

Who We Are

The Evanosky Foundation was formed in 2005 by Grant Gu, Barb Hoskins, and Elizabeth Lyons--close friends of Bob and Sonya Evanosky--after John, Christopher, and Jack Evanosky were diagnosed with metachromatic leukodystrophy (MLD). The foundation's goal is to generate money to fund research toward curing pediatric leukodystrophies as well as to provide support and care for children and families affected by one of the leukodystrophies and/or other disabling conditions.

Foundation Partners with Hewlett-Packard to Provide Laptops to 5200

After spending nearly two months on Duke University Children's Hospital bone marrow transplant unit ("5200") with their son Jack, Bob and Sonya Evanosky identified a need for laptops for each room. Using a laptop borrowed from a friend allowed them to communicate with friends and family, and provided a vital link to the outside world while Jack was isolated on the unit. Most families on the unit, however, didn't have a computer of their own. The Family Support Center on 5200 had two desk tops for use by patients and their families, but due to demand, the computers were not always available, plus they were located outside of the patient's room.

In an effort to meet this need, a partnership was forged between The Evanosky Foundation and Hewlett-Packard (HP).

The agreement provided laptops at a reduced cost for each of the 16 patient rooms on the pediatric bone marrow transplant ward, plus HP agreed to donate two extra machines. In addition, The



The Evanosky Foundation presents the Duke Family Support Program with a check for funds to purchase 18 laptops. From left to right, Jane Schroeder, Director, PBMT Family Support; Jana Campbell, HP; Bob Evanosky, The Evanosky Foundation; Mark Coen, Carotek; Dr. Suhag Parikh, Duke Children's Hospital (Jack's doctor); Barb Hoskins, The Evanosky Foundation
January 26, 2006

Evanosky Foundation donated one gently used laptop. Mark Coen, a former HP sales representative who is now with Carotek, facilitated the arrangement. The business laptops include a DVD/CD-RW combo drive along with wireless Internet capabilities. In addition, an HP color laser printer will be available for use by the patient families. The computers will be used by patients to watch movies, instant message friends back home, and surf child-friendly Internet sites. Parents and other

caregivers can also use the laptops to maintain contact with friends and family, update CaringBridge web pages, and manage finances while they are away from home. The equipment will be delivered to 5200 in mid-January.

While at Duke, Barb Hoskins, a director of The Evanosky Foundation and K-9 educator, also met with local educators who work with student patients isolated on 5200. "It is our hope that we, The Evanosky Foundation and the Home Hospital Educators, will form a 'partnership' working together to best utilize these laptops to enhance and enrich the learning process for the children of 5200. Whether it be searching for the most age-appropriate software, locating web-based learning programs, providing support for touchscreen technology, or supplying a fund for consumable items - most everything that needs to be touched by students - we want to help the Duke Hospital School Educators take these kids to an outstanding world of learning," Hoskins said. At this time, the hospital educators are creating a prioritized wish list of software and educational items that The Evanosky Foundation could donate and/or fund.

To read news stories about the event, visit:

- <http://www.herald-sun.com/durham/4-694367.html>
- <http://dukemednews.duke.edu/global/print.php?id=9460>

Marathoners' Efforts Benefit The Evanosky Foundation

On Sunday, October 9, 2005, the annual 26.2 mile The LaSalle Bank Chicago Marathon® started and finished at Grant Park near Chicago's famous Buckingham Fountain. The Evanosky Foundation was

fortunate to have three runners compete on its behalf - Mark Matsuo (who works with Sonya), Mike Duvall (who worked with Sonya at A.T. Kearney), and Jana Lindley (who works with Mike). It was a nice day, but according to Mark, it got a little warm. Their hard work and perseverance earned enough money to allow The Evanosky Foundation to provide laptops for the "5200" unit at Duke University Children's Hospital (see story above). ***Special thanks to Mark, Mike, and Jana, and all who donated!***



Mark Matsuo



Mike Duvall



Book Fair Stocks Jack's Library

Jack's Library is a project in the making. The ultimate goal is to provide entertainment in the form of books and movies to patients in children's hospitals. Because there are infection control concerns, books can be used by only one child. Therefore, Jack's Library will work more as a just-in-time library for patients than a permanent one. The Evanosky

Foundation is working to define the process for ensuring that these materials are available on an ongoing basis to children of all ages.

In late November, Kandi Horton, a family member of one of Sonya's co-workers, hosted an Usborne book fair to benefit Jack's Library. Due to the generosity of many supporters, Kandi's book fair raised **\$450** worth of books and materials for Jack's Library at Duke University! Jack's Library will greatly benefit patients on the unit. Thanks to everyone who participated and stay tuned for more details on the program and ways you can contribute.

Website Takes Shape

Two of Sonya's colleagues at HSBC, Elisabeth Klann and Jim McNally, are donating their time to design the website for The Evanosky Foundation.

Elisabeth and Jim specialize in designing user-friendly websites for HSBC and they have developed a great website concept. Alok Agarwal, another HSBC colleague, has been helping with technical design. The Evanosky Foundation envisions that the site will serve as a resource for MLD information as well as foundation news and research progress. Look for the new site at www.evanoskyfoundation.org in the first quarter of 2006! Until then, you can get updates at

www.caringbridge.org/il/evanosky.



What Is 5200?

(Information courtesy of Duke Comprehensive Cancer Center)

Since its creation in 1990, the Duke Pediatric Blood and Marrow Transplant (PBMT) Program has transplanted over 1200 children suffering from cancer, genetic defects or blood disorders. Today, over half of these children are surviving long-term, cured of their underlying disease by their transplant. The first step in the transplant process involves a stay at the inpatient unit at Duke University, also known as 5200, which is a 16-bed state-of-the-art protective isolation unit. This is where Jack Evanosky (see picture below) received his stem cell transplant on April 1, 2005. With a current waiting list of 30-40 children, and a referral base that is worldwide, the Duke Pediatric BMT Program is the largest children's transplant program in the world, now transplanting some 100 children annually. This program is a last resort for many children - the children treated here have a life expectancy of less than one year without a transplant.



*04/01/05 - Bob and Jack Evanosky on transplant day on 5200
(Photo courtesy of the Evanosky family)*

For more information, visit <http://cancer.duke.edu/pbmt/>

President Signs Bill Establishing National Umbilical Cord Blood Program

Some time ago on their CaringBridge website, Sonya encouraged readers to petition their lawmakers regarding pending legislation to establish a national umbilical cord blood program. The legislation unanimously sailed through both houses of Congress, and on December 20, 2005, President Bush signed the bill into law.

This legislation provides \$79 million in funding and creates a new Federal program to collect and store cord blood. It also expands the current bone marrow registry program to also include cord blood. Thousands have been successfully treated with cord blood stem cells for more than 67 diseases including MLD, leukemia, and sickle cell anemia.



*12/20/05 - President Bush signs H.R. 2520 into law
(Photo courtesy of The White House)*

“The creation of a national umbilical cord program significantly improves access for patients in need of transplants to treat blood diseases, metabolic and other rare disorders,” said Joanne Kurtzberg, M.D., medical director of the Center for Cord Blood at the National Marrow Donor Program (NMDP) and founder and director

of the Duke University Pediatric Bone Marrow Transplant Program and Director of the Carolina Cord Blood Bank. “The national program also holds great promise and potential to treat other blood diseases not currently treated by transplants.”

Umbilical cords are a rich, non-controversial source of stem cells. Currently hospitals throw millions of them away each year because the infrastructure required to properly collect and store them is not available.

Help Us Help Others!

If you want to help The Evanosky Foundation in its efforts to fund research for a cure for metachromatic leukodystrophy and support families affected by the disease, you can send a gift to:

The Evanosky Foundation

PO Box 9234, Naperville, IL 60567

Phone (630) 236-8039

www.caringbridge.org/il/evanosky

Also, watch for upcoming news on how you can support a runner for the 2006 The LaSalle Bank Chicago Marathon®!