



THE EVANOSKY  
FOUNDATION

*We Win in the End*

## **Son's Life-Saving Transplant Inspires Dad to Donate Laptops to Duke** Duke Med News - January 24, 2006

DURHAM, N.C. -- Isolated for months at a time with his critically ill son, Bob Evanosky's only connection to the outside world was his laptop computer. Through his computer he could update his family and friends on Jack's progress and catch a fleeting glimpse of the real world outside of their isolated existence.

There, in the tight confines of the Duke Pediatric Blood and Marrow Transplant Unit, fourteen-month-old Jack was receiving umbilical cord blood derived from a newborn baby in the hopes of correcting his rare and fatal metabolic disease, Metachromatic Leukodystrophy (MLD).

The transplant was his only chance for surviving this horrendous disease, which robs children of all physical and cognitive function before eventually claiming their lives. The transplant in April, 2005 has been a success, thus far, and the Evanoskys want to share their gratitude with the team of caregivers at Duke – and other families in the unit – who saved their son's life.

On Thursday, the Evanosky Foundation will present a check for 18 laptop computers and a laser printer to the Duke Pediatric Blood and Marrow Transplant Unit. Their donation grew out of a last-minute response to a friend who was running in the Chicago Marathon. Their friend, along with two other runners, signed on sponsors to raise money for the newly formed foundation, to benefit Duke's program and the families who were undergoing transplants there.

The request resulted in donations of \$14,000 from hundreds of sponsors that were generated by just three runners.

Evanosky said it was word of mouth alone that spread the news about the Evanosky Foundation's mission. Evanosky then contacted Hewlett Packard and explained his mission. They responded by reducing the price of each computer by almost half the retail cost, enabling the Evanosky Foundation to spring for 18 computers – one for each patient room plus a few extras.

On Thursday, the Evanosky family will join representatives from Duke Hospital and Hewlett Packard to present a check to the Duke Pediatric Blood and Marrow Transplant Unit for the purchase of the laptops and the printer. Jack's doctor, Suhag Parikh, MD, and other caregivers from the Duke team will join in the check presentation.

"What made me think of the laptop project is that I had a borrowed laptop when Jack was undergoing his transplant," said Evanosky. "It made such a big difference that I could connect with my family in Chicago and the outside world through my laptop." Evanosky's wife, Sonya, stayed in Chicago with their two older twin sons, both of whom are also afflicted with MLD.

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Currently, two desktop computers are available in the patient and family lounge, but they are frequently in use and many patients are unable to leave their isolation rooms to utilize these computers. Putting a laptop in every room provides each family with a means to stay in touch with the outside world when they are confined for months at a time, said Evanosky.

In addition, the Evanosky Foundation will fund a project called "Jack's Library," which will help purchase PC-based curricula for children who are undergoing transplants at Duke.

"Paper carries germs, so papers can't be shared among kids who must be isolated from germs during transplant," said Evanosky. "We are working with the educational staff at Duke and the Durham County Public Schools to develop an electronic curriculum that is PC based so we can aid teachers in effectively teaching kids in the transplant unit," said Evanosky.

Pleased as they are with their initial success in raising funds, the Evanoskys are aiming considerably higher for 2006. They have now been named an official charity for the Chicago Marathon and hope to raise \$100,000 during the 2006 race, said Evanosky. The money would be donated to Dr. Joanne Kurtzberg's research efforts into the prevention and treatment of MLD.

Kurtzberg directs the Duke Pediatric Blood and Marrow Transplant Program and pioneered the use of umbilical cord blood to treat rare metabolic diseases such as MLD. The diseases are among a group of disorders called leukodystrophies, in which children are missing an enzyme that is critical to forming the myelin sheath that protects developing brain cells from damage.

Transplants with cord blood are the only treatment proven to save the lives of children with leukodystrophies, Kurtzberg has demonstrated in the past two years.

"The Evanosky Foundation is here as a tool for Duke to have at their fingertips. If they need something we're going to go out and find it for them," Evanosky said.

*<http://dukemednews.duke.edu/news/article.php?id=9460>*

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