



Family, Hewlett-Packard donate laptops to Duke Hospital

BY PAUL BONNER, The Herald-Sun
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DURHAM -- In the weeks Bob Evanosky spent at the bedside of his 14-month-old son in Duke Hospital, he had few links with the world outside.

But he had a borrowed laptop computer. On it, as he sat in a reclining chair in Jack's room in the Pediatric Blood and Marrow Transplant unit, he could correspond with his wife, Sonya, back at their home in Chicago with their two other sons. He could commiserate or celebrate with other parents going through similar ordeals as Jack's treatment for metachromatic leukodystrophy, or MLD, a rare genetic disorder of the nervous system.

In August, after treatment at Duke that had begun in March, Evanosky went home with Jack, whose transfusion of stem-cell-rich blood from a newborn's umbilical cord was successful.

On Thursday, Evanosky returned to Duke Hospital with a check for \$13,805 that with discounts and donations from computer company Hewlett-Packard will provide 18 laptop computers and a printer for the unit's 16 patient rooms. A foundation the Evanoskys started aims to raise \$100,000 more this year to support umbilical blood transplant research at Duke.

"It was my communication device to the outside world," Evanosky said of the borrowed computer. On a Web site, caringbridge.org, he could keep an online journal with updates on Jack's treatment for friends and family to read and write back with encouragement.

"It was kind of therapy for me," he said. "On days when Jack wasn't doing so good, I could talk about it; on the days Jack was doing good, I could talk about it."

The doctors and nurses at the pediatric transplant unit "were extraordinary," he said. "I've made friends I'll have for life."

After a ceremonial presentation of an oversized check Thursday in a hospital lobby, Evanosky, Hewlett-Packard representatives and Duke Hospital officials including Jack's doctor, Suhag Parikh, visited the unit, where several nurses greeted Evanosky with a hug.

"This was where Jack and I lived," he said outside Room 5212. On the room's window was a sign made of construction paper that said "Happy Transplant Day," with a date and "Grow Cells, Grow!" Hanging beside several doors were quilts made by one of the nurses, with blank patches where well-wishers could write notes to the children inside.

After the Evanoskys returned home last year, three friends raised money by running for donations in the Chicago Marathon. Now the Evanosky Foundation is an official charity of the marathon, meaning it can raise more money.

The \$100,000 the Evanoskys hope to raise next fall will go to research supervised by Joanne Kurtzberg, a Duke physician who pioneered the cord-blood transplants that Parikh said have been successful in treating childhood leukemia and other life-threatening illnesses. Duke performed the first umbilical cord blood transplants between related children and, later, by matching unrelated donors, he said.

MLD is caused by a genetic abnormality that interferes with the production of myelin, the brain's white matter that insulates and increases the conductivity of impulse-carrying nerve cells. It can cause loss of motor control and is often fatal.

The family's twin sons John and Christopher, now age 4, who also have MLD and are "basically quadriplegic," Evanosky said.

When friends and neighbors joined the Evanoskys in forming the foundation, the couple gave it a motto, "we win in the end." It's a statement of faith, Evanosky said.

"Regardless of how it works out for these kids, they'll go to heaven," he said. "We're going to take it head on, but sometimes it's not up to us how things turn out."

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Caring Bridge: caringbridge.org

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