionals. This generous contribution from the IT support group has a value of more than \$10,000 per year!



Race Against Time

Did you know that The Evanosky Foundation is an Associated Charity of The 2006 LaSalle Bank Chicago Marathon®? Affiliation with the world's greatest race is significant because it will be a major driver toward the Foundation's lofty goal for this year—supporting human safety trials for cell

replacement therapy at Duke University Children's Hospital. This therapy not only has the potential to stop metachromatic leukodystrophy (MLD), but it may also repair *prior* damage! In other words, it has the potential to save the life of a child who has exhausted all other options. As a result, this fundraising effort has been aptly named **THE RACE AGAINST TIME**.

If you are thinking of running the marathon and would like a support network and a cause to motivate you, consider running with Team Evanosky. Chicago is a great race and **THE RACE AGAINST TIME** is a worthy cause. Registration for the Sunday, October 22nd marathon is handled through the www.chicagomarathon.com website. During the registration process, just select "The Evanosky Foundation" from the "Make my marathon more meaningful" drop-down menu. If you have already registered or are planning to register, please send a courtesy e-mail to Mike Duvall at miked@evanoskyfoundation.org to let him know you want to run on behalf of Team Evanosky. Also, if you know of other runners that might be interested in running with Team Evanosky, please let them know about **THE RACE AGAINST TIME**.



Foundation Teams With Online Merchants

Tax time has come and gone and you may be wishing you would have had a few extra deductions to help increase your refund or decrease your tax bill. The Evanosky Foundation is now associated with iGive.com, an online mall that includes retailers like Barnes & Noble, Gap.com, eBay, The Children's Place, Best Buy, and Kodak EasyShare Gallery. All you have to do is go to iGive.com before you make a purchase from one of their vendors, and a portion of your purchase will be donated to The Evanosky Foundation! Plus, the donation is a tax deduction for you! Go to www.iGive.com/evanosky, to join iGive.com (it's free!), and if you make a purchase from any vendor in the next 45 days, The Evanosky Foundation will receive a \$5 bonus. So shop, save gas money, and get a tax deduction for 2006 at the same time!



The Evanosky Foundation has also joined forces with MissionFish, a division of eBay. eBay sellers can choose the Foundation from a list of over 8,000 nonprofits and donate a percentage of their total auction selling price to the Foundation. When the auction is over, the seller is paid by the buyer and ships the item. MissionFish then collects the donation from the seller, pays the Foundation and provides the seller with a receipt for their tax-deductible donation. It's a great and easy way to contribute! For more information, visit www.missionfish.org.

Finally, the Foundation has also partnered with Amazon.com. Simply click on the Amazon.com icon on the Foundation's home page at www.evanoskyfoundation.org, and 4% of your purchase will be donated to The Evanosky Foundation!

The Evanosky Foundation Partners with Boy Scouts of America to Provide Adaptive Equipment

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 pressure because of their child's disability. Equipment that can improve the quality of a child's life is often cost prohibitive and in many cases not covered by insurance. In order to address this need, The Evanosky Foundation and several Eagle scout candidates from the Boy Scouts of America are working



An adaptive switch allows children who lack motor skills to activate toys by touch.

together to provide adaptive equipment at no charge to the children of families served by the Early Intervention program within the State of Illinois. Adaptive equipment can include items such as walkers, toys that are operated by switches (which are beneficial for children with limited motor skills), and therapy equipment. We are currently in the early stages of this partnership but the Foundation's goal is to design, produce and distribute adaptive equipment with a retail value of \$50,000 to children within the Early Intervention program by the fall of 2006. Please look for updates on the website and in upcoming newsletters!



A rocker board is a simple platform used to improve balance.



THE EVANOSKY
FOUNDATION

We Win in the End

PO Box 9234
Naperville, Illinois 60567
Phone 630.236.8039
E-Mail
evanoskyfoundation@
evanoskyfoundation.org

**Footnotes is a
quarterly publication
of The Evanosky
Foundation**

Edited by Dana Johansen Smith

Jack Evanosky Celebrates One-Year Post Transplant!

On April 1, 2006, Jack Evanosky celebrated his one year post-transplant anniversary! Bob, Sonya and Jack drove down to Duke University for Jack's one-year tests during the second week in April, and test results show that Jack's MLD has not progressed! This is great news!

While at Duke, the Evanoskys also teamed up



Richard and Parker Fritsch, Jack and Bob Evanosky, Nurse Mary Townley, Connor and Melissa Fritsch on the 5200 unit — April 5, 2006

with Parker Fritsch and his family and brought dinner to the families on the 5200 unit. They were able to see many of the nurses who were with Jack during his transplant as well as meet current families on the unit who are going through the transplant process.

Bob and Sonya also were able to see the color laser printer and laptops in action. The nurses stated that the laptop computers are in constant use—in fact, when Bob walked into a room to meet a family, the laptop was being used! Thanks to your support, we are making a difference!