

Published: Jan 27, 2006 12:30 AM  
Modified: Jan 27, 2006 03:12 AM

## Heartfelt gift at Duke

Patients' families get online option

ANNE BLYTHE, Staff Writer

Robert Evanosky was holed up in an isolated Duke Hospital room for months last year as Jack, his toddler son, battled high fevers, lost clumps of hair and mustered up every bit of strength he could while stem cells were transplanted from an umbilical cord into his little body.

The Evanosky boy has late infantile metachromatic leukodystrophy, a rare genetic disorder that robs the afflicted of their muscle control and cognitive function.

Without the stem cell transplant, Jack had little hope of surviving past his fifth birthday.

He would not have been able to sit or stand on his own.

So Robert Evanosky, a stay-at-home dad who used to be an airline pilot, spent much of his time last year in Durham, far from Chicago, where his wife and older identical twin sons remained.

Evanosky relied on a borrowed laptop to stay in touch with the world outside Jack's sterilized quarters.

Through an online journal, he could go into great detail about his experience in the South.

"It was my communication device," Evanosky said. "It was kind of therapy for me. On days when Jack was not doing so good, I could talk to people, and when he was doing good, I could talk, then, too."

On Thursday, Evanosky returned to the Duke Pediatric Blood and Marrow Transplant Unit, where he and Jack spent 40 isolated days together.

The ward, decorated with children's colorful drawings saying "Grow cells, grow," is a place of last resort for many families.

Evanosky had more than warm hugs for the nurses, social workers and doctors who saw him through dark, lonely and rewarding days.

With the help of a corporate donation from Hewlett-Packard, the proud father came loaded with gifts - laptops for each of the 16 transplant unit rooms, two extras and a laser printer.

Evanosky wanted to give back to a group that gave him hope.





A Christmas photo of the Evanoskys: Sonya, rear, with John, left, Christopher and Robert, holding Jack.

*Photo Courtesy of the Evanosky Family*

### Story Tools

 [Printer Friendly](#)  
 [Enlarge Font](#)

 [Email to a Friend](#)  
 [Decrease Font](#)

### More B City & State

- [Durham city worker's legal quest quashed](#)
- [Blackwater loses appeal in deaths of four in Iraqi city](#)
- [Quiet farmer planted a new life](#)
- [Lead found in schools' water](#)
- [Bail cut in sex crime case](#)
- [The real scoop for Dukies](#)

### Most Popular Stories

#### Last 24 hours

- [N.C. State freshman found dead in dorm](#)
- [NCSU student died of natural causes](#)
- [Search narrows for missing woman](#)
- [McGill's recipe for success](#)
- [Rivers stumbles, fumbles for Bolts](#)

#### Last 7 days

- [Blackwater loses appeal in deaths of four in Iraqi city](#)
- [Two Duke lacrosse DNA tests are positive](#)
- [Garner man held in kidnapping](#)
- [Missing Wendell woman's car found](#)
- [N.C. State freshman found dead in dorm](#)

Ad Links [Buy a link](#) »

His older sons, too, are afflicted with the rare disorder. The twins, just two years older than Jack, were diagnosed too late for a stem cell transplant to help.

Doctors initially thought the twins had cerebral palsy, a medical condition that also creates muscle control problems.

By the time, they were properly diagnosed, Evanosky and his wife, Sonya, both carriers of the genetic disorder, had Jack.

Doctors in Chicago said they could not help the boys.

The Evanoskys were not about to give up, so they put the new medical phrases into a Google search and hit on the name Joanne Kurtzberg, a physician at Duke who is a giant in cord cell transplant research. They set up tests at Duke.

"The earlier you diagnose it, the better it is," said Dr. Suhag Parikh, a doctor in the Duke pediatric bone marrow program.

The disorder is rare, he said. It strikes one in 100,000 people.

Since the transplant, Jack, who turned 2 Jan. 15, has improved. He can sit and stand on his own.

His older brothers, 4, are quadriplegics with feeding tubes who communicate with eye movements.

Evanosky holds hope in an enzyme replacement therapy that might be available for human trial in a year or two at Duke.

"We're going to take this head on, and we're not going to go out without a fight," said Evanosky, a religious man. "But it's not always up to us to decide the fate of our children."

ONLINE

To read the Evanosky journals, go to [www2.caringbridge.org/il/evanosky/](http://www2.caringbridge.org/il/evanosky/)

**Staff writer Anne Blythe can be reached at 932-8741 or [ablythe@newsobserver.com](mailto:ablythe@newsobserver.com).**

#### **Hoodia Diet: Seen on 60 Minutes**

New Hoodia Diet Patch Promises Fast Weight Loss, No Hunger! 1 Week Free  
[www.curbyourcravings.com/hoodia](http://www.curbyourcravings.com/hoodia)

#### **Refinance**

Get quotes from multiple lenders. Save thousands  
- Bad credit OK  
[www.Low.com](http://www.Low.com)

#### **Knee Pain?**

Learn about Stryker Knee Replacements  
Designed with Women in Mind  
[www.aboutstryker.com](http://www.aboutstryker.com)

© Copyright 2006, The News & Observer Publishing Company  
A subsidiary of [The McClatchy Company](#) 