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Columnists

Judy Buchenot

Medical challenges don't stop these heroic parents

June 14, 2007

One of the perks of writing this column is meeting heroic people. Two of those people are Bob and Sonya Evansky. About a year ago, I wrote about their struggles with their three children who all have a rare genetic disease. Their two oldest sons, identical twins who are five years old, were diagnosed with metachromatic leukodystrophy at age three. The disease was too advanced to treat so the parents have had to watch the boys slowly lose control of their bodies.

Currently, the two boys are on nine daily medications to minimize pain and swelling. They also take medications to reduce the saliva in their mouths so they won't choke. Other medications keep their airways open and their digestive system operational. Neither boy can walk or talk anymore.

Jack, the youngest son, was diagnosed early enough to receive a stem-cell transplant in April of 2005. Although the disease had done damage, the progression has stopped and Jack is getting stronger. Jack has a feeding tube and also has to take ten medications a day. This week Bob took Jack to Duke University for his two-year post-transplant checkup.

Despite all of the challenges, Bob and Sonya are reaching out to others. They established the Evansky Foundation, which plays several roles -- from providing needed medical aids for families to raising funds for research. One of their main goals has been to find a way to help other parents cope with genetic disease. This desire helped create Senate Bill 1566, which would require that newborns in Illinois be tested for five diseases known as lysosomal storage disorders.

Currently, newborns are tested for 36 diseases and beginning in July, tests for cystic fibrosis will be added. The cost for the tests will be \$56. Adding the additional five tests would up the total by about \$12. The bill passed unanimously but is awaiting some funding issues keeping the bill from being signed at the present time.

The hope is that by requiring the tests, early intervention will be possible. The couple is encouraging pe

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members of Congress. Information on who to contact plus a sample letter is available at the foundation Web site, www.evanoskyfoundation.org.

After I wrote about the Evanoskys, I received a call from Mary Schneider from Batavia who had read the column. Mary shared the story of her son Ryan who was diagnosed with cerebral palsy at the age of two. His upper body strength was so weak that his hands stayed in fists. Straightening out his arms to dress and wash him caused the child intense pain. His verbal skills were limited to 40 words that only family members could understand.

The morning after his diagnosis, Mary remembered that she had saved Ryan's cord blood in a cord blood bank. After an exhaustive search, she found a doctor willing to infuse the stem cells from the blood. In October 2005, Ryan underwent a simple procedure. For 20 minutes, the stem cells were dripped through an IV in the back of his hand. This was followed by a saline drip for two hours. Ryan went home and Mary waited.

Today, Ryan is a normal four-year-old who walks and talks. He is at his normal weight and his development is at or above his age level. Although there is no guarantee that all children will respond as positively, the results were dramatic. More research is being done.

Like the Evanoskys, Mary has a desire to help other parents. Since last August she has been working hard to get SB0019 passed. This bill will set up an advisory panel to make sure cord blood collection is done properly. It includes education of both the public and medical staff. The bill sets up contracts between blood banks and hospitals for cord blood procedures. Her work has paid off and the bill has passed. The bill is awaiting the governor's signature.

These three people have experienced incredible personal challenges with their children but still found ways to help others. They are heroes. Mary's nine-year-old daughter wrote a school essay about her mom where she pointed out that there are many ways to serve one's country. There are some battles that need to be fought at home. And she is so right.

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